

**Stillbirths in Uganda: National and subnational response, community social support systems and women's perceptions of risk**

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**Date:** November 2021



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## Abstract

**Introduction:** This thesis is an exploratory project on the stillbirth challenges in Uganda. It approaches the subject matter from a global policy perspective to local implementation experiences and community responses. From 2010, accelerated global concern over the stillbirth burden has reflected a lack of proportionate advocacy and attention relative to the magnitude compared to other public health challenges such as HIV/AIDS. At the time of conceptualisation, over 2.6 million stillbirths were occurring annually across the globe, with the majority of the cases in low- and middle-income countries, including sub-Saharan Africa. Many of the cases were happening around the time of delivery although they could have been preventable. This public health concern is examined through the critical lens of the policy transfer theory, a bottom-up implementation theory of street-level bureaucracy, community response through a social network analysis approach and risk perception theories for women's understanding of stillbirth risks.

**Methods:** The study adopted an exploratory approach to investigate the factors that triggered the prioritisation of stillbirth prevention at the national level from the global campaigns (n=20), how those strategies were translated at subnational level (n=16), the role of social networks in the provision of social support to mothers after stillbirth (n=17) and the women's perceptions of stillbirth risks (n=431). Data collection was conducted in a single district and it included qualitative and quantitative methods such as key informant interviews, document review, social network analysis survey and a community survey. Analysis consisted of different techniques, including thematic and content analysis, social network analysis, as well as bivariate and multivariate analysis of quantitative data.

**Results:** The findings indicate that global stillbirth campaigns enhanced norm promotion and, coupled with domestic advocacy, played a significant role in triggering national efforts to align policies to address the same in Uganda. At subnational level, interventions to address stillbirths identified service delivery gaps such as increasing uptake of family planning, boosting antenatal care attendance, streamlining referral systems, increasing the perinatal death audit uptake and improving data systems. Intangible support, such as emotional and informational support, were the most prevalent forms of support among network members towards mothers who had experienced a stillbirth. This followed patterns of network characteristics such as trust and the frequency of contact. Lastly, community survey data revealed that women perceived stillbirth risk factors attributed to them, such as maternal, social demographic and lifestyle risks as being highest, while risks not directly attributed to them, such as health systems and foetal conditions were assigned the lowest score.

**Conclusion:** This study highlights the importance of norm promotion as well as the subnational-level context in influencing the prioritisation of stillbirth reduction

strategies. Coupled with the available intangible support to mothers who experience a stillbirth, such strategies are often met with varying perceptions about risk, thus calling for an integration of women's concerns into interventions to address stillbirths.

**Keywords:** stillbirth, policy transfer, policy translation, policy implementation, social network, social support, risk perception, risk communication.



## List of papers and other scientific products

This thesis is based on four main papers referenced in-text as papers 1-4. They have been included and reprinted with permission from the copyright holder under the Creative Commons License for Open Access. This also serves to confirm that I am listed in all the manuscripts as the first and main author.

1. **Ssegujja E**, Andipatin M. Building on momentum from the global campaigns: An exploration of factors that influenced prioritization of stillbirth prevention at the national level in Uganda. *BMC Globalization and Health*. 2021; 17:66. Available from: <https://doi.org/10.1186/s12992-021-00724-1>.
2. **Ssegujja E**, Ddumba I, Andipatin M. Prioritization of interventions in pursuit of maternal health policy objectives to mitigate stillbirth risks. An exploratory qualitative study at subnational level in Uganda. *BMC Health Services Research*. 2021; 21:53. Available from: <https://doi.org/10.1186/s12913-020-06046-z>
3. **Ssegujja E**, Mulumba Y, Guttmacher S, Andipatin M. The role of social networks in provision of support to women after stillbirth. Experiences from Uganda. *BMC Women's Health*. 2021; 21:352. Available from <https://doi.org/10.1186/s12905-021-01498-9>
4. **Ssegujja Eric**, Mulumba Y, Guttmacher S, Andipatin M. Perceptions of stillbirth risk among women from a community sample in Uganda. A cross-sectional study. (Submitted to BMC Public Health)

### ***Additional papers already submitted for publication***

Three additional papers from the study have already been submitted to different peer-reviewed journals for publication.

1. **Ssegujja E**, Andipatin M. Accounting for variations in implementing of interventions to address stillbirth from national to sub-national levels. Experiences from Uganda. 2021. (Submitted to BMC Health Systems Research and Policy).
2. **Ssegujja E**, Ddumba I, Andipatin M. Health workers' social networks and their influence in the adoption of strategies to address stillbirth burden at a subnational level health system in Uganda. 2021. (Submitted to BMC Global Health Research and Policy).
3. **Ssegujja E**, Ddumba I, Andipatin M. An exploration of health workers' experiences providing care to stillbirth grieving mothers: Results from a qualitative study conducted in Mukono district of Uganda. 2021. (Submitted to BMC Public Health).

### ***Conference presentations resulting from this work***

Four conference presentations accruing from the different studies under this work were prepared and presented at different local and international conferences. They are listed here with specific details about the title of presentation, conference, venue and date of event:

1. **Ssegujja E**, Andipatin M. Production and use of evidence to translate global campaigns into national policy priorities to address stillbirth in Uganda. 2019. (Presented on 19<sup>th</sup> October 2019 at the Canadian Conference on Global Health in Ottawa, Canada).
2. **Ssegujja E**, Andipatin M. Understanding stillbirth prevention strategies at sub-national level in Uganda. 2019. (Presented on the 5<sup>th</sup> October 2019 at the International Stillbirth Alliance's 15<sup>th</sup> Annual Conference on Perinatal Mortality and Bereavement Care held in Madrid, Spain).
3. **Ssegujja E**, Andipatin M. Health workers' experience of communicating the bad news to parents following a stillbirth at sub-national level in Uganda. 2019 (Presented on the 5<sup>th</sup> October 2019 at the International Stillbirth Alliance's 15<sup>th</sup> Annual Conference on Perinatal Mortality and Bereavement Care held in Madrid, Spain).
4. **Ssegujja**, Andipatin M. Value frameworks and policy processes; How Global partnership values shaped the translation of stillbirth campaigns into national policy priorities for Uganda. 2019. (Presented on the 28<sup>th</sup> September 2019 at the UHC Symposium held in Kampala, Uganda).

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## Declaration

I hereby declare that this thesis "**Stillbirths in Uganda: National and subnational response, community social support systems and Women's perceptions of risk**" is my own. Unless otherwise specifically stated to the contrary in-text, I have not submitted it or any part thereof for any academic award at another University.

However, some of the materials contained in this thesis or arising from the study have been previously published in the form of journal articles or presented at local and international scientific conferences. These have jointly been co-authored with Assoc. Prof. Michelle Andipatin, my main supervisor. The work was published and/or presented after the onset of the study and before this thesis was submitted and approved.

This thesis and the related research products on which it is based are the result of the sole effort of the author. All sources that have been used have been quoted and acknowledged with complete references.

Signature.....



Date.....

29/11/2021

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## Acknowledgements

I wish to acknowledge the following for their contribution towards the successful completion of this work:

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9. The respondents that agreed to be interviewed for this study.
10. And finally, to God the Almighty, the giver of life.

## Dedication

I would like to dedicate this work to the following persons:

1. My parents Mr. John Ntambi (RIP) and Mrs. Margaret Nakamanya.
2. My wife Dorine Nakalanda and our children Esther Nassanga and Elijah Ntambi.



## Abbreviations and acronyms

AHSPR	Annual Health Sector Performance Report
ANC	Antenatal Care
AOGU	Association of Obstetricians and Gynaecologists of Uganda
APHSR	Annual Health Sector Performance Report
ART	Antiretroviral Therapy
CEmONIC	Comprehensive Emergency Obstetric and Neonatal Intensive Care
CHEW	Community Health Extension Workers
CME	Continuous Medical Education
CSOs	Civil Society Organisations
DHIS	District Health Information Systems
DHMT	District Health Management Team
DHT	District Health Team
DOT	Directly Observed Therapy
EmOC	Emergency Obstetric Care
ENAP	Every Newborn Action Plan
GAPPS	Global Alliance to Prevent Prematurity and Stillbirth
GFF	Global Financing Facility
HBB	Helping Babies Breathe
HC	Health Centre
HIV	Human Immune Virus
HSDP	Health Sector Development Plan
ICCM	Integrated Community Case Management
ISA	International Stillbirth Alliance
LMIC	Low- and Middle-Income Country
MCH	Maternal and Child Health

MCH-TWG	Maternal and Child Health – Technical Working Group
MDG	Millennium Development Goals
MoH	Ministry of Health
MPDSR	Maternal and Perinatal Death Surveillance and Responses
MPDSR	Maternal and Perinatal Death Surveillance and Review
NCD	Non-Communicable Diseases
NGOs	Non-Governmental Organisations
PMTCT	Prevention of Mother-to-Child Transmission
RMNCAH	Reproductive Maternal Newborn and Child Health
UDHS	Uganda Demographic and Health Survey
UHC	Universal Health Coverage
UPA	Uganda Pediatrics Association
VHTs	Village Health Teams



## Table of Contents

Supervisors.....	3
Abstract.....	4
List of papers and other scientific products .....	6
Declaration .....	8
Acknowledgements .....	9
Dedication .....	10
Abbreviations and acronyms.....	11
Table of Contents.....	13
Definitions .....	17
CHAPTER ONE .....	19
<b>Introduction and Background.....</b>	<b>19</b>
Scope of the chapter.....	19
List of figures.....	19
Background.....	20
Rationale for the thesis .....	28
General aim.....	35
Outline of the Thesis.....	36
Ethical Clearance.....	38
Funding.....	38
Chapter One References .....	38
CHAPTER TWO.....	45
<b>Building on momentum from the global campaigns: An exploration of factors     that influenced prioritisation of stillbirth prevention at the National Level in     Uganda. ....</b>	<b>45</b>
Scope of the chapter.....	45
List of tables.....	45
List of figures.....	45
Abstract.....	46
Introduction.....	47
Methods.....	49
Results.....	52



Discussion .....	67
Conclusions .....	70
Chapter Two References .....	71
CHAPTER THREE .....	75
<b>Prioritisation of Interventions in pursuit of maternal health policy objectives to mitigate stillbirth risks. An exploratory qualitative study at subnational level in Uganda.....</b>	<b>75</b>
Scope of the chapter.....	75
List of tables.....	75
Abstract.....	76
Background.....	76
Methods.....	77
Results.....	80
Discussion.....	87
Conclusion.....	92
Chapter Three References .....	92
CHAPTER FOUR .....	95
<b>The role and attributes of social networks in the provision of support to women after stillbirth. Experiences from Uganda. ....</b>	<b>95</b>
Scope of the chapter.....	95
List of tables.....	95
List of figures.....	96
Abstract.....	96
Background.....	97
Methods.....	100
Results.....	103
Discussion.....	121
Chapter Four References .....	125
CHAPTER FIVE.....	129
<b>Perceptions of stillbirth risk among women from a community sample in Uganda. A cross-sectional study. ....</b>	<b>129</b>
Scope of the chapter.....	129
List of tables.....	129

Abstract.....	130
Background.....	131
Methods.....	133
Results.....	135
Conclusions .....	150
Chapter Five References .....	150
CHAPTER SIX.....	155
<b>Accounting for variations in implementing interventions to address stillbirth from national to subnational levels. Experiences from Uganda. ....</b>	<b>155</b>
Abstract.....	155
Background.....	156
Methods.....	158
Results.....	164
Discussion.....	175
Conclusion.....	177
Chapter Six References .....	178
CHAPTER SEVEN .....	181
<b>Health workers' social networks and their influence in the adoption of strategies to address the stillbirth burden at a subnational-level health system in Uganda. ....</b>	<b>181</b>
Abstract.....	181
Background.....	182
Methods.....	183
Results.....	185
Discussion.....	189
Conclusions .....	192
Chapter Seven References.....	192
CHAPTER EIGHT .....	195
<b>An exploration of health workers' experiences providing care to stillbirth grieving mothers: Results from a qualitative study conducted in Mukono district of Uganda.....</b>	<b>195</b>
Abstract.....	195
Background.....	196

Methods.....	197
Results.....	201
Discussion.....	210
Conclusion.....	214
Chapter Eight References.....	215
CHAPTER NINE .....	217
<b>Conclusions and Recommendation.....</b>	<b>217</b>
Scope of the chapter.....	217
Recommendation for policy and programmes .....	217
Recommendations for subnational-level health systems strengthening .....	218
Recommendations for community-level action .....	220
Recommendations for individual-level action (perception of stillbirth risk) .....	221
Conclusion.....	222
CHAPTER TEN.....	224
<b>AFTERWORD: Addressing stillbirth in Uganda .....</b>	<b>224</b>
<b>Reflections from the study.....</b>	<b>224</b>
APPENDICES.....	228
<b>Appendix 1: Ethics clearances and permission letters .....</b>	<b>228</b>
UWC Ethics Letter .....	228
Makerere University Ethics Letter .....	229
Uganda National Council for Science and Technology Letter.....	231
District administrative clearance.....	233
<b>Appendix 2: Participant information sheet .....</b>	<b>234</b>
<b>Appendix 3: Published papers .....</b>	<b>237</b>
Paper one .....	237
Paper two .....	238
Paper three.....	239
<b>Appendix 4: Copyrights and permissions of published papers .....</b>	<b>240</b>
Paper 1 rights:.....	240
Paper 2 rights:.....	241
Paper 3 rights:.....	242



## Definitions

**Stillbirth:** WHO (2006) defines stillbirth as the death of a foetus of 28 completed gestation weeks or more where a child did not at any time after delivery show signs of life such as breathing, heartbeats, pulsation of the umbilical cord, or definite movements of voluntary muscles. The same definition has been used for this study.

**Risk perception** refers to the individual's subjective beliefs and feelings about a potential disease or harm to their health. It has been observed to motivate health behaviour change.

**Risk communication:** WHO defines risk communication as the exchange of real-time information between experts and people under a health or social wellbeing threat to their lives whose aim is to trigger informed decision-making processes to avert the risk or take appropriate measures to better protect themselves.

**Health risk:** According to Menon et al. (2008) in Brake (2013), health risk refers to the "the perception of the subjective likelihood of the occurrence of a negative event related to the health for a person over a specified period of time". The same definition has been used for this study.

**Perinatal mortality:** According to WHO (2006), perinatal mortality refers to the "number of stillbirths and deaths in the first week of life per 1,000 total births". The same definition has been adopted for this study.

**Social network:** According to Wasserman (1994), a social network refers to the set of social structures that are composed of individuals, their ties, and other social interactions among those individuals. The same definition has been adopted for this study.

**Social capital:** The actual value embedded within the social relations that demonstrates the quality and quantity of such relationships. It manifests through the connections among network actors who demonstrate care by providing the different types of support.

**Social network analysis:** According to Scott (2000), social network analysis refers to a method of conceptualising, describing and modelling society as a set of actors linked to one another by specific relationships. The same definition has been adopted for this study while investigating the social support relationships among actors.

**Emotional support** refers to behaviours that foster a feeling of comfort which leads a person to believe that they are being admired, respected and loved and that others are available to provide care and safety.

**Information support:** Knowledge, advice or information that helps an individual to understand their world and adapt to the change that comes with it.

**Instrumental support:** The help from other people in terms of activities that the ego is unable to perform or for which others are required to help solve a problem [help with household chores, accompanying one to hospital]. Instrumental support is separated from material support, as the former refers to services while the latter refers to tangible goods.

**Financial support:** Assistance in terms of money to help buy goods or facilitate a service.

**Material support:** This refers to tangible goods received to help solve a particular problem.

**Policy:** Three definitions have been applied: 1) first, as statements of intent (Sethi 1999, Dye 1972), such as specific targets with timelines for milestones; 2) second, policy as practice reflecting on what actions are implemented by the frontline actors (Lipskey 1998); and third, understanding policy as formal documents stipulating clear actions and strategies (Dye 1972).

**Policy transfer:** A process by which knowledge of policies, administrative arrangements, institutions and ideas from one system are used to guide the development of policies in another system.

**Policy implementation:** According to Kraft and Furlong (2007), it refers to the process of translating a policy into actions and its translation into results. The same definition has been adopted for this study.

**Street-level bureaucrats:** According to Erasmus (2014), street-level bureaucrats refer to the frontline public servants who are responsible for the translation of policy into practice. In this study, the term refers to frontline health workers.

## CHAPTER ONE

### Introduction and Background

#### Scope of the chapter

This chapter presents the background and introduction to the study which provides context to the entire thesis. It describes the phenomenon from a global perspective, and provides causes and classification systems while zeroing in on the situation in sub-Saharan Africa, a region disproportionately affected. Global efforts, starting in 2000 with the MDGs, the UN Global Strategy for Women, Children and Adolescent Health and Every Newborn Action Plan, among others, that have brought the stillbirth problem to the fore and set targets for reduction, are discussed. The influence on national-level strategies with regard to the adoption and revision of policies at the national level with the implementation of the same at subnational level as well as the community response is elaborated. The chapter ends with the rationale and objectives of the study, which provide the foundation for the four sub-studies that are presented in subsequent chapters that have been submitted to different journals for publication.

#### List of figures

- Figure 1.1: Global distribution of stillbirth burden in 2015
- Figure 1.2: Conceptual framework for known stillbirth pathways
- Figure 1.3: Classification system for stillbirth cause of death
- Figure 1.4: Stillbirths, live births and neonatal deaths
- Figure 1.5: Availability and type of stillbirth data by region
- Figure 1.6: Global progress towards the ENAP to end preventable stillbirth by 2030
- Figure 1.7: Stillbirth prevention within the ARMNCH continuum of care
- Figure 1.8: Interventions which impact on stillbirth by timing
- Figure 1.9: The effects of stillbirth originating from the death of the baby
- Figure 1.10: Survey data on perception of stillbirth in high-income countries
- Figure 1.11: Time for each region to reach the same stillbirth rates
- Figure 1.12: Stillbirth rates in countries by SDG region

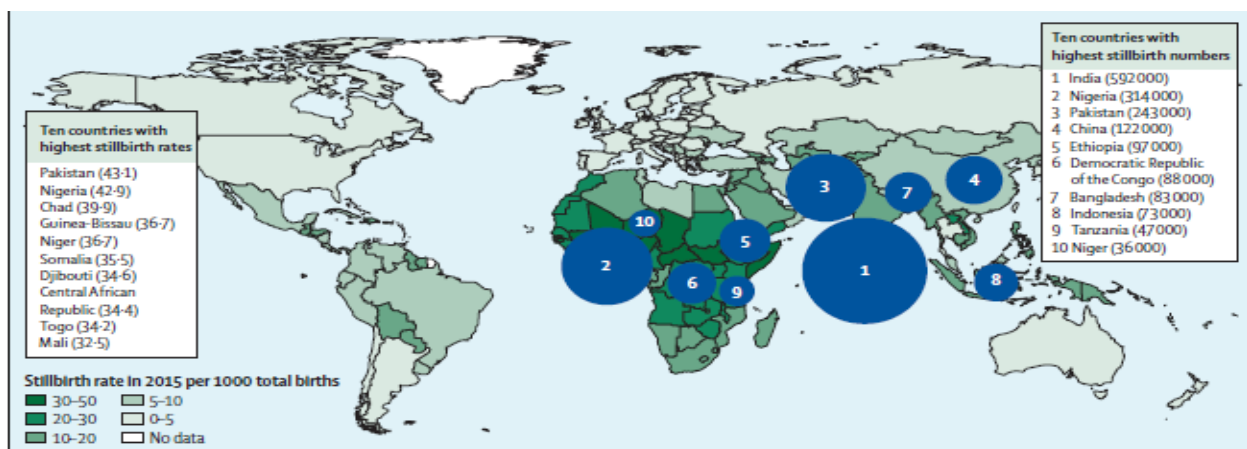
## Background

Sustained progress was registered in the areas of maternal and child health at the close of the Millennium Development Goals (MDGs)(1). With targeted efforts, some indicators registered impressive improvements. Since neonatal mortality rates (NMR) were clearly stipulated in the MDGs, the global NMR was reduced by 37% from 33 to 21 deaths per 1,000 since 1990 (2). This reflected a significant improvement in health outcomes. Although this is a positive sign for improved maternal and child health, other indicators lagged behind, thereby denting this progress. A case in point is the perinatal mortality rates (3) where progress has been slow (4). The rates were disproportionately skewed by the very high rates of stillbirth, implying that many of the deaths occurred after the 20<sup>th</sup> week of gestation and around the time of delivery (5, 6). According to the World Health Organisation (WHO), stillbirth rates accounted for 18.4% of every 1,000 babies born in 2015 alone (6).

## Magnitude of stillbirths

Every year 2.6 million stillbirths occur (7, 8), with sub-Saharan Africa facing the highest burden (9, 10). About half of these occur during the intrapartum period and up to 98% of the cases occur in low- and middle-income countries, where rural areas account for 60% (11). In sub-Saharan Africa, the highest burden recorded was in Nigeria and Senegal. Other countries with similar rates include the Democratic Republic of Congo (DRC), Ethiopia and Tanzania, South Africa (12) and Zimbabwe (13). By 2015 Uganda ranked 125<sup>th</sup> out of the 194 countries globally with the highest stillbirth rates (14). In Uganda, stillbirth rates have been estimated at 13.8 and 25/1,000 live births (15,16), with most cases happening intrapartum (17).

**Figure 1.1: Global distribution of stillbirth burden in 2015**

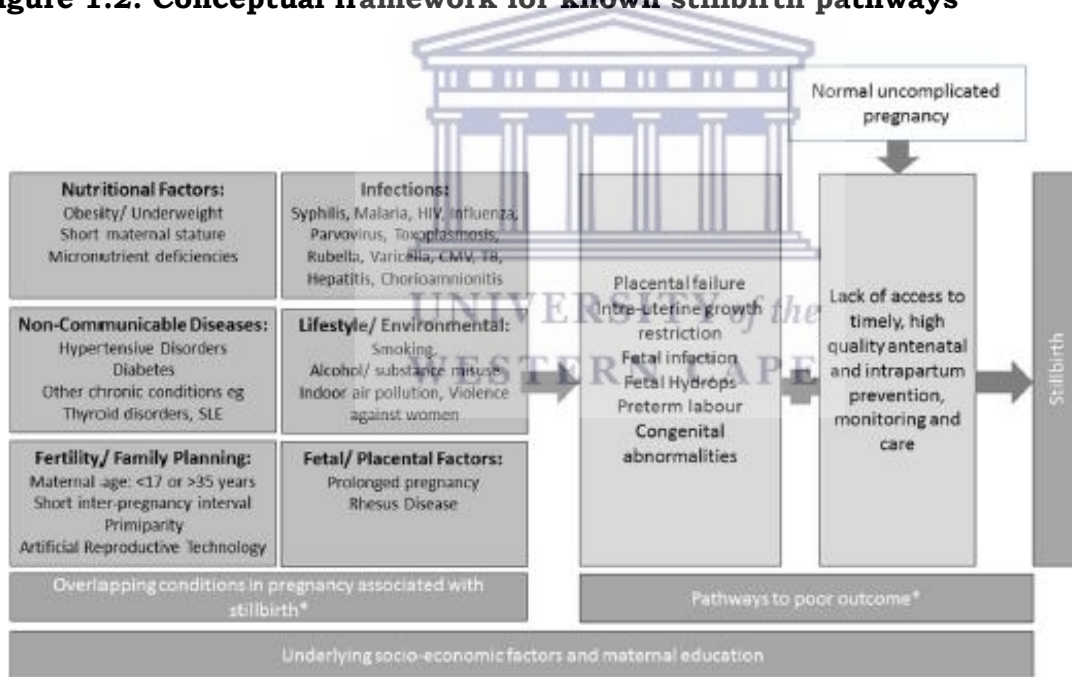


**Source:** Blencowe et al. 2016(8)

## Stillbirth causes

The cause of stillbirths, newborn and maternal deaths are known and closely related (6, 18). Common causes of stillbirths include intrapartum complications (19), previous stillbirth, twin births, short birth intervals, haemorrhage and maternal conditions, among others (20). Two studies from Uganda found stillbirth indirect causes to be nulliparity, home deliveries, living in urban centres and not sleeping under a bed net (16) and pregnancy loss as a common occurrence for women reporting stillbirths (21) as well as distance to the health facility (22). These findings concur with research conducted elsewhere that found a relationship between stillbirth occurrences and a history of pregnancy loss. Maternal conditions associated with stillbirth in low- and middle-income countries (LMIC) included hypertension, diabetes, maternal infections such as HIV, malaria, syphilis among others, maternal undernutrition, obesity and smoking (9). Frameworks for establishing stillbirth causes have been proposed to improve knowledge so as to design appropriate interventions (23).

**Figure 1.2: Conceptual framework for known stillbirth pathways**



**Source:** Blencowe et al.2017(23)

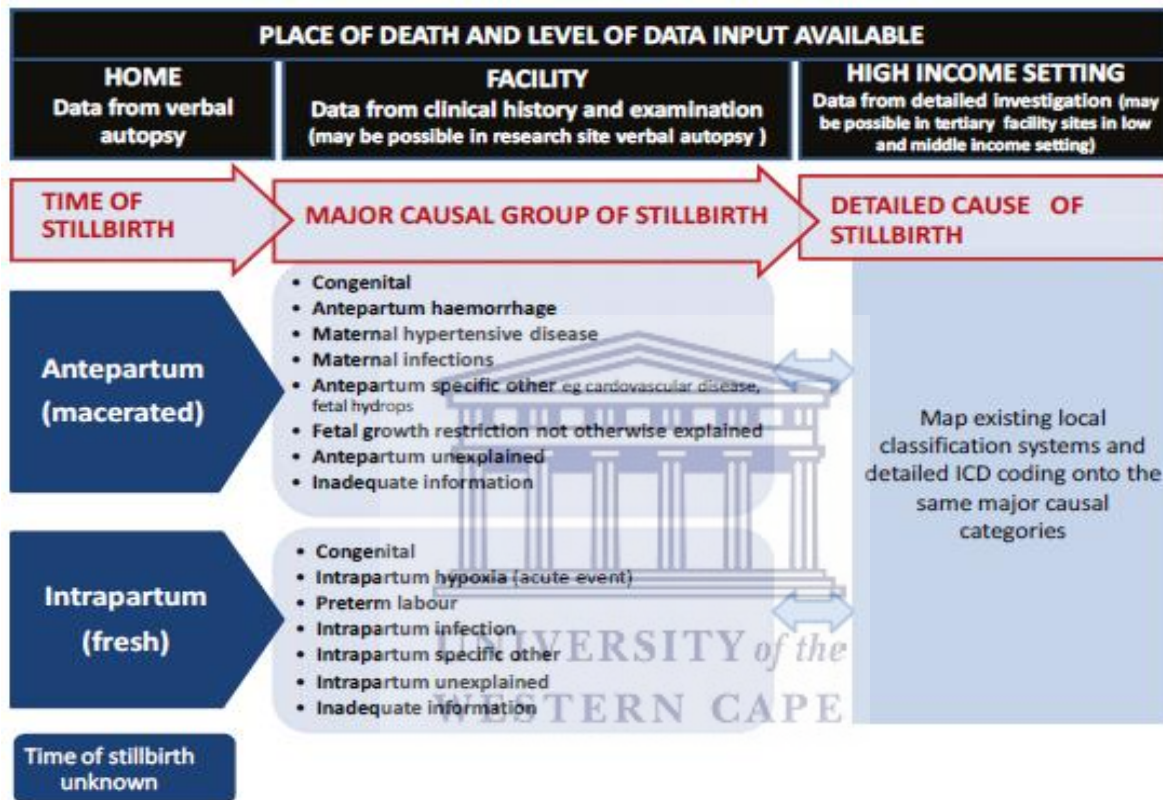
## Stillbirth classification

Differences still persist with regard to stillbirth classifications (24). The variations in definitions have been attributed to medical advances elsewhere that have seen pre-terms survive even before 28 weeks of gestation. In such circumstances, the definition of stillbirth has been adjusted to include foetal loss as early as 18 and 20 weeks. The USA National Center for Health Statistics, Canada and Australia, for example, defines stillbirths as a baby born at least at a gestation age of 20 weeks or more irrespective of



the timing (25) and that did not show any sign of life after delivery such as breathing and heartbeat (26). On the other hand, Canada adjusted the definition further to include pregnancy termination (27). Owing to this, the rates were reported to have increased in Canada from 7.1/1,000 births in 2009 to 10.24/1,000 in 2010 and in Australia to 7.8/1,000 by the close of 2009(25).

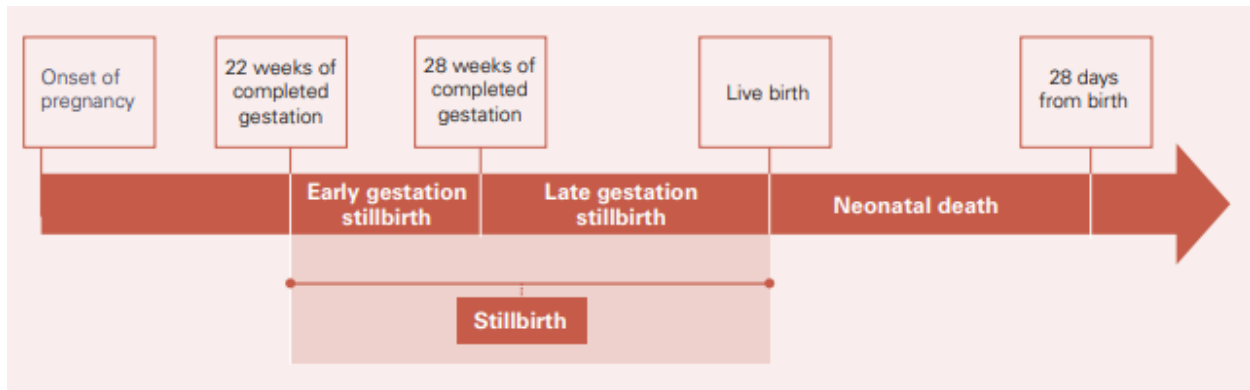
**Figure 1.3: Classification system for stillbirth cause of death**



**Source:** Lawn et al. 2010(24)

For international comparisons WHO recommends reporting of stillbirths as death of a foetus in the third trimester (28 completed weeks) of gestation (28) where a child did not at any time after birth show signs of life such as breathing, heartbeats, pulsation of the umbilical cord or definite movements of voluntary muscles(29).

**Figure 1.4: Stillbirths, live births and neonatal deaths**

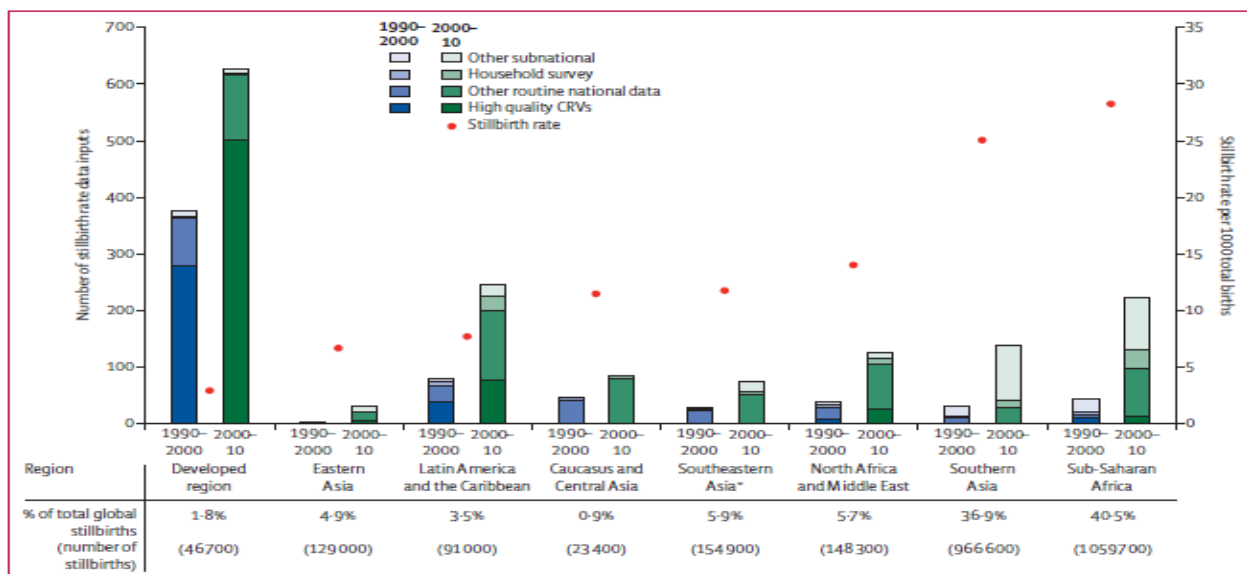


**Source:** UNICEF et al. 2020: A neglected tragedy: the global burden of stillbirth 2020

### Stillbirth rates in sub-Saharan Africa

Sub-Saharan Africa remains one of the regions worst affected by stillbirths. Even then problems of recording continue to hinder proper planning to address stillbirths (30). Globally, only 2% of annual stillbirths are reported (4) while others go unrecorded (31, 32). Under-reporting is cited in many of the statistics. In Ethiopia, for example, the Demographic Health Survey (DHS) underreported perinatal mortality due to omission (33) while in Tanzania only one question eliciting pregnancy-related information was used (34). Elsewhere, underreporting has been attributed to a lack of acceptance of newborn deaths as normal. Perceptions that newborns are not humans for a specified period still hold (35). While data challenges persist, efforts have been devised to estimate the burden.

**Figure 1.5: Availability and type of stillbirth data by region from 1990-2000 and from 2000-2010**

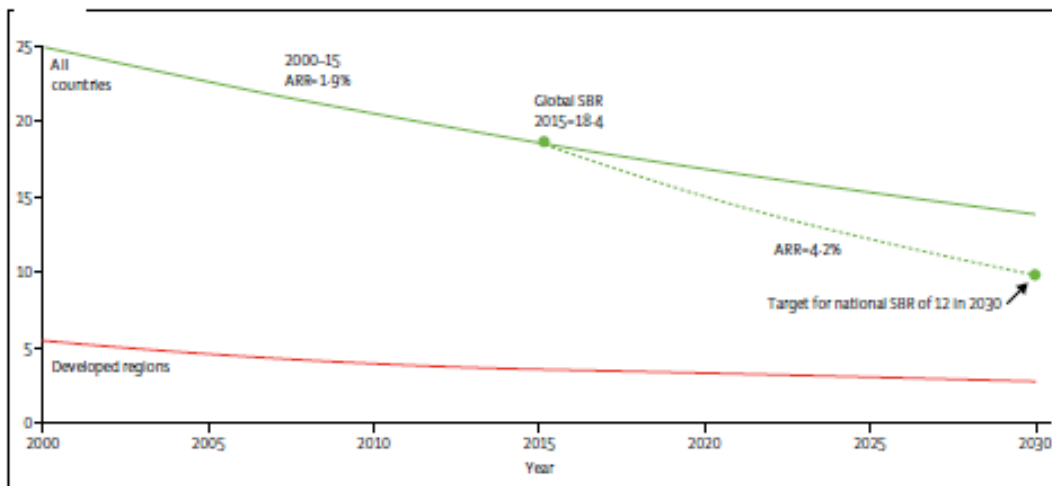


**Source:** Blencowe et al. 2016(8)

### **Global targets for stillbirth reduction**

Global health initiatives starting from the MDGs (2000), which targeted improvements in maternal and child health indicators, attracted investments in health systems which had an effect on stillbirth reduction. Subsequent efforts, for example the UN Global Strategy for Women, Children and Adolescents' Health, included goals for stillbirth reduction. Similarly, the Every Newborn Action Plan (ENAP) set targets for stillbirth reduction (36, 37). The global norms of shared responsibility meant that the obligation for stillbirth reduction transcended borders, with countries expected to do everything within their means to address the problem locally. The 2011 Lancet Stillbirths Series call to action highlighted the gap between this burden and a lack of attention in the global health agenda. The series urged key actors to pay particular attention, especially in the policy arena, to prenatal health and the survival continuum of care (6). The key aspects emphasised for national response included the use of data-driven country analysis, improved care around pregnancy, labour and birth, improved quality of care, strengthened health systems, addressing equity issues, community components, and improved vital statistics. Heightened attention led to the 67<sup>th</sup> World Health Assembly Resolution in 2014 to endorse the ENAP, which targeted a reduction of 12/1,000 by 2030 in support of the UN Secretary-General's global strategy, Every Woman Every Child (36). Countries are at different levels of translating interventions into service delivery (38), with sub-Saharan Africa having the slowest rate of reduction, reflecting extended years to even out the difference and to level with other regions of the world.

**Figure 1.6: Global progress towards Every Newborn Action Plan to end preventable stillbirth by 2030**



**Source:** Lawn et al. 2016(6)



## Health systems response for stillbirth reduction

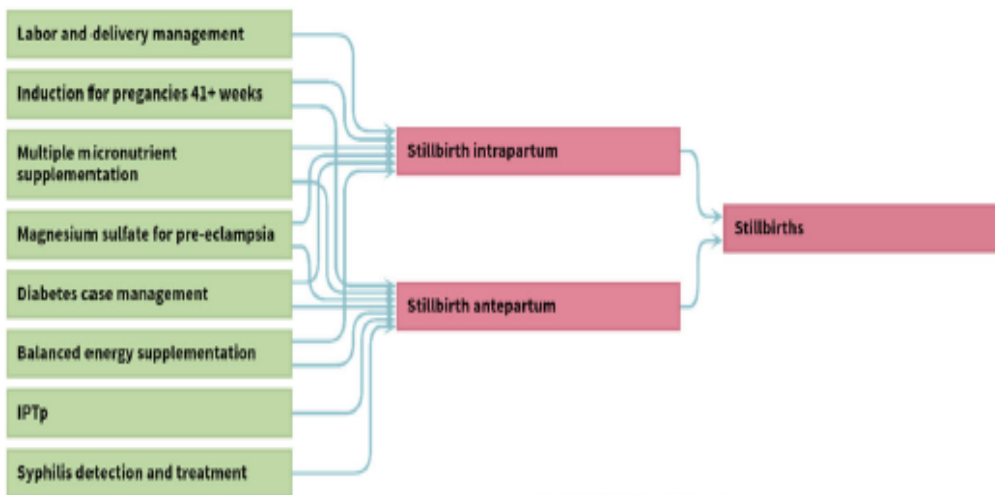
Interventions to address stillbirth risks exist (1, 31). In sub-Saharan Africa, where most of the stillbirths occur, simple and low-cost interventions in maternity care could save many of the cases (39). For example, if backed by a referral level providing comprehensive obstetric care, many stillbirths can be prevented (40). However, suboptimal investments to address stillbirth reduction has resulted in slow and minimal progress (31). The absence of counting stillbirth rates (SBR) has contributed to invisibility and the absence of accountability (9, 41). Slow progress in preventing stillbirths, therefore, suggests an almost public acceptance that it is “one of those things”(39). Different approaches to stillbirth reduction within the health system exist; while some focus on the overall continuum of adolescent maternal, newborn and child health, others focus on the timing of stillbirth.

**Figure 1.7: Prevention of stillbirth within the continuum of adolescent, maternal newborn and child health services**



**Source:** de Bernis et al. 2016(38)

**Figure 1.8: Interventions which impact on stillbirth by timing (antepartum/intrapartum)**

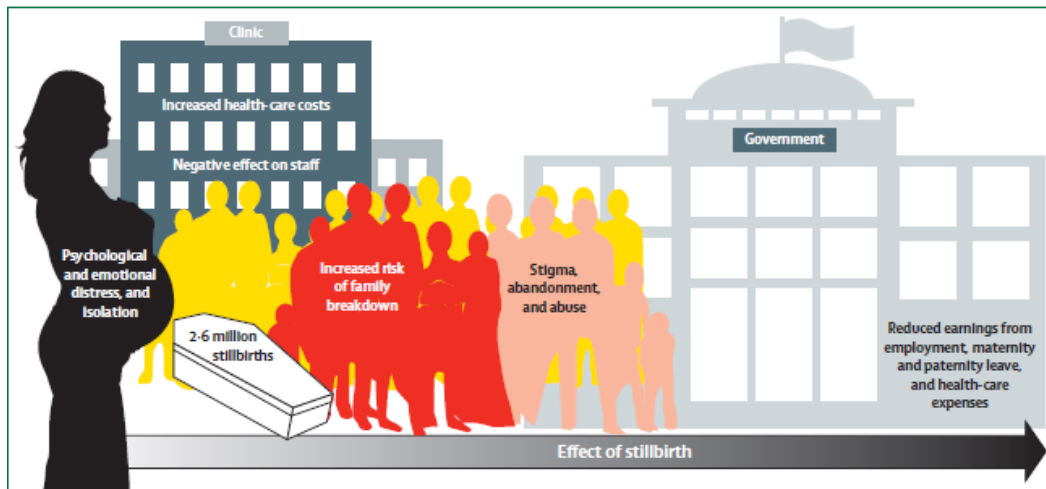


**Source:** Blencowe et al. 2017(23)

### **Community-level efforts in terms of social support**

The effects of stillbirths are varied and these manifest at different levels, such as individual, family, community and health-systems levels (42, 43). Communities have a greater role to play in addressing stillbirths. Managing and preventing loss are largely social processes which are informed by social meanings, expectations and relationships (44). Even when women may prefer to mourn in public, the influence of such relationships forces them to keep stillbirths a family secret (45). Hidden mourning practices of stillbirths are embedded in diverse cultural contexts (46) that are characterised by high infant mortality (47). In the end women avoid care, support and even public burials or display of grief (48). One reason for secrecy is the fear among women that they might be accused of having had an induced abortion (49). Owing to many people attributing stillbirths to witchcraft and evil spirits, beliefs emerge that public burials and displays of grief may evoke future malice that could lead to infertility (34). For these reasons it is critical to address negative community perceptions regarding stillbirths (21).

**Figure 1.9: The effects of stillbirth originating from the death of the baby affecting mother, family, health services, society and government**



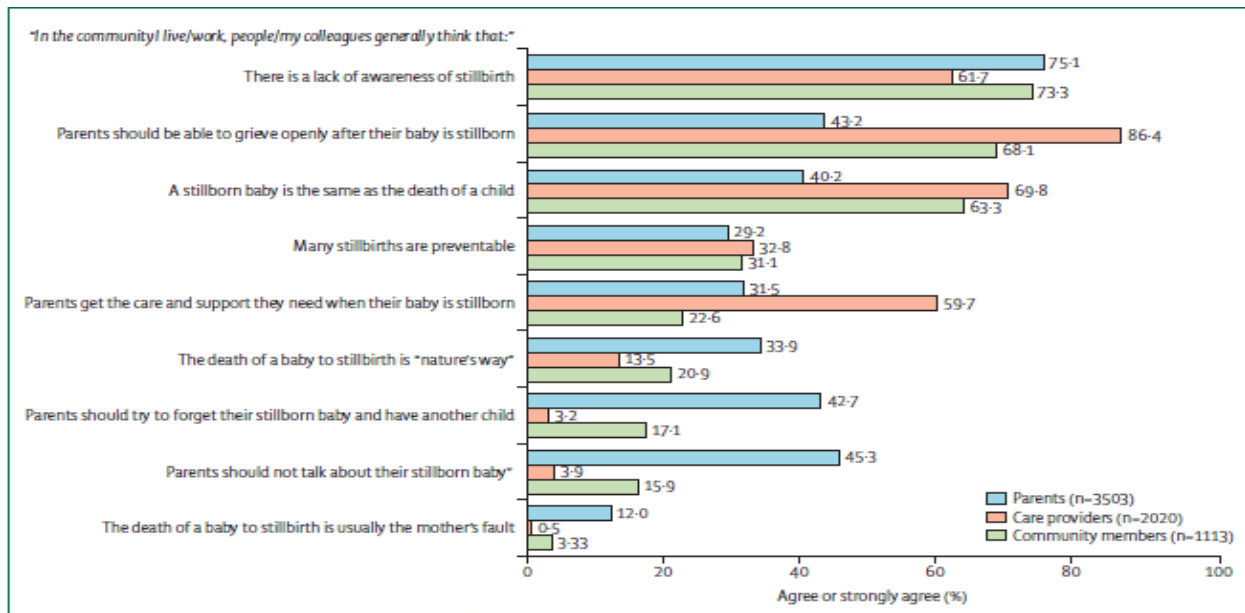
**Source:** Heazell et al. 2016(43)

In the area of maternal health, documented evidence reveals that social networks have provided varied support at different stages, such as pregnancy management, delivery and during postnatal care (50). The social environment has the potential to influence health-seeking behaviours (51). Social networks where pregnant women interact could, therefore, have a significant influence on someone's perceptions of stillbirth risk and subsequent care-seeking. Where the Sustainable Development Goals (SDGs) have placed emphasis on access as a driver of improved health service delivery (52), social networks could be one of the avenues through which better access to health services can be achieved.

### **Individual perceptions of stillbirth risk**

The perception of risk is a major driver in triggering positive health care-seeking behaviours. Differences in risk perception between laypeople and experts see low weights assigned to risk by lay people. This is due to the communication challenges that exist between health workers and laypeople (53). In most cases, laypeople define risk according to local contexts, which subsequently influences their care-seeking behaviours. Cases of inadequate knowledge (54) have also been reported which, in turn, compromises their perceptions of risk. Many of the stillbirth risk factors have the potential to be modified with the correct interventions. Through treatment and support, health complications can be delayed or prevented, with mortality and disability being reduced as well (55). Elsewhere lack of adequate knowledge about stillbirths has been reported, even in developed countries (56).

**Figure 1.10: Survey data on perception of stillbirth in high-income countries**



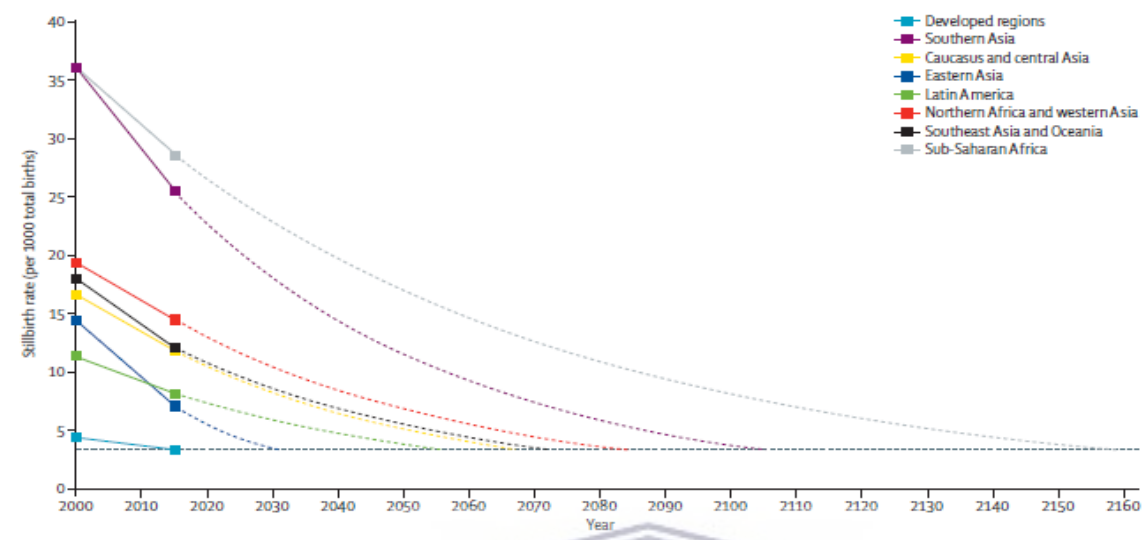
**Source:** Flenady et al. 2016(56)

Tailoring information to individuals' unique needs has been positively associated with promoting risk-reduction behaviours. Several approaches exist to address stillbirth risks. One such approach places emphasis on screening during antenatal care to identify, manage and refer cases for further management (57). Another approach communicates risk using numerical probability (58). This specifically focuses on the presentation of numerical information regarding the probability of the given risk occurring (59). It borrows from the belief that health problems are conceptualised in relation to causes and consequences. The strategy, therefore, presents risks in terms of causes and potential consequences. It links the risk to the individual's own behaviours or medical history that relates to the potential risk (60).

### Rationale for the thesis

At the health-system and national levels, understanding the response to stillbirth is important because the potential of a stillbirth occurring within a short time among normally progressing pregnancies is high, especially intrapartum stillbirth (61). So a health system that can prevent such a death has the potential of responding to other health conditions that are not as delicate and require a quick turnaround time for interventions to yield positive results (62). Weak interventions around emergency obstetric care, poor screening and management of risk factors during antenatal care (ANC) as well as poor recording and lack of autopsy to ascertain the magnitude and possible causes increase the risk of stillbirth. At the moment, sub-Saharan Africa lags behind in efforts to reduce the overall burden and it has been projected that it will take the region more years to even out the gap compared to other continents. Understanding the strategies undertaken to address the problem has the potential of identifying gaps and hence devising strategies to address each.

**Figure 1.11: Time for each region to reach the same stillbirth rate as developed countries in 2015**

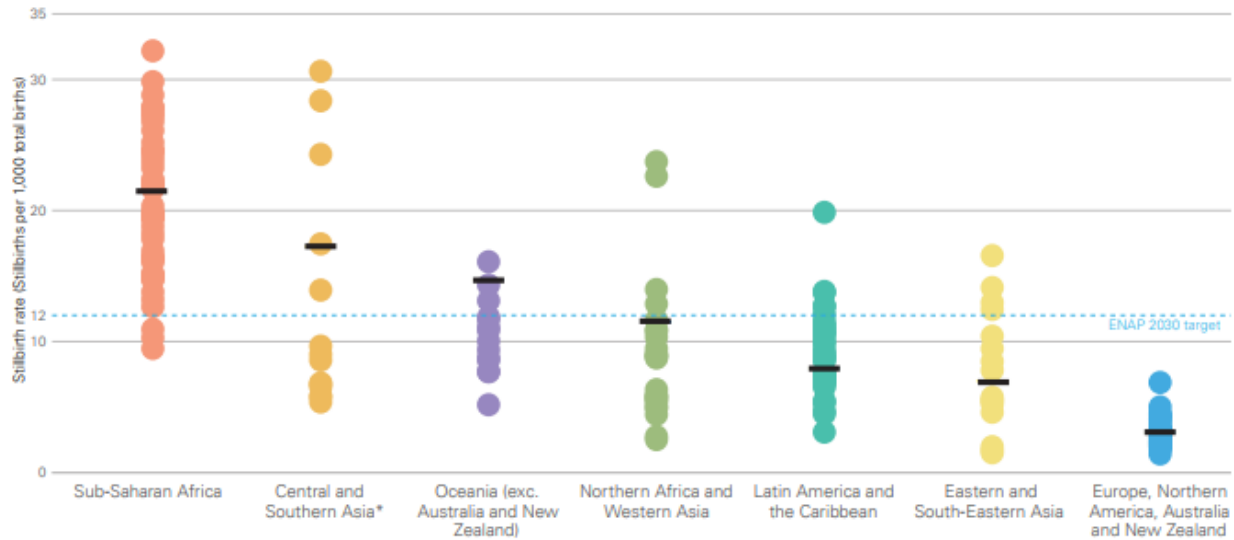


**Source:** Lawn et al. 2016<sup>1</sup>

Stillbirth studies also matter at the population level because previous studies have established that the desire for children increases with the loss of a baby (63, 64). In the process, this increases both the fertility rates and an increased risk of the subsequent pregnancy ending in a stillbirth more so when the pregnancy interval is short (29). This consequently leads to possible population explosions and in an era where demographic dividends are yet to be harnessed, the resulting negative effects call for robust population management interventions. Considering the analysis of global trends, both the stillbirth and fertility rates are highest in sub-Saharan Africa (5) and other regions with a large populations. Addressing the problem therefore has spillover effects and this study set out to explore various efforts undertaken in Uganda with community initiatives to offer support to mothers affected by stillbirth.

**Figure 1.12: Stillbirth rates in countries by SDG region**

<sup>1</sup> Stillbirths: rates, risk factors and acceleration towards 2030



**Source:** UNICEF et al.2020: A neglected tragedy: The Global burden of stillbirth 2020

At the individual level, literature has documented the unspoken grief and pain that the mother and family members go through (65). This is in most cases perpetuated by the cultural beliefs surrounding the management of stillbirths (45). It also arises from the intrinsic pain that comes with human loss after enduring the duration of the pregnancy and several months of anticipation (66). It is, therefore, important to study stillbirths at an individual level because parents that have had this experience before will get to learn of the circumstances that led to it in order to devise ways of avoiding it in future. In the context of this study, results are likely to influence the community's perceptions of risk (67), which has the potential to trigger support-seeking.

### Conceptual framework

The conceptual framework in this study is informed by four theories that guided the development of the research questions, study objectives, data collection and analysis and writing of the final results. They include policy transfer theories, policy implementation theories (bottom-up theory of street-level bureaucracy), social network analysis (network episode model) and risk perception theory. All together, they guided the study through which national level experiences regarding stillbirth prioritisation, intervention implementation and community-level responses were analysed. The study approach took on an exploratory strand to understand the policy translation and implementation processes as well as distil the community-level responses and perceptions of stillbirth risk among mothers.

### Policy transfer theory

The internationalisation of global health norms ushered in an era with new opportunities for nations to bypass the local policy development process characterised by incrementalism to instead learn and adapt from abroad where policy aspects have



been successful. Policy transfer processes emerge from global health norms promoted through the right to health. The global right to health refers to affirmation of the existence of a shared obligation to respect, protect and fulfil the right to health (68). It places an obligation on countries, as one of their primary roles to ensure that these rights are upheld while international actors are involved in ensuring that the same rights are not a privilege of the few (69). The life cycle of norm acceptance involves three stages: proposal of new standards and expectations for behavioural change; acceptance by a critical mass, leading to the cascade of norms across the international systems; and the internationalisation of norms (70). Global solidarity through financial and ethical cooperation is then enforced in bilateral and multilateral arrangements. The aspiration of addressing the global stillbirth burden was one such health norm that received acceptance leading to promotion, transfer and subsequent adoption.

Mechanisms of movement of global health norms from the global level to the national level exist. Within the sub-Saharan African setting, many of the policy initiatives tend to be influenced from the global perspective (71). They are moved through a process termed as policy transfer, and in a number of LMICs trends reveal that it happens around the same time (72). Dolowitz defines policy transfer as a process by which knowledge of policies, administrative arrangements, institutions and ideas from one system are used to guide the development of policies in another system (73). It describes both the push factors from the global level and the pull factors at the national level which, when favourable, can motivate the transfer and adoption of recommendations into policy.

Transfer mechanisms refer to the factors that facilitate the eventual movement of policy ideas in another system. Broadly, they can be categorised as voluntary and coercive. Specifically, at the national level, they can take any of the following forms: learning, competing, coercion and emulation (73). Learning is adopted when success or failure of policy implementation from elsewhere is used to guide the adoption of policy aspects (74). Competition, on the other hand, is ideal in circumstances where countries are competing for resources which make them adjust policy aspects to suit the eligibility requirements for funding support. Sometimes national-level diffusion is influenced by pressure/coercion from international bodies for conformity with set international norms. Emulation happens when there is a general perception of the appropriateness of set international norms to respond to a national health challenge.

### **Policy implementation theory**

The foundation for understanding how frontline health workers implement strategies to address stillbirth risks lies in bottom-up policy implementation theories. The theory of street-level bureaucracy (SLB) postulates that frontline health workers are faced with dilemmas while delivering services (75). This is characterised by a lack of adequate resources to support implementation infused with the desire for continuity of service provision (76). In the end, they devise ways to use the available resources to attain the high-level implementation of policy recommendations. This cannot be done without the

cooperation of the service users and, therefore, attempts must be made to ensure that whatever actions are taken, the cooperation of service users is secured.

At the time of theorising this policy implementation discourse, policy implementation was mainly a top-down affair and the desire to understand policy failures and why anticipated policy objectives were not achieved was often not realised. Lipsky came up with the theory in the late 1960s in an attempt to understand urban politics in North America. It expanded the scope of public administration at subnational level beyond consisting only of traditional approaches that primarily focused on formal structures and rules to include discretion and control manifested in the day-to-day operations of street-level bureaucrats which, in a real sense, became the implemented policy (77). Discretion as a glue that binds the frontline workers' operations enables the smooth operation and continuity of service delivery without much friction or antagonism in service delivery (78).

The main driver of this apparent context of implementation stems from the confusing and complex guidelines that nonetheless have to be translated into service delivery (79). Policy intentions often manifest as overly vague, ambitious, ambiguous and conflicting with the requirement to fit them in scarce resources, further warranting the prioritisation of policy aspects. The multiple interpretations by the different frontline workers create variations in implementation which is informed by the discretionary privileges at their disposal (80). This is mainly compounded by the pressure to follow official guidelines and a balance between contextual aspects for particular cases.

Further to policy ambiguity, high service user expectations and insufficient resources to support implementation create fertile ground for the exercise of discretion (76). The bid to ensure uniformity of implementation renders managers' roles of controlling and directing even more complicated, given the scarce resources and varying interpretations of the policy requirements by the frontline workers (80). This is partly explained by the differing goals of managers and frontline workers, where the former focus on uniform implementation while the latter pay attention to maintaining their discretionary powers, which enables them to deliver services. Nonetheless, their relationships remain interdependent because each needs the other in the pursuit of the policy goals (75).

### **Social network analysis**

Social network analysis refers to a set of methods to map, measure and analyse social relationships (81). Recent advances in social network theory postulate that it is one of the invisible social assets with the potential to influence health care-seeking behaviours but also support-seeking, especially when faced with health complications. This realisation has long been established in explaining the health service utilisation patterns. Its utility lies in its ability to be applied both as a theory and as a method (82). The network context in which individuals make decisions about health, illness and care-seeking is critical in determining health-seeking behaviours.



Two mechanisms of connection and contagion have been especially critical in explaining the trigger for the flow of resources within networks. Whereas connection refers to the proximity and interrelationships among individuals of a particular network, contagion refers to the spread of particular behaviours of reciprocity among members (83). The mechanisms for social networks function through social-centric and egocentric approaches. Social-centric looks at the network as a whole with actors embedded in a web of direct and indirect relationships within a closed environment and is better used to explain shared or group effects. Egocentric, on the other hand, places emphasis on the unique features of individuals and the connections they have with others with whom together they form the networks in which relationships and exchanges occur (84).

The amount and quality of assets are informed by the strength or weakness of particular networks. Stronger networks are composed of close members, such as family and friends, or contain social network quality measures, such as trust, emotional closeness and frequency of contact (85). Conversely, weak networks have been observed to compose of acquaintances or among network members with loose interactions (86). Normative influence on behaviours, social safety nets and social control exerted by network members are mechanism known to motivate or curtail health-seeking behaviours (87). As a theoretical framework, the Network Episode Model (NEM) guides the understanding of support-seeking within a network context and the role that interactions play in shaping decision-making (88).

The network episode model emphasises social rather than individual action in conceptualising the support-seeking processes. The model's point of departure is that support-seeking processes are a result of the society in which people live. It relies on four basic assumptions, which include: 1) the availability of many actors to whom the network member turns for support; 2) actors that rely on more than the cost-benefit rationality; 3) decision-making as a dynamic process; and 4) decision-making based on interactions. Social fabrics – known as norms – define parameters for health care-seeking behaviours. Decisions around care-seeking are a process informed by dynamics such as social settings and severity of the condition. Applied to explore social support after experiencing a stillbirth, the NEM model postulates that the relationship between social network and social support holds a reciprocal influence and changes over time as individuals recover from the grief period.

### **Risk perception theory**

Risk is the possibility of an adverse outcome and uncertainty over the occurrence, timing or magnitude of that adverse outcome (89). According to Menon et al. 2006, it is the perception of the subjective likelihood of the occurrence of a negative event related to the health of a person over a specified period of time (90). Variations exist in the perception of risk between experts and laypeople (89). On the one hand, risk perception is informed by the numerical probability-based approach (91) that specifically focuses on the presentation of numerical information regarding the probability of the given risk occurring (92). On the other hand, perceived risk is a product of a contextualised

approach where meaning, reason and understanding of risk are considered (93). Scientific risk is mainly communicated from the technical parameters and probabilistic statistics while laypeople factor in other aspects, such as catastrophic potential, involuntariness, controllability, and equity in sharing potential risk among the community (89).

WHO defines risk communication as the exchange of real-time information between experts and people under a health threat whose aim is to trigger informed decision-making to avert the risk or take appropriate measures. Consensus around the need for specific capacities for effective risk communication includes preparedness, response and recovery to effect evidence-informed decision-making, positive behaviour change and trust maintenance. To this end, a clear understanding of people's beliefs and concerns which informs their perceptions about a particular risk is key.

Situations arise when individuals previously at an elevated risk tend to respond to particular risk reduction strategies in ways that are less safe. The scenario is known as risk compensation (94). In peculiar situations, individuals tend to have a minimum level of acceptable risk informed by our subconscious mind and will play out through increased engagement in risky behaviours when perceived risk decreases. This places value on including different variables such as the cognitive (people's knowledge and understanding about risk), emotional and traditional experience (personal experience), the socio-cultural (social amplification of risk, trust, values) and individual difference (education level). In investigating stillbirth risk perception, bearing in mind the different dimensions are key to understanding women's views regarding the subject.

### **Professional background and motivation**

Save for the study background, public health significance, health systems relevance and the applied conceptual and theoretical frameworks, the decision to undertake this study was to an equal extent informed by my professional background and exposure. This was due to the access of study topic-related information that I had prior to undertaking this journey. My first encounter with work on stillbirths was around 2014-15 during a scoping review task in preparation for an article for the Lancet Stillbirth Series 2016. The gaps identified in the community and health systems response towards affected mothers and their families seemed to me a convincing rationale for the desire to pursue more knowledge and contribute towards addressing the same. Within the Ugandan context, it seemed to me that there were many gaps in existing knowledge in which to anchor my future research projects. My interest in stillbirth research has continued to grow since then and the culmination is this PhD project.

Since 2010, I have been working with the Makerere University School of Public Health (MakSPH) in the Department of Health Policy Planning and Management (HPPM) as a research fellow. I once worked under the close supervision of Assoc. Prof. Peter Waiswa, whose work in reproductive maternal and newborn health has made a global mark, especially with regard to learning from the Global South. Within that time, the global

call to action towards stillbirth as a neglected public health challenge saw the publication of two Lancet Series dedicated to the same (2011 and 2016) and the BMC Stillbirth Series in 2016. I contributed to the 2016 Lancet Series as a co-author highlighting the unspoken grief by mothers and their families after experiencing a stillbirth. The first ever Maternal and Newborn Health Conference, which was supported by Save the Children, was held in Kampala and organised by the HPPM Department of which I am a member and with which was actively involved.

Between 2011 and 2016, I worked on the Community and District Empowerment for Scaling-Up (CODES) project under the HPPM. It was implemented with support from the Bill and Melinda Gates Foundation and UNICEF. It was a district health system strengthening project whose aim was to build district-level capacities through a management intervention to equip district health management teams to respond and address the burden of diarrhoea, pneumonia and malaria among children under five years in high-burden districts in Uganda. My lasting impression from this work was the hardships that district health managers endured to plan for the delivery of services, including maternal and neonatal health, which was often constrained by the lack of adequate fiscal and decision space to execute all planned activities. In the end, many found themselves having to recycle work plans from previous years, thus opting to carry forward and prioritise the implementation of interventions that were missed out in the previous year. This made me appreciate the challenges of planning for health systems at subnational level even when the individual district managers are well intentioned with regard to addressing the stillbirth burden.

### **General aim**

The general aim of this study was to explore and provide an overall understanding of the national policy response to the stillbirth burden, including the translation of global campaign strategies into national health systems aspirations, how interventions are adapted at subnational level to translate into service delivery, the community response in terms of social support to women after experiencing a stillbirth and how individual women perceive the stillbirth risks.

### **Specific aims**

1. To analyse the policy response and current strategies to reduce the stillbirth burden in Uganda.
2. To explore the subnational-level prioritisation of interventions through the influence of frontline health workers in the translation of policies to mitigate the stillbirth burden.
3. To examine the role of women's social networks in the provision of social support to mothers after a stillbirth.
4. To assess women's perceptions of stillbirth risks.

## Outline of the Thesis

In this chapter, I highlighted stillbirth as an area requiring further research. With specific information, I have demonstrated the global burden, existing frameworks for stillbirth pathways, classification systems, the rates in sub-Saharan Africa and the global targets for reduction. The chapter also highlighted the progress towards the set targets, community-level efforts towards reduction and the individual-level perceptions of stillbirth risks. Finally, it pointed to the discomfiting situation the sub-Saharan African region is currently faced with regarding the time required to attain global targets vis-à-vis other regions. As I conclude this first chapter, the structure and flow of the remainder of the thesis is outlined. This thesis follows a research paper style as recommended by the University of the Western Cape guidelines for doctoral theses by publication and approved by Council in 2012. The thesis results section forms seven of the chapters (Chapters Two to Five) that are objective-specific stand-alone manuscripts whose slightly modified versions have either been published, submitted for publication or are being prepared for submission to peer-reviewed journals for publication as soon as they are formatted per journals' guidelines. Chapters Six to Eight contain additional results that have been submitted for publication arising from the data collected.

Starting with **Chapter One**, I provide the background to the study, specifically looking at the global stillbirth burden, the trends in rates over the years, the situation in sub-Saharan Africa as a region having the greatest burden, the global efforts to respond to the problem and how that has been embraced in Uganda, as well as the rationale and motivation for conducting this study.

**Chapter Two** draws on the global perspectives to establish a link to how recommendations from the global norms/campaigns get adapted into the national health systems through revisions to or the introduction of new policy aspects to accommodate these recommendations. It describes the findings of an exploratory study focusing on the factors that influenced the prioritisation of stillbirth reduction in Uganda. This chapter was published in the journal BMC Globalization and Health. (Ssegujja E, Andipatin M. Building on momentum from the global campaigns: an exploration of factors that influenced prioritisation of stillbirth prevention at the national level in Uganda. BMC Globalization and Health. 2021; 17:66 Available from: <https://doi.org/10.1186/s12992-021-00724-1>).

**Chapter Three** addresses the second objective and documents a detailed account of the prioritisation processes at the subnational level spearheaded by the frontline health workers in responding to stillbirth risks. Adopting an exploratory approach, it details the mechanisms and strategies taken by frontline health workers that negotiate between the resources available while paying attention to the overall health systems aspirations. This chapter was published in the journal BMC Health Services Research. (Ssegujja E, Ddumba I, Andipatin M. Prioritisation of interventions in pursuit of maternal health policy objectives to mitigate stillbirth risks. An exploratory qualitative study at



subnational level in Uganda. BMC Health Services Research. 2021; 21:53. Available from: <https://doi.org/10.1186/s12913-020-06046-z>).

**Chapter Four** draws on the community perspective by investigating aspects of social support to women during pregnancy and after experiencing a stillbirth. Communities have been known to attach stigma to mothers and their families after experiencing a stillbirth. This paper explores the positive aspects of social support prevalent in the women's networks that can be harnessed to address some of the challenges impeding efforts to respond to stillbirth risk factors at the community level. This work was published in the journal BMC Women's Health. (Ssegujja E, Mulumba Y, Guttmacher S, Andipatin M. The role of Social networks in provision of support to women after stillbirth. Experiences from Uganda. BMC Women's Health. 2021; 21:352 Available from: <https://doi.org/10.1186/s12905-021-01498-9>).

**Chapter Five** presents a research paper that explores the women's perceptions of stillbirth risk at the community level. Risk perceptions have been known to motivate health care-seeking behaviours but they vary significantly between laypeople and health workers. This study therefore had an interest in establishing the women's perceptions of stillbirth risk and how that can be tapped into to create awareness of the same and stimulate utilisation of the available maternal health care services. This work has been submitted to the journal BMC Public Health.

**Chapters Six, Seven and Eight** present results from additional papers which specifically cover results from further analysis of the data, including Chapter Six, which reports on the variations in the implementation of interventions to address stillbirth between the national and subnational levels. The next chapter covers health workers' social networks and their influence in the adoption of strategies to address the stillbirth burden at subnational level. Chapter Eight covers an exploration of health workers' experiences in providing care to stillbirth-grieving mothers. They, too, have been submitted to the journals BMC Health Systems Research and Policy, BMC Global Health Research and Policy, and BMC Public Health, respectively, for publication.

**Chapter Nine** presents the conclusions and recommendations that delve into the take-home message from all the sub-studies that were conducted and draw on recommendations for consideration, moving forward.

**Chapter Ten** presents a PhD and thesis afterword which presents reflections from study experiences and the author's deduction of the learning acquired along the way.

**The next section (Appendices)** presents a compilation of all the materials that were used during this study as appendices. These include study tools, ethical and administrative clearance letters and correspondence as well as reviewers' comments while submitting the manuscripts for publication.

### **Ethical Clearance**

Ethical approval was granted by the Ugandan National Council for Sciences and Technology (SS 4575) while the study received scientific review from the University of the Western Cape Biomedical Research Ethics Committee (BM/17/9/1) in South Africa and from the Makerere University School of Social Sciences Research and Ethics Committee (MAKSS REC 12.17.110) in Uganda. Administrative clearance to conduct the study was obtained from the district authorities. Individual written/verbal informed consent was obtained from all respondents before the interview were conducted.

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## CHAPTER TWO

### Paper One

#### **Building on momentum from the global campaigns: An exploration of factors that influenced prioritisation of stillbirth prevention at the National Level in Uganda<sup>2</sup>.**

##### **Scope of the chapter**

This chapter presents results from the first paper that conducted an exploration of factors that influenced the prioritisation of stillbirth prevention at the national level in Uganda. It adopted a framework from Schiffman (2007) that guides the analysis of political prioritisation for global health-related interventions. Specific to stillbirth reduction efforts, global campaigns played a key role in drawing attention to stillbirth as a major public health concern that was affecting both the developed and low- and middle-income countries in different measures. Adoption and integration of strategies from those campaigns into the national-level health systems, however, have a great deal to do with national priorities and implementation contexts to realise the set objectives. This paper explores the processes leading to national-level adaptation and political commitment to address stillbirths arising from the set agenda by the global stillbirth prevention campaigns. The results of this research were published in the journal BMC Globalization and Health.

##### **List of tables**

Table 2.1: Schiffman's framework for analysing political priority

Table 2.2: Global events and timelines

Table 2.3: Key events for national-level stillbirth prioritisation

##### **List of figures**

Figure 2.1: Trends in national average performance in the district league table indicators

##### **Data sharing arrangements**

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<sup>2</sup> A slightly modified version of this article was published in the journal BMC Globalization and Health

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## Abstract

**Background:** Of the close to 2.6 million stillbirths that happen annually, most are in low-income countries where, until recently, policies rarely paid special attention to addressing them. The global campaigns that followed called on countries to implement strategies that address stillbirths and the adoption of recommendations varied according to contexts. This study explored factors that influenced the prioritisation of stillbirth reduction in Uganda.

**Methods:** The study employed an exploratory qualitative design that adopted Shiffman's framework for political prioritisation. Data collection methods included document review and key informant interviews (KIIs) with a purposively selected sample of 20 participants from the policy community. Atlas.ti software was used for data management while thematic analysis was conducted to analyse the findings.

**Findings:** Political prioritisation of stillbirth interventions gained momentum following norm promotion from the global campaigns which peaked during the 2011 Lancet Stillbirth Series. This was followed by funding and technical support of various projects in Uganda. A combination of domestic advocacy factors, such as a cohesive policy community converging around the maternal and child health cluster, accelerated the process by vetting the evidence and refining recommendations to support the adoption of the policy. The government's health systems that strengthened aspirations and the integration of interventions to address stillbirths within the overall maternal and child health programming resonated well.

**Conclusion:** Transnational influence played a key role during the initial stages of drawing attention to the problem and the provision of technical and financial support. The success and subsequent processes, however, relied heavily on domestic advocacy and the national political environment, and the cohesive policy community.

**Keywords:** stillbirth, global campaigns, national prioritisation, norm promotion, policy community, maternal and child health

## **Introduction**

Globally, up to 2.6 million stillbirths occurred in 2015, with most of the cases occurring in low and middle-income countries (LMIC), in rural areas, and during the intrapartum period (1-3). Campaigns to draw attention to the problem called for particular attention, especially in the policy arena, to respond to prenatal health and the survival continuum of care (4). Earlier responses included estimation of the burden (3), although this was constrained by inadequate data due to inadequate data captured in the vital statistics (5). This was evident while compiling the countdown to the Millennium Development Goals (MDG) reports which, despite its burden, was initially not one of the indicators for tracking (6). As global momentum grew, punctuated by a “Call to action”, “ENAP” and “Ending preventable stillbirths”, so did national-level efforts to translate campaign recommendations into service delivery (1, 7-9).

The adaptation of global recommendations into national and subnational-level service delivery involves negotiating blurred lines between interventions to address maternal and neonatal mortality(10). As such, the potential to save mothers and neonates led to calls for the strengthening of health systems for a triple return on investment (11). However, despite this potential, it is not clear why stillbirths did not receive the same rates of reduction as maternal and child mortality (12). Maternal and child health (MCH) interventions include the promotion of early antenatal care attendance and completion of the recommended antenatal care visits as well as the promotion of facility delivery under a skilled attendant. For this study, we restrict the discussion of interventions to address stillbirths that were promoted through the global campaigns whose momentum peaked with the 2011 Lancet Stillbirth Series: Call to action. Stillbirth is understood as foetal death after twenty-eight weeks of gestation(13). The campaign postulated that improving care around delivery through offering emergency obstetric care services has the greatest effect, with syphilis treatment having a moderate effect while advanced antenatal care (ANC) would have the least effect. Delivering such services at universal coverage (99%) was estimated to lead up to 45% of third-trimester stillbirths being averted on top of 54% maternal deaths and 43% neonatal deaths being averted per year (9, 10).

In the sub-Saharan African region, and Uganda in particular, delivering interventions to address stillbirths include improving the quality of services during the intrapartum period, antenatal care, and along the continuum of care for women’s health. Available evidence suggests that interventions during the intrapartum period have the potential to address most risk factors once identified early with relevant remedies provided (10). These include facility delivery under a skilled birth attendant and delivery of emergency obstetric care services. In Uganda, several interventions have been implemented in this direction, such as operationalisation of Health Centre (HC)IVs to deliver comprehensive emergency obstetric care, with HCIII offering basic emergency obstetric care and HCIIIs

delivering outpatient maternal health services, among others (14). Interventions implemented during antenatal care include the detection and management of maternal disorders and foetal complications, while interventions along the continuum of care for women's health include folic acid fortification, sleeping under insecticide-treated bed nets, malaria prevention using the intermittent preventive treatment, and syphilis detection and management (9). Some interventions are currently integrated within the routine standard of maternal health care services, with referrals recommended at service provision level unable to offer the required services (14).

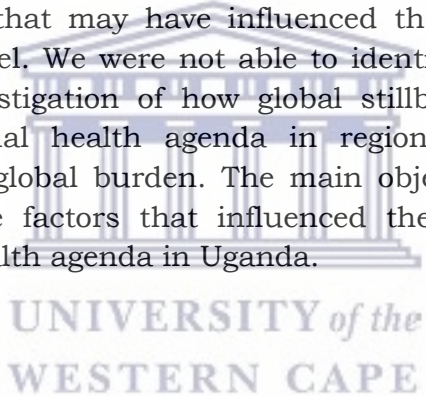
A demand-side gradient of the causes of and response to stillbirths is also evident. The high rates of teenage pregnancy in Uganda mean increased risks of stillbirth (15). The distance to health facilities, where the average distance is within five kilometres, is still a major barrier to health services access (14). Inadequate knowledge about stillbirth and measures to mitigate the risk factors (16) contributes to the poor health-seeking behaviours towards maternal health services, as reflected in suboptimal completion of recommended visits and health facility deliveries (17). The resultant effect is that women miss out on the opportunity to benefit from this vital care which is crucial for identifying and responding to stillbirth risk factors. The negative cultural dynamics surrounding maternal health care-seeking decision-making coupled with stillbirth taboos impede support-seeking due to the stigma attached to the mother and her entire family (16). At the health system level, the postnatal care services offered to mothers after a stillbirth is still inadequate (18).

More remains to be seen regarding how national-level governments embraced global stillbirth campaign recommendations and translated them into service delivery. Evidence from similar efforts within maternal and child health demonstrates mixed levels of adaptation (19, 20). In some of the cases, countries were quick to embrace the recommendations and results were visible on some key indicators, while it has taken time for others to adopt the recommendations (20). In Malawi and Mali, for example, initiatives to promote neonatal survival led to the adoption of effective interventions (21). Slow adaptation of global campaigns led to suboptimal progress in addressing maternal mortality reduction in Nigeria (20).

The global response towards the stillbirth burden offers a unique opportunity to understand the influence of global campaigns on national-level policy processes and political prioritisation. According to Shiffman (2007), political priority is present when leaders publicly and privately express concern and support for an issue, the government through its legislative function enacts policies and guidelines that embrace strategies to address the problem, and the government allocates and releases funds that are commensurate to the problem (20). In Uganda, the accelerated political prioritisation was reflected in efforts to implement interventions geared towards stillbirth reduction. This followed the formulation of global strategies aimed at reducing stillbirth rates, and the campaigns prioritised regions with the highest contribution to the burden, which included sub-Saharan Africa and Asia (13). The initiative called upon countries to

strengthen health systems, and to implement proven high-impact low-cost interventions during the antenatal and intrapartum periods along the continuum of care for women and children (10). We noted recommendations for the integration of targeted interventions within women and children’s health programmes from the campaigns (22). Country-level data on the extent to which these recommendations were implemented remains minimal since each country adopted varying strategies according to their health systems capacities (10).

The global campaigns played a key role in drawing attention to stillbirths as a neglected public health problem (11). The campaign was in part accelerated by its adoption within the United Nations (UN) system, thereby committing member countries to devising and implementing strategies to reduce the burden at the national level (8). In 2014, the Every Newborn Action Plan (ENAP) set a stillbirth reduction target of 12/1,000 or less by 2030. This reflected commitment to the set targets and the implementation of strategies at the country level has varied based on contexts as witnessed elsewhere from country-level experiences (20). There remains a paucity of information on the extent of prioritisation and the underlying factors that may have influenced the prioritisation of stillbirth reduction at the national level. We were not able to identify any previous study that conducted an in-depth investigation of how global stillbirth campaigns influenced prioritisation on the national health agenda in regions that were identified as contributing to the highest global burden. The main objective of this paper was to explore and understand the factors that influenced the prioritisation of stillbirth reduction on the national health agenda in Uganda.



**Methods**

**Study design**

The study adopted an exploratory qualitative design as part of a larger mixed-methods study. To capture national-level factors that influenced prioritisation of stillbirth reduction, a national-level qualitative study employing a document review and key informants’ interviews with respondents knowledgeable about national-level maternal and child health policy process drawn from established policy networks was conducted.

**Framework**

We adopted Shiffman’s framework for analysing political prioritization (20). It analyses nine factors grouped into three dimensions that include transnational influence, domestic advocacy, and national political environment. It is described in detail in Table 2.1 below.

**Table 2.1: Shiffman’s framework for analysing political priority**

Category	Factor	Description
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Transnational influence	Norm promotion	Efforts by international agencies and actors to establish global norms.
	Resource provision	Provision of financial and technical support from international agencies to address the problem.
Domestic advocacy	Policy community cohesion	The degree to which national-level promoters coalesced as a political force to push the government to act.
	Political entrepreneurship	The presence of respectable and capable national champions willing to promote the cause.
	Credible indicators	The availability and strategic deployment of evidence to demonstrate the presence of the problem.
	Focusing events	The organisation of forums to generate national attention to the cause.
	Clear policy alternatives	The availability of a clear policy alternative to demonstrate to political leaders that the problem is surmountable.
National political environment	Political transition	Political changes that positively or adversely affect prospects for promotion.
	Competing health priorities	Priority for other health causes that divert policymakers' attention away from the problem.



### Study sample

The sample comprised purposively selected individuals from the national-level maternal and child health policy communities. At the design stage, the inclusion criteria were set to interview only those respondents that had spent at least two years in their positions. These key informants were pre-identified as eligible for interview. These were the same criteria applied to respondents that were snowballed after study commencement from leads provided during the interviews. A list of potential respondents with their contacts was generated following consultations with contacts familiar with national-level maternal health policy processes. Additional respondents were selected based on leads from the Ministry of Health (MoH) depending on the contribution of such individuals to the policy processes. They were drawn from the MoH, professional associations, implementing partners, academia and the private sector.

Respondents were approached through telephone calls via which the objectives of the study were explained and they were asked if they were willing to participate. An indication of willingness to participate was followed with arrangements being made for a day, time and place where the interview would be conducted that is convenient and



secure for the respondent. A total of 20 key informants (KIs) were interviewed and only three potential respondents who had indicated willingness to participate were not interviewed after failure to schedule an interview on the third call-back. The common reason given by two of them was their busy schedule as this was the time of finalising the health sector budget for the subsequent financial year beginning July 1<sup>st</sup> while the third potential respondent could not find time within the data collection period. For the document review, a process tracking method of key events guided the sampling of key documents used in this review. They included discussion papers, reviews, original studies, editorials, commentaries, web articles, government policy documents and guidelines, as well as reports from government and other organisations.

### **Data collection**

The data collection process deployed two main methods, including key informant interviews and document review. Key informant interviews were conducted by the first author (ES) assisted by two female graduate-level research assistants. The key informant interviews were conducted between March and June 2019 primarily at the respondents' places of work or any other preferred convenient location. Interviews were conducted face to face with audio-recording and with field notes taken during the interview that lasted between 45 minutes and one hour, depending on the point at which saturation was attained. An interview guide was specifically developed for this study by the first author and reviewed by the last author. It contained open-ended questions and probes to stimulate discussion, which were later harmonised and organised following the factors reflected in the applied Shiffman's theoretical framework (20). A maximum of two call-backs were made in case the first appointment did not materialise after which another respondent would be identified. Field notes were taken during the interview process and at the end of each field day during the debrief meetings. Overall, 17/20 were females and drawn from the Ministry of Health (5), non-governmental organisations (NGOs) (4), professional associations (6), private-not-for-profit health facilities (2), academia/researchers (2) and from private-for-profit health facilities (1). However, the respondents' places of work were not mutually exclusive as some doubled as providers of varying services in the categories used in this study.

The document review involved a search strategy following the process tracing technique (20, 23) guided by key milestones identified in the earlier literature review. It followed global health initiatives to draw attention to the burden of stillbirth and efforts towards reduction as highlighted in global health databases and journals. The second stage included searching through grey literature. This was followed by a search on Google Scholar in line with the grey literature search approaches used elsewhere (24). Key organisations involved in stillbirth advocacy were targeted via some of the grey literature (25). Lastly, a backward and forward search through reference lists of included documents was done. The document search and analysis (26) were done by the first author with a second review done by the last author (MA), who was the supervisor. The review sought to document the global processes that culminated into campaigns that

led to the translation of emerging ideas and frames into national-level prioritisation of interventions to address stillbirths.

### **Data analysis**

All interviews were conducted in English and hence the audio-recordings were transcribed verbatim by two research assistants who participated in the data collection. The first author read through each of the transcripts to ensure all the information was captured. Data were analysed using Atlas.ti, a qualitative data management software package (27). The process involved entering transcripts into the software where a codebook following the Shiffman theoretical framework was developed by the first author and used for coding. Chunks of text relating to a particular code were highlighted and attached to specific codes. Thereafter query reports were run for each of the codes and a manual pile sorting exercise was conducted to identify underlying meanings, which led to the grouping of texts with similar meanings under different sub-themes within the main framework construct. Finally, we employed the Consolidated Criteria for Reporting Qualitative Results (COREQ)(28) to guide the reporting of the qualitative data where selected typical quotes representing the sub-theme were used to support the presentation of the results. To control for bias, analysis of data from the two data collection sources was done concurrently with a back-and-forth triangulation.

### **Methodology integration**

The research question and the study design were informed partly by the literature review, the result of which informed the sub-study investigating national-level prioritisation of stillbirth reduction in programmes and policies. The document review informed the process tracing exercise (23) and was confirmed through key informant recollection of the process and highlighted key events. In the first section of the results, the timelines reflecting international and local events leading to the prioritisation of stillbirths were re-constructed. This informed the development of the interview guide used during data collection among national-level key informants, whose qualitative results are presented in the subsequent sections. They correspond to the categories highlighted in Shiffman's framework that include transnational influence, domestic advocacy and the national policy environment (20). A complete range of integration of the document review and qualitative results is reflected in the results section where both findings augment each other in explaining the main themes of the study and in the discussion section.

### **Results**

To understand stillbirth prioritisation in Uganda, reference is first made to global events. Table 2.2 shows that stillbirths did not receive much global recognition before 2005. Earlier national-level efforts were mostly led by bereaved parents organising themselves to bring the issue of stillbirths to the fore (29). Specifically, the International Stillbirth Alliance (ISA) was started in the USA in 2003 by three mothers to stillborn babies and was aimed to push for improvements in bereavement care, prevention research and

clinical care, which has since grown into a global movement (30). The publication of the countdown reports that reflected it as a missing maternal and child health indicator amplified these efforts (31). Global momentum to draw attention to this omission was building alongside pre-term birth and neonatal health and during 2009 a prematurity and stillbirth conference was held where participants designed a roadmap to address the issue (32). Subsequent initiatives led to the publication of the Lancet Stillbirth Series in 2011(2) and its inclusion in the countdown report to raise global visibility and call to action (33). National efforts to prioritise stillbirth reduction were not new to the health systems strategies but rather only received a boost from these global campaigns. With time, they were reflected in the Annual Health Sector performance reports, with some interventions being included to reduce stillbirths as part of programme components in maternal and newborn projects. Later, stillbirth reduction strategies were included in the national guidelines.

## **Transnational influence**

### ***Norm promotion***

A key factor of transnational influence was the promotion of norms that are critical for addressing a public health challenge. Initially excluded as one of the indicators for tracking under the MDGs, stillbirth came to the fore while the report for the countdown to the MDG targets was being prepared in 2015(33). The report was intended to act as an accountability measure to keep up the MDG pace while recognising achievements (12), wherein the 2010 countdown report reflected stillbirth as one of the indicators for tracking. The global estimate of stillbirth was approximately 18.9 per 1,000 total births in 2009, translating into 2.64 million stillbirths worldwide (13). Global campaigns held the view that the burden of stillbirth was unacceptably high, was receiving less attention from the health systems, and that negative cultural practices were being embraced that were characterised by secret burial practices (11, 16), and yet many of the cases were largely preventable (33). A call was made to policymakers and health systems managers in all countries to pay attention to this problem by implementing proven low-cost interventions to address the same while global actors were called upon to increase global visibility and dedicate resources, especially in regions with the highest burden (10). A Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) conference held in May 2009 in Seattle (32) set an objective of developing a roadmap for global action. At the same time, the International Stillbirth Alliance (ISA) was expanding and beginning to exert a global influence. They drew attention to the problem while forming alliances with other national-level associations with shared objectives (29).

The 2011 Lancet Stillbirth Series was a call to action which adopted a mix of advocacy and hard data to promote normative consensus and was estimated to have reached 1 billion people in coverage (4, 34). It drew attention to the invisibility of stillbirths from global statistics and at the family level, where secret bereavement rituals were practiced (11), while highlighting the potential of available low-cost interventions to address neonatal mortality and stillbirth (3). The 2011 Lancet Series was an effective tool for

global advocacy (9) which called for the prioritisation of stillbirth reduction by at least half of the 2009 baseline of 18.9 per 1,000 total births by 2020, as well as increased investment in stillbirth research while improving data systems (7). The UN embraced the norm by endorsing the ENAP during the World Health Assembly in 2014, which operationalised the earlier United Nations (UN) Secretary-General's Every Woman Every Child global strategy through the World Health Assembly (WHA) Resolution 67. Member countries committed to the strategy with explicit stillbirth reduction targets of 12/1,000 by 2030 10/1,000 total birth by 2035, especially for high-burden countries (8). Stillbirths were reflected as an indicator within the maternal newborn and child health service provision (35). The reflection of stillbirth as a vital indicator with deliberate actions to address the burden became a norm for the UN member countries to adopt. Uganda was one of the countdown priority countries and ENAP countries reporting country progress. ENAP targets were reflected in the Investment Case for the Sharpened Plan (36) and the Health Sector Development Plan (HSDP) (14). Besides, it was reported annually as an efficiency and quality-of-care indicator in the Annual Health Sector Performance Report (APHSR) (17). Details are reflected in Table 2.2 hereunder.

### ***Resource provision***

Technical and financial resources are critical for the political prioritisation of public health problems. For stillbirths, political prioritisation was enhanced by the increased funding for maternal and child health interventions having a neonatal health component. Uganda is a recipient of numerous grants that support projects that have generated evidence to address stillbirths. Uganda is one of the pilot countries for the Saving Mothers Giving Life project (37, 38) that piloted the use of the Babies Matrix, the evidence-informed revisions to the national Maternal and Perinatal Death Surveillance and Responses (MPDSR) guidelines(39). The matrix streamlined the audit of perinatal death and helped in improving the classification of stillbirth as well as informing appropriate interventions. This was re-echoed by a national-level key informant that worked closely in generating and disseminating this evidence:

Well [the] Ministry is spearheading along with implementing development partners to see that they tighten up on guidelines first of all; ... and there is also an aspect on quality improvement that the team focuses on and maybe I will just cite one example that we fronted to the Ministry of Health. It is called the Babies Matrix, which is a quality improvement tool. It is a very simple tool for one to use both at the facility and even at the community level that focuses just on birth weight and age at death. So if you are able to collect that data you are able to determine the different categories of newborn deaths both pre-discharged and also those who died at the intrapartum; ... and to know the various interventions to target. So those are the things that were fronted by the project and we believe through the continued technical working groups that are happening at the Ministry it is something that would be taken to scale. **(KII\_NLI019)**



**Table 2.2: Key global events and timelines**

<b>Year</b>	<b>Key event</b>	<b>Link to global campaign theme</b>	<b>Relevance to stillbirth response</b>
<b>2003</b>	Foundation of the International Stillbirth Alliance in the USA	Actions against stigma. Research. Improved care. Advocacy.	Combining health care professional knowledge and passion for families to advance stillbirth prevention research, medical/clinical care, and bereavement services.
<b>2005</b>	First MDG report of the countdown to 2015 with stillbirth not reflected as an indicator	Establishing burden and disparities.	Absence of stillbirth as an indicator for maternal and neonatal health outcomes later informed WHO's decision to include it as a quality-of-care indicator.
<b>2009</b>	Seattle conference convened by Global Alliance for Prevention of Prematurity and Stillbirth (GAPPS)	Evidence of cost-effective interventions. Global and country targets for stillbirth reduction.	Drawing global attention to pre-term and stillbirth which had shown less progress compared to maternal and child mortality.
<b>2010</b>	Countdown to 2015 decade report (2000–2010): taking stock of maternal, newborn and child survival	Establishing burden and disparities. Integrated prevention.	<ul style="list-style-type: none"> <li>• Considering stillbirth as a vital indicator for maternal and child health outcomes.</li> <li>• Provision of evidence on the scale of stillbirth and amplifying the global burden.</li> <li>• Raising visibility.</li> <li>• Promoting prioritisation of intervention to address the burden.</li> </ul>
<b>2010</b>	Launch of the UN Secretary-General's "Every woman every Child" Global Strategy	Integrated prevention.	Highlighting key areas for urgent attention to enhance financing, policy and service delivery with a newborn survival component, which included addressing stillbirth
<b>2011</b>	Lancet Stillbirth Series: Call to action	Evidence of cost-effective intervention. Progress monitoring. Integrated prevention.	Reviewed the status of stillbirth and advocacy to get stillbirth out of the shadows with a call to all stakeholders to take action geared towards reduction.

		Investigate causes. Establishing burden and disparities. Research. Action against stigma. Advocacy.	
<b>2011</b>	Launch of Saving Lives at Birth	Integrated prevention.  Evidence of cost-effective interventions.	Increased funding from global health stakeholders for maternal and child health interventions with a neonatal component and specifically targeting combating preventable stillbirth.
<b>2012</b>	Rollout of Saving Mothers Giving Lives (SMGL)	Integrated prevention. Evidence of cost-effective interventions. Progress monitoring. Actions against stigma.	<ul style="list-style-type: none"> <li>• Enhance existing district maternal and child health services to strengthen evidence-based interventions through a three delays model.</li> <li>• Reduce pregnancy and childbirth related deaths including stillbirth and primarily focusing on the critical period of labor, delivery, and 48 hours postpartum when most maternal and newborn deaths happen.</li> <li>• Harnessing of the public-private partnership.</li> </ul>
<b>2013</b>	First Global Conference on Newborn Survival held in April 2013 in Johannesburg, South Africa	Evidence of cost-effective interventions. Integrated prevention. Progress monitoring. Establishing burden and disparities. Global and country targets for prevention.	<ul style="list-style-type: none"> <li>• First global conference for newborn summit aimed at accelerating the scale-up of high impact interventions to address leading causes of newborn mortality.</li> <li>• Reviewing progress on tackling preventable newborn deaths and call to action for urgency to address the problem.</li> <li>• Developing ENAP in support of Global Strategy for Women's and Children's Health, Every Woman Every Child movement and making recommendations for UN Commission on Life-Saving Commodities, committing to Child survival; A promise Renewed to child survival and Family Planning 2020 objectives.</li> </ul>
<b>2014</b>	Every Newborn Action Plan (ENAP) in support of the earlier Every Woman Every Child	Integrated prevention. Evidence of cost-effective interventions. Global and country targets for prevention.	<ul style="list-style-type: none"> <li>• Advancing the objectives of the Global Strategy for Women and Children by focusing on quality of care at birth with special attention to newborn health and stillbirth as an unfinished agenda from the MDGs.</li> </ul>



<b>2015</b>	World Bank Business Plan-GFF in support of Every Woman Every Child	Integrated prevention. Evidence-based cost-effective interventions.	<ul style="list-style-type: none"> <li>• Setting global and national targets for preventable stillbirth reduction and milestones for quality of care.</li> </ul> Operationalising the UN Secretary-General's global strategy objective of innovative approaches to financing for health in response to the funding gap to address the RMNCAH unfinished agenda post-MDGs, including reduction in stillbirth
<b>2016</b>	Lancet Series; ending preventable stillbirths	Progress monitoring. Evidence of cost-effective intervention. Integrated prevention. Establishing burden and disparities. Research. Action against stigma. Advocacy.	Global advocacy and call to action to address preventable stillbirth.
<b>2016</b>	ISA Five-Year Strategic Plan	Progress monitoring. Evidence of cost-effective interventions. Integrated prevention. Action against stigma. Advocacy.	<ul style="list-style-type: none"> <li>• Through the strategic plan led to the establishment of a technical working group strategy to pursue the objectives of the five-year duration while coordinating international response.</li> <li>• Establishment of technical working groups for global coordination of efforts.</li> </ul>
<b>2016</b>	BMC Stillbirth Series (care after stillbirth)	Actions against stigma. Evidence of cost-effective intervention. Integrated prevention.	Burden of stillbirth, impact on families and calls for action to address social determinants of health which are the underlying causes. Calls to link research to interventions to address the causes.
<b>2020</b>	UNICEF/WHO stillbirth epidemiology report	Establishing burden and disparities. Progress monitoring.	Global estimates of stillbirth burden.

One of the aims of the World Bank's support through the Global Financing Facility was to reduce stillbirths by 21 million in high-burden countries by 2030 (40). Through this support, Uganda is implementing an integrated health systems approach that has fast-tracked the implementation of interventions to address stillbirths (17), in line with the first MCH Conference 2015 statement that calls for the implementation of scalable programmes beyond pilots (41). Other components under this support include improvements in data capturing through support for a community arm and civic registration systems, and operationalising the ENAP strategic objective to count every newborn through investing in birth and death registration(42). A respondent thus noted:

We have accessed a loan (WB) whereby it has three components and one is system strengthening and the other is result-based financing at least to finance health care delivery through the system and the third component is through National Identification and Registration Authority (NIRA). We have birth and death registration. So Ministry of Health is working together with NIRA to develop the tools, to build a system that can capture the data and deaths and also the aspects on macerated deaths, some few reasons why that death happened for quality so that we have a system of notifying the maternal deaths and the perinatal deaths and also we shall go into another arm of notification which is the verbal autopsy. The biggest deaths of mothers are in communities and this system (DHIS2) cannot capture that but now with NIRA, we shall have a community arm through maybe the VHTs, maybe it could be a community system to capture them and they are notified to the districts to the NIRA office and then we capture that. It will improve on our notification and registration. **(KII\_NLI007)**

International organisations and funders also contributed resources specifically towards fast-tracking the policy-making processes to streamline policies responsive to stillbirths. This is echoed by a respondent thus:

Currently, UNICEF is sponsoring the Newborn Steering Committee meetings to see that the policies on newborns are going ahead. They work with UNFPA that is really improving maternal mortality rate. They are working with different [partners]; like Save the Children, USAID to see that some of these policies are implemented. I think they are trying their level best, and they are also working with different associations like AOGU, UPA and WHO as well. **(KII\_NLI016)**

## **Domestic advocacy**

### ***Policy community cohesion***

National efforts to enhance stillbirths as a political priority are partly attributed to a cohesive policy community converging around the Maternal and Child Health-Technical Working Group (MCH-TWG) known as the MCH cluster. Its diverse composition includes researchers, professional associations, practitioners, implementing partners, policy implementers and policymakers, among others. The group sifts through the evidence for policy consideration (39) and its members have previously supported moves for resource mobilisation (43). The level of organisation and proximity to decision-making worked in favour of promoting stillbirth prioritisation. Commenting about the work of this team, a respondent noted:

We have what we call the RMNCH [cluster]; the technical working group which meets every month and now there is a bigger forum which brings on board other multi-sector practitioners who meet on a quarterly basis. So these two I think have added a lot of value because when we meet we share experiences and we try to identify the bottlenecks and solutions. I think that has helped and of course there is also the Health Assembly which is held once a year that brings together even practitioners from the district. So all these are forums that have harnessed the synergies of civil society, private practitioners to come together and find ways of improving this, but the Assembly also gives an opportunity to citizens to speak and say what they think. **(KII\_NLI013)**

The ability to mobilise members and vet issues where evidence is synthesised before recommending policy actions was mentioned as one of its strengths. A respondent recalled an incident where this technical working group vetoed a guideline which was being pushed without their involvement and other stakeholders in a participatory manner:

They call stakeholders from the Regional Referral Hospitals to come and input into the policy formulation or guidelines-making [process] except that recently the SRH guideline we were not happy about the involvement because you don't get a consultant to revise a guideline which is going to affect the whole country. No wonder it was rejected. **(KII\_NLI009)**

The diversity of the MCH cluster meant that they hold diverse forms of power, such as knowledge, fiscal and political power, which is crucial in influencing the agenda and framing the stillbirth issues in the country. Unique to the ongoing monitoring of policy implementation was the feedback loop linking subnational and national policymakers such as the Parliament of Uganda for up-to-date information on the policy implications of the strategies implemented. Commenting on this relationship, a respondent observed:

We have quarterly meetings with stakeholders at the districts and we share the data and now on the quarterly basis, we visit the parliament to brief it[them] on issues of maternal newborn to lobby for resources, lobby for attention which is a good platform. **(KII\_NLI007)**

### ***Policy entrepreneurs***

Policy entrepreneurs have been critical in the national MCH agenda, particularly newborn survival, thus contributing through the MCH cluster and global collaborators on research and actively being involved in global stillbirth working groups. The professional bodies, particularly the Association of Obstetricians and Gynaecologists of Uganda (AOGU) and Uganda Paediatrics Association (UPA), were part of the strategic partnerships offering technical support for project implementation and policy. An Assistant Commissioner within the child health division of the Ministry of Health was designated as the national focal point officer for newborns to track the country's progress towards ENAP targets, including stillbirth reduction (44). The leader of the Centre of Excellence for Maternal and Newborn Health Research at Makerere University is a newborn health researcher who spearheaded the first Maternal and Newborn Health Conference in Uganda in 2015. As part of global stillbirth coalitions, he is involved in

both global and national-level advocacy and contributes to setting newborn research priorities (45). Recognising this contribution, a respondent noted:

Maybe I start from the Newborn Committee at the Ministry and the School of Public Health; ... doing his things in project mode but at least communicates and passes on the information and the evidence to the Ministry, hoping that they would catch fire and continue. **(KII\_NLI007)**

### ***Credible indicators***

National-level stillbirth indicators were for long masked within perinatal mortality in the routine data. The sharpened plan relied on data from the Uganda Demographic and Health Survey (UDHS) 2011 to make a case for the national stillbirth burden. However, it was also reported under the perinatal mortality data to reflect the hidden burden. At the household, community and facility levels, the burden and effects of stillbirth were a felt problem. The lack of reliable stillbirth data triggered national efforts to address the issue. In response, the Ministry of Health first migrated to the DHIS2 in 2012/13 and by 2015, the country had a stillbirth rate of 21 per 1,000 total births (46). It was later followed up with the inclusion of stillbirth as a notifiable condition captured through the surveillance systems and also as an indicator for monitoring district and health facility performance captured through the routine data systems. The focus was on responding to facility-based fresh stillbirths while interventions during antenatal care continued to address macerated stillbirth. Commenting on this approach, a respondent noted that whereas attention was paid to both, the focus was more on fresh stillbirths:

They capture data for both macerated and FSBs but you know a fresh stillbirth can be easily more avoidable than an MSB. The factors are there like a mother comes and then you delay to operate, so all those things and they can be easily addressed. Of course for macerated stillbirths, we need to improve our quality of antenatal care which also still in bits; much as mothers attend antenatal, you may find that our antenatal care is still not quality. **(KII\_NLI016)**

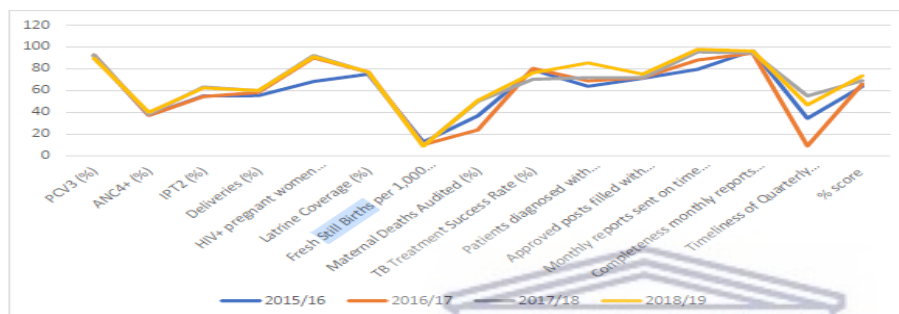
Commenting on the desire to improve quality of care as the rationale for prioritising fresh stillbirths, another respondent noted:

We are saying that the third delay is dominating and if all the facilities are providing quality, we will be able to provide safe obstetric care so that we reduce on the fresh stillbirths. **(KII\_NLI008)**

It was also echoed that the need to find the cause and identify possible interventions to address the problem was another reason for prioritising fresh stillbirths:

Because fresh is easy to prevent and you know fresh it has just died. So you want to quickly know what is it that has caused this baby to die, and how can we address this gap which caused the baby to die. The macerated is in antenatal, the woman is at home and you know that is a bit (.) these [fresh births] are easier to address than the macerated. **(KII\_NLI009).**

The 3<sup>rd</sup> Health Sector Development Plan (HSDP) translated both the ENAP and the UN Global Every Woman Every Child strategy into national policies(14) where the facility-based fresh stillbirth reduction target as a health sector performance indicator was set at 11/1,000 by 2020 using the 2013 baseline prevalence of 16/1,000. This was in line with the ENAP national stillbirth reduction target of 12 or less by 2030 and 10 or less by 2035 if global stillbirth reduction targets were to be achieved (42). Ever since, performance has exceeded set targets year on. By 2018/19, the rate stood at 9/1,000 above the HSDP target of 12/1,000 (17), with stillbirth consistently performing ahead of other indicators used for computing the district annual health performance.



**Source: Ministry of Health. Annual Health Sector Performance Report 2018/19**

From 2016 stillbirths were included among the indicators for measuring and comparing health performance across districts. At the health facility level, it is a measure of the quality of care during antenatal care for macerated stillbirths and delivery services for fresh stillbirths (17). At the national referral hospital, it is considered an indicator for measuring efficiency as viewed from inputs against outputs. Commenting on the role of documentation in facilitating reflections to devise strategies for improvement, a respondent noted:

...and then, of course, the issue of documentation, the HMIS but also locally be able to look at their own data in the districts and identify what the problem is and of course the way they are working towards to locally address it... I have been looking at stillbirths. I would say that one of the things which came through with HMIS which was actually very important that we collect proper data right from the grass roots to the Ministry where it is analysed and that actually shows where the problem is and once you have the problem then they identify what should be done to actually prevent the problem you see at the end. **(KII\_NLI017)**

### ***Focusing events***

At the global level, the GAPPS conference in Seattle, which had major funders present, was one of such focusing events to draw attention to the need to address stillbirths and come up with a roadmap (32). The launch of the global strategy, Every Woman Every Child and the subsequent inclusion of stillbirths in the countdown reports (33) were the other focusing events, with the turning point being the publication of the 2011 Stillbirth



Lancet Series: Call to action (2). Another Stillbirth Lancet Series published in 2016 to end preventable stillbirth was also a key focusing event (22). It drew attention to the potential of available low-cost interventions to address stillbirth risk factors (4). The launch of the ENAP and its adoption during the World Health Assembly the same year drew political commitment from 194 member countries to address the problem. Consequently, some of the key targets and elements from ENAP were reflected in national guidelines, such as the Health Sector Development Plan and the Sharpened Plan. A respondent thus noted:

One of the big ones is the Sharpened Plan. Having written this Sharpened Plan, the next level will be the implementation. The implementation of the Sharpened Plan is actually working through the investment case. So investment case I think is an important area that is trying to translate the policy. **(KII\_NLI004)**

The first Maternal and Newborn Health Conference held in 2015, with support from Save the Children, and which had the objective of linking the country's ENAP outcomes, global research and advocacy to action to support the implementation of national policies and guidelines, was another such focusing event. The conference highlighted the national stillbirth burden and drew the attention of stakeholders to the need to do things differently in the post-MDGs period (41). Other funding for newborn health interventions provided evidence for the policy as well as systems strengthening to address stillbirth. Among these was the World Bank's launch of the Business Plan for Maternal and Child Health in 2015, which was yet another focusing event for political prioritisation of stillbirth in Uganda (40). Its implementation in the country has seen the fast-tracking of interventions at the subnational level, which will see the implementation of activities such as perinatal death audits and improving civic registration systems, among others. A chronology of key events at the national level are presented in Table 2.3 below:

**Table 2.3: Key events for national stillbirth prioritisation**

<b>Year</b>	<b>Key event</b>	<b>Link to theme from global campaign</b>	<b>Objective and relevance to stillbirth response</b>
<b>2012</b>	Rollout of the Saving Mothers Giving Life (SMGL) pilot project in Uganda	Integrated prevention.  Evidence of cost-effective interventions.  Progress monitoring.	<ul style="list-style-type: none"> <li>• Uganda was one of the two countries where intervention was rolled out with stillbirth reduction indicators.</li> <li>• Piloting of evidence-based interventions at district health systems level.</li> </ul>
<b>2013</b>	Sharpened Plan 2013-2017	Actions against stigma. Country targets for stillbirth reduction.  Integrated prevention.  Progress monitoring.	<ul style="list-style-type: none"> <li>• Reflection of stillbirth as indicator for subnational level outcome performance indicators.</li> <li>• Stillbirth as an outcome indicator for tracking of a national reduction target of 11/1,000 by 2020.</li> </ul>
<b>2015</b>	ENAP country progress report with stillbirth as one of the indicators	Progress monitoring.	Tracking intervention effects on reducing stillbirth burden while monitoring progress.
<b>2015</b>	HSDP includes stillbirth as an outcome indicator for tracking with a national target of 11/1,000 by 2020	Country target for stillbirth reduction.  Establishing burden and disparities.	National commitment to stillbirth reduction.  Improved quality of care around the time of delivery to avert most stillbirths happening at that time due to poor quality of service.
<b>2015</b>	Health Financing Strategy (2015/16-2024/25)	Evidence of cost-effective interventions.  Integrated prevention.	<ul style="list-style-type: none"> <li>• Addressing financing bottlenecks to improve funding for health and aligning with international norms and funding opportunities.</li> </ul>

			<ul style="list-style-type: none"> <li>Altering incentive structure in health system to improve motivation at final point of service delivery and access to quality health care.</li> </ul>
<b>2016</b>	Investment case – 2016.	Integrated prevention.  Evidence of cost-effective interventions.	<ul style="list-style-type: none"> <li>Aligning with global funding opportunities.</li> <li>Revised in the context to support implementation of key interventions addressing stillbirth risks.</li> </ul>
<b>2016</b>	AHSPR with stillbirths reflected as an indicator for district performance	Progress monitoring.  Improving quality of care.  Establishing burden and disparities.	<ul style="list-style-type: none"> <li>Getting stillbirth out of the shadows within the health systems by reporting the burden at subnational level.</li> <li>Responding to stillbirths occurring around the time of delivery as a reflection of the poor quality of care provided during late term and labour.</li> </ul>
<b>2016</b>	RBF framework institutionalisation	Integrated prevention.  Evidence for cost-effective interventions.	<ul style="list-style-type: none"> <li>Compensation for outputs, including interventions to investigate and address stillbirth causes such as MPDRS among other maternal and prioritised child health interventions to incentivise performance at final point of service delivery.</li> </ul>
<b>2017</b>	Revised MPDSR guidelines	Integrated prevention.  Evidence for cost-effective interventions.	<ul style="list-style-type: none"> <li>Improved investigation of stillbirth cause and classification of stillbirth.</li> <li>Babies Matrix to guide review of perinatal deaths incorporated from the SMGL project.</li> </ul>

### ***Clear policy alternatives***

Addressing stillbirths through attention to health systems strengthening coincided with government efforts towards the same in response to maternal and child mortality reduction. Global strategies highlighted in the 2011 Lancet Stillbirth Series (7, 9) and the Every Newborn Action Plan 2014 (8, 42, 47) observed the need for health systems strengthening through improved quality of services during delivery through basic and comprehensive emergency obstetric care due to its greatest effect on stillbirths (10). National strategies for achieving the MDG targets witnessed the rollout of some interventions to improve emergency obstetric care services at the subnational level. HCIVs were to be headed by medical doctors specifically to deliver emergency obstetric care, among other services (48), training would be prioritised, and rare cadres at HCIV, such as anaesthesiologists, would be recruited. Other initiatives included increased training and deployment of midwives at HCII to offer outpatient maternal health services and improving HCIII to provide inpatient maternal health services and basic emergency obstetric care, among others(48).

The MoH health systems strengthening plans were accelerated by the new PEPFAR change of strategy to scale down the direct donor support announced by the US government in 2012 (49). PEPFAR, the lead financier for HIV response, was switching from emergency response to a targeted sustainable approach with greater country ownership (50) under the PEPFAR 3.0 (2013-2019) strategy, which aimed to maximise evidence-based intervention through the impact of investment by providing technical support. Part of the transition process included the targeting of resources to high-burden regions through geographical pivoting (51), where facilities were prepared to receive that support from the government. During FY 2012/2013, the government spent 7.4% of the annual budget on financing health systems strengthening (52). These would later turn out to be the same interventions that would improve maternal health services, thereby preventing stillbirth, especially at the facility level. The emphasis on improved care during antenatal care received attention right from the MDG era with interventions for early reporting for the first antenatal care visit and increased completion rates for the recommended four visits. Such interventions included focused antenatal care (FANC), male involvement in birth preparedness, addressing the distance to health facilities, the provision of MAMA kits for pregnant mothers, and the Village Health Team (VHT) strategy. Although global stillbirth campaigns recommended improvement in the delivery of advanced antenatal care services, they cautioned that it would come at a higher cost, and yet the call was for the implementation of interventions that suited the health systems capacity to deliver the same. This resonated well with another recommendation that calls for the delivery of linked services.

### **National political environment**

#### ***Political transition***

A major political transition that shaped the acceptance and integration of global stillbirth recommendations into national priorities was the decentralisation system of service delivery (48, 53). Under the arrangement, decision-making responsibilities were delegated to the subnational level with a focal person in charge of maternal and child health services at every district. Although these processes had happened earlier, they worked to anchor interventions responding to stillbirth at the subnational level. Unique to the health sector, another managerial layer below the district and headquartered at HCIV, known as the health sub-district, was introduced to improve management at the subnational level (53). Infrastructural improvements have included renovations and upgrading of functional maternity wards and operational theatres to provide comprehensive emergency obstetric care (CEmONIC) as well as mentorship and supervision for lower-level facilities. It is from this structure that national efforts to operationalise the global campaign strategy of improving access to quality maternal health services are being delivered.

Health in Uganda, particularly the poor state of maternal and child health services, has been a sensitive political issue, attracting attention during political sentiments which have previously led to the scrapping of user fees and salary enhancement for health workers (53). The national commitment to improve maternal health services stems from being a signatory to global agreements on improving maternal health such as the MDGs and Sustainable Development Goals (SDGs) (54, 55). Reproductive health services are highlighted as part of the tracer indicators for monitoring the country's progress towards universal health coverage (UHC) targets (56). The country's engagement of the private sector improved coverage of MCH service delivery through the private sector and was operationalised when Uganda rolled out the Health Financing Strategy (2016/2025) which introduced reforms in pursuit of health sector progress towards UHC. It laid the foundation for Results-Based Financing, the main financing mechanism for the GFF with a strong component of reimbursing facilities for outputs attained, including perinatal death reviews (40). This project has a strong component of interventions responding to stillbirth.

As a result, maternal health services face a web of interlocking accountability mechanisms comprising the political, administrative and technical. Within the district league table, stillbirth was included as a performance indicator in 2016/17, meaning that leaders charged with accountability at that level have to monitor to ensure stillbirths do not happen to improve district performance. Civil society organisations (CSOs) all insist on accountability to ensure the delivery of quality maternal health services in the country. Previously CSOs have successfully lobbied Parliament to block the health budget if it did not address systemic health systems challenges leading to a reallocation of approximately \$15 million to address health worker shortage. They have also used strategic litigation as a political tool to influence norms and to steer processes towards social change aimed at pushing the government to be more accountable for maternal deaths (57).



### ***Competing health priorities***

Maternal and child health enjoys political attention due to the sensitivity of the indicators associated with it and the momentum built during the MDG era. Neonatal survival received global attention that trickled into national interventions. Grants supporting projects with neonatal components increased and this further catapulted neonatal survival within the donor community. The health sector's pursuit of the health systems strengthening strategy to build capacity has seen HCIVs being equipped with functional theatres; it has also seen the recruitment of anaesthesiologists and laboratory technicians to support the delivery of CEmONIC. Elsewhere, midwifery skills have been strengthened to deliver PMTCT and maternal health services and health facility data improvement through continuous quality improvement. The outcome of this has been innovative strategies such as the integration of services within the Reproductive Maternal Newborn and Child Health (RMNCAH) continuum of care, making maternal health one of the highly prioritised RMNCAH indicators. The district scorecard has stillbirth as one of the outcome indicators (Sharpened Plan) while district performance in health is assessed based on selected indicators, including stillbirth (17).

### **Discussion**

This study sought to establish reasons and provide explanations for the rise of political priority for stillbirths in Uganda. The framework factors support providing explanations for the observed developments with regard to prioritising stillbirths. Using the applied framework, the results show important aspects that may have played a role in prioritising stillbirth reduction. Despite its neglect, the global burden and feasibility of implementing the available proven low-cost interventions with the highest impact merited its attention. It also benefited from its linkage with maternal and newborn mortality risk factors and the potential of interventions to address all risk factors. Stillbirth campaigns were driven by an established and powerful policy community already converged around neonatal survival which was at the time working on the Lancet Neonatal Survival Series 2003.

Attention to stillbirths appears to have picked up momentum as an offshoot of earlier global newborn survival campaigns that sought to correct the prevailing assumption then that newborn health was automatically being addressed through existing maternal and child health programmes (21). In this context, subsequent national-level efforts can be traced to the consistent and protracted global campaigns around maternal and neonatal mortality reduction which later culminated in newborn survival campaigns. The earliest recognition of stillbirths as a global problem is traced to its omission as one of the indicators for tracking progress towards the attainment of MDG targets. The team compiling the countdown to the MDG report was already an established policy community that was working on the Lancet Newborn Survival Series. This may have worked to bring the issue close to what the policy communities were already working on, hence the reflection of stillbirths in the 2010 countdown report (12). Despite its

strong grounding in MCH, stillbirth still receives slightly less attention at the national level compared to maternal and child mortality reduction.

In this study, the international norm promotion is seen to have influenced the national-level prioritisation of stillbirth. This was key as it triggered the other factors, such as the provision of funding for interventions with stillbirth reduction targets and focusing events. In line with what has been revealed elsewhere (21), the motivation to act in response to reducing stillbirth shares aspects of what was highlighted at the global level. Shiffman contends that, other than material factors such as data on the national stillbirth burden, the power of ideas and how they are framed may draw more attention to the problem. At the time, indications were that more countries were likely to miss out on MDG4 because the rate of mortality reduction in neonates was slower compared to children over 28 days, hence the focus on neonatal survival was extended to stillbirth reduction. In Uganda, stillbirth data was being captured primarily using facility-based records at that time (AHSPR 2011/12). Many of the community cases were going unrecognised owing to the negative cultural practice involving secretive burials and the stigma stillbirth caused to the bereaving family (16). Similar findings have been reported from Bangladesh, Malawi and Bolivia, where international norm-setting for the reduction of newborn deaths opened final windows of opportunity for national governments to act on the problem (19, 58).

Policy formulation and intervention rollout to address stillbirths is attributed to resource provision, particularly financial and technical support from global stakeholders. Increased funding for newborn health in Uganda played a role in varying ways. Consistent with political prioritisation literature, the alignment of policy with potential funding led to the rollout of the investment case which highlighted some interventions to address stillbirth in Uganda in time for the World Bank funding (59). Similarly, the revision of the MPDSR guidelines with a strong component of auditing perinatal deaths was informed by evidence from supported projects that reflected the feasibility of some of the tools recommended in the guidelines (39). Further, recommendations for improved stillbirths reporting emerged from collaborative participation in evidence generation with global actors (60) similar to what has been reported elsewhere (58).

A cohesive policy community, as articulated by Shiffman (20) in the framework, was key to influencing the prioritisation of stillbirths. Already, these were familiar and working on the national maternal and child health agenda. The MCH cluster was highlighted as having been swift in adopting global recommendations into the national context to inform policy and practice. The provision of evidence for policy formulation and the translation of the ENAP strategies and targets into the Health Sector Development Plan(14) and the investment case(59) are some of the examples. A number of the political entrepreneurs were already advocates for the MCH and this advocacy was not exclusive to stillbirth. This background helped generate ground from which stillbirth prioritisation was anchored. None of the political entrepreneurs championed stillbirths in isolation of maternal and child health. The fact that the framers of stillbirth as a major public health

problem pointed to the feasibility of implementing recommended strategies along the continuum of care and in an integrated manner meant that the policy community advancing it would also have an interest in maternal and child health with the promise of a triple return on investment from such interventions.

When targets were set for stillbirth reduction(14), the Ministry of Health had specifically focused on addressing those risk factors occurring intrapartum. Integrating these indicators within ongoing quality improvement efforts at health facilities meant that, while working on achieving the targets was ongoing, the general quality of maternal and child health services was also improving. Inclusion of stillbirth in the district league table meant that those charged with accountability would ensure that this indicator performed well to raise the district ranking among peers. This could partly explain why stillbirth performed well compared to other indicators in the period following the rollout of the Health Sector Development Plan. Experience from implementers shows that whereas perinatal reviews should be conducted on all cases, they were mainly conducted for early neonatal deaths (17) that called for targeted follow-up beyond policy provision.

The framework emphasises the importance of focusing events in drawing attention to the public health problem. Our results indicate that some focusing events, such as the integration of ENAP targets into national policies, the first maternal and neonatal health conference, as well as funding, triggered the acceleration of stillbirth prioritisation. Related to the policy alternatives, the focus of implementing strategies along the continuum of care in an integrated manner resonated well with the Ministry of Health's aspirations at the time, in addition to strengthening health systems.

Other than the political transition, as proposed from the framework, the decentralisation of health services had happened some time back and what was put in place as a result only helped to anchor the recommendations to address stillbirth at the subnational level in Uganda. On the contrary, the decentralisation process in Indonesia is reported to have hurt the prioritisation of safe motherhood (20). The time of accelerated advocacy to prioritise interventions that address stillbirth coincided with the post-MDGs health agenda driven in part by the desire to attain universal health coverage(14). This finding compares well with what has been established elsewhere as having facilitated the prioritisation of maternal and newborn survival (21). The sensitivity of maternal and child health as a political issue benefited the prioritisation of interventions to address stillbirth (48). Already, the country was implementing interventions to address persistent MCH problems, many of which have the potential to address stillbirth.

The role of civil society in drawing attention to maternal and child health has been observed elsewhere (57). Consistent with this observation, civil society played a key role in raising the maternal health issues, especially the poor quality of emergency obstetric services. They engaged in strategic litigation aimed at compelling government to improve the quality of maternal health services through proposed interventions with the potential to address stillbirth risk factors. In line with what has been reported elsewhere

(58), we did not find competing priorities that may have impeded stillbirth prioritisation but instead favourable factors that helped it accelerate. Maternal and child health programmes were already being prioritised by the Ministry of Health and had been earmarked as one of the indicators for tracking national progress towards universal health coverage (56).

### **Limitations**

This study had some limitations. First, the study analysed events retrospectively and, where no proper documentation of events existed, results would be subject to recall bias of the respondents. However, this limitation was mitigated through triangulation of data from multiple sources such as document review and multiple key informants. The applied framework also had limitations whereby some of the factors within the framework were contextually not applicable. A case in point is the political transition. Regarding this, in our case, the decentralisation of health services had happened much earlier and the established structures only worked to anchor the recommended interventions from the global campaign but not because they were intended for that purpose in the first place. To address this, we have highlighted this shortcoming and have made recommendations for adjustment of the framework to accommodate short-term events attributed to political changes and with long-term effect on service delivery.

### **Conclusions**

The application of the framework helped unveil the factors behind the prioritisation of stillbirth reduction in Uganda. The transnational influence played a key role in triggering interest in the issue during the initial stages of raising awareness of the problem. The success and subsequent processes, however, relied a great deal on domestic advocacy and the national political environment. The key factors for this include the cohesive policy community converging around maternal and child health, which was able to embrace the recommendations from the global campaigns and translate them into policy priorities. Political transition, in this case, appealed more to systems improvement through proposing new policies and guidelines to streamline the implementation of interventions, which was an important factor, in addition to the health systems capacity to embrace the recommendations.

From our analysis, it appears that political transition is more applicable in settings with major political events. From our study, we observed that small-scale incremental changes that later played a role in facilitating prioritisation of stillbirth reduction also happened during the processes. Mahar and Sridhar (2012) summed this up as the role of institutions in the priority-generation process (61). Within the Ugandan context, the establishment of the MCH cluster within the MoH in a way accelerated the political prioritisation of stillbirth reduction. Indeed, the principal architect of this framework acknowledges this shortcoming in understanding the political prioritisation for neonatal mortality reduction in Bangladesh (58). He notes that political transition is applicable when its meaning is stretched. We observe from our case study that in the absence of fundamental political events in the country, incremental institutional transformations



occurred that were crucial in shaping political prioritisation of stillbirth reduction. At the global level, McDougall (2016) notes that the expanding power of non-state actors in the global health governance space has, in a way, influenced political prioritisation (62). Globally, private philanthropies are increasingly getting immersed in policy communities that shape political prioritisation. A similar occurrence extends to national-level efforts. We have argued earlier that the policy community converging around the MCH cluster within the MoH with representation from diverse stakeholders worked to synthesise the evidence, which later informed policy provisions and the prioritisation of stillbirth reduction. Future application of this framework would benefit more from incorporating peculiar aspects such as institutional/organisational transformation into the political transition factors. To this end, we propose a revision or modification to include organisational/institutional transformations to cater for the small-scale incremental changes to the institutions and health systems that are targeted for political prioritisation of global health issues.

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## CHAPTER THREE

### Paper Two

#### **Prioritisation of Interventions in pursuit of maternal health policy objectives to mitigate stillbirth risks. An exploratory qualitative study at subnational level in Uganda<sup>3</sup>.**

##### **Scope of the chapter**

Renewed calls from global campaigns to address the stillbirth burden, especially in regions worst affected, called for deliberate national level adaptation of strategies to address the same. At the national level, policy provisions were made to incorporate proposed strategies but information about their implementation at subnational level remained scanty. This chapter presents results from an exploratory study examining subnational-level implementation of strategies to address the stillbirth burden through the lens of frontline health workers. It discusses how resource availability and the implementation context influenced aspects to be prioritised at subnational level and pays attention to the overall health systems aspirations, such as streamlined referral systems, improving uptake of the available services and differentiated care, and derives conclusions based on these.

##### **List of tables**

Table 3.1: Respondents' occupational characteristics

##### **Data-sharing arrangements**

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## Abstract

**Background:** Global calls for renewed efforts to address stillbirth burden highlighted areas for policy and implementation resulting in national-level translations. Information regarding the adapted strategies to effect policy objectives into service delivery by frontline health workers remains scanty, especially at subnational level. The study explored strategies prioritised to mitigate stillbirth risk in the context of operationalising recommendations from the global campaigns at the subnational level in Uganda.

**Methods:** A cross-sectional qualitative exploratory study was conducted among a purposively selected sample of 16 key informants involved in the delivery of maternal and child health services in Mukono district. Thematic content analysis was used that deductively focused on those policy priorities highlighted in the global stillbirth campaigns and that are reflected at the national level in the different guidelines.

**Results:** Interventions to address stillbirth followed the prioritisation of service delivery aspects to respond to identified gaps. Efforts to increase the uptake of family planning services, for example, included offering it at all entry points into care, with counselling forming part of the package following stillbirth. Referrals were streamlined by focusing on addressing delays from the referring entity while antenatal care attendance was boosted through the provision of incentives to encourage mothers to comply. Other prioritised aspects included perinatal death audits and improvements in data systems while differentiated care focused on aligning resources to support high-risk mothers. This was in part influenced by the limited resources and skills which made health workers adapt their routine to fit the implementation context

**Conclusions:** Resource availability determined aspects of policy to prioritise while responding to stillbirth risk at subnational level by frontline health workers. Their understanding of risk, the feasibility of implementation and the desire for optimal health systems performance contributed to defining the nature of services delivered, calling for purposeful consideration of resource availability and the implementation context while prioritising stillbirth reduction at subnational level.

**Keywords:** stillbirth, policy translation, subnational level, service delivery, health workers

## Background

Close to 2.6 million stillbirths occur every year. Most of the cases happen in low- and middle-income countries (LMICs)(1, 2), with rural areas being disproportionately affected. Addressing the burden attracted global campaigns with country targets of



14/1,000 live births by 2030 (3). Policy options included the adoption of best buys at global level, followed by national-level translation (4) for sustainability (5). The 2011 Lancet Stillbirth Series call to action urged countries to ensure that stillbirths are reflected in maternal and newborn health plans (6) by linking stillbirth reduction to maternal and newborn care (7) with specific time-bound goals. Proposed actions included collection and reporting of accurate stillbirth rates, causes of death, auditing of stillbirths and actions to reduce the stigma, among others (8).

National-level strategies around prenatal, antenatal and postnatal care (4) alongside health systems strengthening follow an integrated approach, with experiences from elsewhere suggesting that implementation is affected by contextual complexities, hence affecting results (9). Uganda embraced themes from the global stillbirth campaigns, with some being integrated into the national reproductive maternal, newborn and child health policies (10). However, information regarding the extent of implementation at subnational level remains scanty. We sought to understand the extent to which the frontline health workers influenced the implementation of interventions adopted from the global stillbirth campaigns into national priorities.

The non-linear nature of policy implementation processes (11) means that frontline health workers are critical in determining implementation success (12). In resource-limited settings where almost 98% of the global stillbirth burden occurs (9), maternal and child health services are mainly delivered by nurses/midwives, who form the bulk of the health workforce. Inability to achieve policy objectives becomes chronic. With inadequate support supervision from the centre to ensure compliance, interpretation of policy intentions becomes subject to individuals' understanding. Harmonisation with available resources determines what finally gets delivered. Frontline health workers hence become key to the success of policy translation influenced by the discretionary powers they wield on a case-by-case basis (13). Such a role compels them to determine the implementation dose depending on the resources available.

## **Methods**

### ***Design***

This study adopted a cross-sectional qualitative design to address subnational health systems perspectives related to frontline health workers' translation of interventions to respond to the stillbirth burden at that level.

### ***Setting***

The study was conducted in Mukono district for an in-depth case following criteria informed by subnational-level performance derived from the Annual Health Sector Performance Report (AHSPR) 2015/16, where district comparisons in terms of stillbirth burden are computed among other health indicators. At the time of conceptualising this study, Mukono was ranked in the second tier of

districts with high stillbirth rates ranging between 9-14.9/1,000 live births, with malaria as the leading cause of morbidity and mortality. Located in the central region of the country, the population was estimated at 599,817, of whom 307,927 were female, and it was ranked the 7<sup>th</sup> most populous district in Uganda. Of the 14,240 deliveries conducted at the health facilities, 240 were stillborn, of which 112 were fresh stillbirths (District Health Report 2016/17) and yet less than half (49.4%) of the deliveries were conducted by public sector facilities, where data is routinely collected. A number of the known stillbirth risk factors were common in the study area, for example, malaria, with rates during pregnancy at 42.4%, early initiation of childbearing and early marriages with a high ideal number of children. The district had a fully constituted District Health Management Team (DHMT) with four health sub-districts. The characteristics of a pluralistic system are evident with a relatively fair distribution of public, private not-for-profit health facilities and a heavy presence of the private-for-profit health facilities. The community component is served with a community health worker structure known as the Village Health Team (VHTs) and civil society organisations (CSO) implementing health-related interventions. The district is categorised as hard-to-reach by the Ministry of Health (MoH) because it is partly comprised of peninsulas stretching into Lake Victoria. It was one of the districts where the national-level rollout of Helping Babies Breathe (HBB) and HBB plus (an evidence-based capacity-building programme to teach neonatal resuscitation techniques in resource-limited settings) were piloted. It, therefore, presented a unique and interesting case to understand how frontline health workers influenced the translation of global campaign strategies to address stillbirth through the implementation of policy guidelines at the subnational level.

### ***Participants' characteristics***

Six health facilities were selected for an in-depth case study in addition to the District Health Management Team (DHMT) purposively selected based on the level of service provision and ownership. Face-to-face interviews with managers and frontline health workers directly involved in clinical and managerial decision-making were conducted. A list of all health facilities was obtained from the Annual District Health Report from where respondents were purposively selected, on top of district health managers and sub-district health managers. A total of 16 respondents were purposively selected where, at the DHMT level, the respondents doubled in more than one role. For example, the head of the health sub-district is by mandate a member of the DHMT and may be the head of one of the health facilities. The same applied to some of the midwives interviewed where they doubled as maternity unit officers-in-charge. The inclusion criteria

were specific to respondents who, through their clinical practice or managerial functions, influenced decisions related to addressing the stillbirth burden. Details of respondent characteristics are set out in Table 3.1 below.

**Table 3.1: Respondent characteristics**

Cadre	Level of service provision				Total
	DHMT	Hospital	HCIV	HCIII	
Medical officer	1	2	2		5
Nurse	2	2	1		2
Midwife		2	2	2	9
<b>Total</b>	<b>3</b>	<b>6</b>	<b>5</b>	<b>2</b>	<b>16</b>

### ***Description of the process***

Contacts were initiated with the District Health Team (DHT) while introducing the study, from where discussions about potential respondents were raised. A list of health facilities was shared and from each of the facilities, a potential respondent would be identified. At the facility level, after introducing the study, further consultations regarding the participation of other staff were conducted besides the one identified from the district. Finally, potential participants were contacted and the study purpose explained and written informed consent obtained before the interview. Interviews were conducted by the first author together with the study research assistant and lasted approximately one hour and were conducted at the respondents' places of work. Overall, none of the contacted potential respondents declined to participate. Broadly, the interview guide was developed for this study and informed by the literature. It contained eight questions which explored the health worker's experiences, as well as the role of both facility management and individual health workers in ensuring that stillbirth risk factors were responded to appropriately. It further explored the influence of the workplace context and mothers' characteristics in translating guidelines at the frontline. All interviews were audio-recorded with a digital recorder and at the end of each field day, field notes were expanded and recorded data downloaded onto the computer with a copy saved on the hard drive.

### ***Data analysis***

Thematic content analysis was employed that focused on those policy priorities highlighted in the global stillbirth campaigns and that was reflected at the national level in the different guidelines. Transcriptions were typed into Microsoft Office Word by the first author and a research assistant who participated in data collection and thereafter entered into Atlas.ti, a data management software. Textual data relating to a particular theme corresponding to the policy priorities highlighted from the global stillbirth campaign would be highlighted and attached to a code within a codebook developed by the study team. A manual process of pile sorting similar quotes attached to particular codes was conducted, which led to the identification of sub-themes under each code. Summarised mini-statements were generated from which, following a perusal process, the main themes were derived. Particular quotes from transcripts were used while presenting results to emphasise specific themes and illuminate the voices of the study participants. Preliminary results were discussed with two of the participants for feedback and the revisions following the incorporation of feedback are what are reported here.

## **Results**

### **Prioritisation of health service delivery to respond to identified gaps**

#### ***Delivery of family planning services at all entry point***

Health facilities continued to pursue policy provisions from the Ministry of Health despite the acknowledgment that current models of delivery contributed to loopholes. Frontline health workers altered the delivery model to prioritise all women presenting for other health services. As a result, family planning services were introduced at all entry points into care. The level of integration and compliance depended on health workers' innovativeness with variations across facilities. As a respondent remarked:

These days FP is at every entry point. There are FP methods and all health workers, including the clinicians and nurses, are taught how to deliver the services so immediately the mother is delivered there they are counselled about the FP methods.  
**(PF\_HCIV\_004\_IC\_Mat)**

For mothers that experienced a stillbirth, family planning counselling formed part of the key timely interventions, where they did not stop at providing emotional support and wait for mothers to return for postnatal care to introduce family planning. Depending on the circumstances surrounding the delivery, health workers used their discretion to determine whom and what method to propose to the mother and under what circumstances.

We counselled that mother and we even advised her to first use family planning for some time. And by the time she feels like getting pregnant again, she will be ready. We sat them down together with the husband and they agreed to come back and indeed they came back after two weeks **(PF\_HCIII\_005\_IC\_Mat)**

### ***Management of infections during pregnancy***

To enforce MoH policy strategies targeting HIV among pregnant women, a double-check approach to tracking all HIV+ mothers within antenatal care (ANC) was enforced. Facilities would review records at the end of every month to identify HIV+ mothers, where efforts would be initiated by the officer-in-charge to ensure that all were initiated onto antiretroviral therapy (ART).

At the end of the month we even go to the antenatal register. We review and identify HIV+ mothers and check whether they were started on medication and those that were not started because they were still in denial but returned after a week. **(PF\_HCIII\_006\_IC\_Mat)**

Delivery of services to prevent malaria during pregnancy was re-purposed to have it as a directly observed therapy (DOT) within the facility. This was a deviation from earlier arrangements which involved the provision of drugs at the facility or recommending drugs to be bought by the mothers, who would then take them from home. Safe drinking water was provided to the mothers, where some facilities started mothers at 12 weeks, while others did this at 13 weeks. This was sometimes hampered by inadequate supply, leading to stock-outs. Under such circumstance's women would be asked to buy from private pharmacies.

MoH has a programme of giving them presumptive preventive treatment where we give Fansidar to these women. Initially, we were giving them two doses. Now they tell us we should give them monthly so long as the women are 12 weeks pregnant. Each time they come for antenatal we give them a dose ... We used to tell mothers to take Fansidar from home but now it is on DOT, even the water is there. **(PNFP\_Hosp\_001\_IC\_Mat)**

### ***Improving ANC attendance***

To boost antenatal care attendance, some facilities aligned resources to introduce incentive packages targeting good adherence and completion rates. A reward system based on compliance within ANC was rolled out, as exemplified by the following quotation:

We have now designed an intervention of giving out incentives to the mothers. When they come for the first ANC visit we give them a mosquito net and when they come for the second ANC we give them a leaflet that has information about labour, outcomes of labour and about the child. And when they come for the third ANC visit, we give them a baby cloth and when they come for the fourth, we give them a mama kit and when they deliver from here, we give them an overall and a blanket for the child. **(PNFP\_Hosp\_001\_MO)**

The referral system was re-purposed to focus on the place of origin of referrals from one level to another in a bid to improve the turnaround time. Innovative strategies were implemented focusing on referring facilities other than waiting for cases. Frontline health workers initiated communication with referring facilities not to withhold mothers for too long, and encouraged communication with the receiving facility before referral, close supervision and supplying referring facilities with referral forms to streamline the process:



So what they do because they have got a file for a referral or prolonged labour, ruptured uterus, our doctor who is the medical superintendent and he heads the sub-district, he goes there [referring facility] and asks them what is happening. Like previously we had one from XXX HCIII, so the doctor had to go there and find out but the mother had a ruptured uterus and she lost the baby, so we had to tell the doctor to talk to them. (PNFP\_Hosp\_002\_IC\_Mat)

### ***Review of perinatal deaths***

In some health facilities, health workers prioritised the review of perinatal deaths to focus on case assessment with staff that handled the mother before the Maternal and Perinatal Death Surveillance and Review (MPDSR) Committee meeting. After identification of the circumstances surrounding a particular case, the review meetings would be made aware of such information. Others would brainstorm a particular case during departmental meetings to make recommendations and agree on possible interventions to address the identified gaps. These would inform part of the content during continuous medical education (CME) sessions.

In case we get one, in maternity as a department we sit with the in-charge and brainstorm on what the cause could have been and when they reach in the committee they are already aware of what could have caused that. (PF\_HCIV\_003\_MW)

### ***Efforts to strengthen data systems***

Reporting about stillbirth at health facility level was one of the performance indicators prioritised for capture in the daily handover reports from the maternity unit. This was in addition to other existing reporting such as the surveillance, monthly and perinatal death review reports:

So you make sure you have given them indicators that they report about like the perinatal death, stillbirth, and maternal deaths. So we have given them particular things that they report about such that we can monitor what is going on. (PNFP\_Hosp\_002\_MW)

In particular instances, efforts to strengthen data capture were reportedly unpopular, especially among grieving parents. Some mothers were noted to be unappreciative of the exercise behaviour occasioned by circumstances related to rushing the stillbirth for burial, and hesitant to provide information.

When one sees that hers didn't survive and the others are having their babies, she becomes desperate and by the time you think of sitting and completing this form she will just tell you that *musawo* [health worker], I will come back to complete this form, they want to take the dead body and will pretend that they are in a rush and want to leave ... sometimes we fail to sit with them and complete the forms (PF\_HCIII\_006\_IC\_Mat)

### ***Strengthening health systems***

Causes attributed to gaps within the health systems identified during a perinatal death review, such as inadequate health worker skills or perceived negligence, acted as the trigger for facility-wide improvements. In such instances, the review extended to ensuring that agreed-upon actions to address the gaps are implemented without

necessarily communicating to the mother in detail. In some cases, detailed investigations were conducted for fresh stillbirths rather than a macerated stillbirth. The same was true while responding to cases emanating from delayed referrals from known facilities compared to the ones from unknown ones or facilities with fewer linkages to the receiving facility, such as private clinics and traditional birth attendants (TBAs).

We now know that if we receive a referral-in from a government health facility or private clinics. It is very important that we act very fast because we are quite sure that these mothers could have had delays from very many points. **(PNFP\_Hosp\_002\_MO)**

### **Differentiated care to match the perceived risk**

Depending on resource availability, frontline health workers offered differentiated care while delivering interventions to respond to stillbirth risks depending on the magnitude of the risk. In four of the six health facilities, all presumed high-risk mothers were referred to doctors for management at tertiary facilities while the ones perceived as low-risk continued receiving services from midwives.

If a mother comes with hypertension, previous fresh scar diabetes, they are always referred to the doctor and they are always seen after two months depending on the treatment and the degree of the case. **(PNFP\_Hosp\_002\_MW)**

### ***Individualised ANC and delivery package for pregnant women***

During antenatal care, health workers based themselves on the assessment of risk to identify mothers for retention at health facilities until delivery. Mothers in their fourth trimester with transport challenges were retained until delivery, based on health workers' assessment of timely arrival at the facility to avoid delays in reaching the facility.

Like today we have a woman from the islands whom we are accommodating in the labour ward waiting to deliver. **(PF\_HCIV\_003\_MW)**

Delivery by caesarian section depended on the ability to pay for services by the mothers and whether the particular cases required blood transfusion. It enabled frontline health workers to determine which cases to attend to. Whereas some facilities insisted on payment beforehand or referred out in case of inability to pay, in others, assessment helped determine cases to attend to, especially ones that did not require blood transfusion.

Because we have skilled staff who can easily detect something and you know in this hospital if everything fails we would rather do a C-section and then have a live baby and a normal mother than keeping you there. **(PNFP\_Hosp\_002\_IC\_Mat)**

### ***Aligning available resources to assessed risk***

The face-to-face interactions during assessments were characterised by the desire to secure the mother's cooperation throughout care provision. Interactive group ANC

according to age group, where mothers engaged actively in health education and monitoring their pregnancies, was one of the strategies. It particularly characterised service access for younger mothers while older ones continued receiving individualised antenatal care services.

Yes, it's peer where mothers of the same age group are arranged into the same group and when they come at the facility they are involved in doing certain simple things like taking BP, discussing issues that affect them in the presence of a health worker in the presence of a health worker that can help them realise the interventions that are necessary in keeping their pregnancies health and their lives. **(PF\_HCIV\_004\_MO)**

Information on the availability of complementary services that are crucial for the prevention of stillbirth was in some cases offered using a differentiated approach where perceived risk informed which services a mother would be referred to. Mothers with perceived elevated risk, such as a history of stillbirth, were occasionally directed to such services. Specifically, the delivery of family planning services was common as well as the provision of emotional support, whose quality was shaped by the limited skills of the health workers. This is acknowledged in the quote below:

Sometimes when it's hard for them[midwives]we involve the counsellors because for us the counselling we do is the midwifery part but [if] there are some social issues we have a social worker in the hospital whom we sometimes involve when issues are involving social issues after getting the medical counselling. **(PNFP\_Hosp\_002\_MW)**

Not all mothers received the same quality of counselling when presented for care. The level of cooperation with the frontline health workers influenced the quality of counselling received by the mothers. Instances of withholding vital information or referral to other sources for management were cited in the case of non-cooperating mothers. Nonetheless, no standard counselling package was reported. Some health workers preferred to focus on the cause only when more depended on the mother's behaviour.

At times these mothers feel it was the negligence of the health worker who handled her. At times they may not want to see that midwife again so at this time we engage the in-charge or someone senior or if it's beyond we consult and engage the doctor to help us. **(PF\_HCIV\_004\_IC\_Mat)**

When it comes to counselling after baby loss, I counsel her about the cause and I also emphasise that next time don't allow to use the herbs, just come to the hospital and be handled by qualified health workers. **(PNFP\_Hosp\_002\_IC\_Mat)**

### **Rationing of services to fit existing resources**

Some health workers addressed stillbirth by rationing information and services to fit existing resources. This was observed to be true in the context of inadequate resources to support policy requirements. Limiting the choice of family planning methods offered was observed where there were conflicting goals between organisational values and policy objectives. Some religious-affiliated health facilities were restrained from offering modern family planning methods. In such instances, the package delivered was reduced

to counselling without the provision of commodities or administering methods. This is exemplified by the following quote:

For the case of family planning, we have nothing to do as Catholics we are supposed to use natural family planning ... We just counsel on natural methods which people don't believe they are effective [and] it becomes a bit of a challenge. Because we tell her to go home and use moon beads. She may not even know [how to use it] and you have to confirm [the effectiveness of] those family planning after six months so before she confirms she has already conceived **(PNFP\_Hosp\_002\_MW)**

### **Limited choice of family planning methods**

Where supplies appeared inadequate, this prompted health workers to use their discretion to fulfil policy objectives by improvising to ensure that mothers received family planning services even when it was not their preferred method.

She insists on that particular method which is not available at the moment. We can suggest to her that since it's the same type let's give you another injectable and when you come back you will get the FP method of your choice. So it may confuse them somehow because it is us who would have diverted them from what they came for. **(PF\_HCIII\_006\_IC\_Mat)**

During the patient-health worker interface, an assessment of risk informed the packaging of information and the mode of delivery. Subsequent prioritisation during service delivery witnessed women perceived as being at high risk of stillbirth being referred from lower to tertiary-level health facilities. Even within facilities, information was packaged depending on perceived risk, with high-risk mothers receiving more information from specialists while the rest continued receiving routine services.

What we do here we have categories of ANC care. We have a nurse-led ANC, we have a doctor-led ANC, and we have a specialist ANC. For the midwife-led ANC when [they] identify a mother that has risk factors that need to be seen by a doctor, they will have to refer them to a doctor. And for the doctor-led ANC, when they have a risk factor [that] can be referred to a specialist and in all those levels, when the mother is not able to pay for the specialist direct is referred from the midwife to the doctor to the specialist and they can have optimum care [without paying] **(PNFP\_Hosp\_001\_MO)**

While receiving services, referred mothers would be attended to first before the ones who started antenatal care services from tertiary facilities. Besides, referred mothers perceived to be high-risk would be closely monitored through shorter return intervals and provided with the specialist's telephone contact(s) for quick consultations.

Some of the very high-risk mothers we usually give them shorter return dates and we work in such a way that we give these mothers sometimes personal contacts or we give them the toll-free line to call. We teach them about any danger signs that if you feel like this it's better for you to call and find out or you come to the facility. **(PNFP\_Hosp\_002\_MO)**

### **Demand for services**

When facilities were overwhelmed by demand, frontline health workers aligned the available human resources to manage high volumes, especially during ANC clinics.

Related challenges in such contexts include the inability by the health workers to dedicate ample time to managing each of the cases. They hence improvised by resorting to selective implementation of policy aspects.

Like if you go to an HCIV there are like 200 mothers and there are four midwives and if one of them worked at night probably another one is going to work during the day. So that means that we have two midwives, so how are you going to evaluate these mothers comprehensively? **(PF\_HCIV\_003\_MO)**

### ***Limited resources and skills***

Delivery of services in the context of limited resources led health workers to dispense services with varying policy aspects of support provision to the mothers. Emotional support after experiencing a stillbirth, which ordinarily extends beyond counselling to include addressing other social issues such as gender-based violence, is sometimes disregarded.

There is a gap when it comes to counselling of these mothers because these days the counselling which is common is HIV counselling. So when it comes to the counselling of these mothers, it is difficult [both to] the health workers and even the mother. **(DHMT\_007\_Nur\_02)**

Other factors related to the limited resources context include lack of ample workspace. For mothers that experienced a stillbirth, the facilities lacked spaces for the mothers to rest while permitting them to grieve and resorted to isolation rather than separation.

Of course, if it was a C-section they will keep around for the healing to take place. Then we usually try to put them in an isolation side which doesn't have mothers with babies because sometimes they go into a bit of depression here and there when they hear the babies cry. **(PNFP\_Hosp\_002\_MO)**

### ***Conflicting organisational expectations***

Whereas some programmes were implementing maternal and child health interventions, focus was more towards the prioritisation of maternal mortality reduction. Stillbirth only came in because of the interconnectedness of interventions to address risk factors for both.

You see, when you look at the indicators our main emphasis is addressing the maternal mortality rates but the issue of stillbirth has not been well advocated for because when you look at how our health facilities are assessed mainly they are focusing on reducing the maternal mortality rate.... But even when we were being taught obstetrics and gynaecology the principle was that if you are caught in between losing the mother and the baby, you should struggle to save the mother. **(PF\_HCIV\_003\_MO)**

### ***Adapted routine to fit implementation context***



In light of the limited resources, efforts to maintain quality standards were evident. Strict use of a partograph for active labour monitoring, conducting perinatal death reviews to identify gaps, dissemination of performance data internally for shared understanding, and proper documentation and submission of data to the district and the MoH were some of the examples. Follow-up to ensure compliance was particularly observed, as reflected in the quotation below:

So we have recommendations and make sure we implement the things we have agreed upon. Like if the issue is using the partograph we will look at how you are using the partograph. **(PNFP\_Hosp\_002\_IC\_Mat)**

Streamlining and improvement of referral saw health workers from tertiary facilities focusing on a particular geographical area or to specific lower-level facilities known to frequently withhold mothers for long, leading to late referrals.

When we look at where these mothers are referred from commonly, there was a time when most of the referrals were coming from a certain health facility, so we had to go to that health facility and we had to talk to those people. **(PNFP\_Hosp\_002\_MO)**

Counselling mothers after a stillbirth was reported to be a daunting task by the midwives. In circumstances where failure to convince the mother about the possible causes was anticipated, such cases would be referred to the medical officers. It was reportedly conducted in a phased manner, where midwives would start off with the emotional support and then refer to the medical officer to clarify circumstances that lead to a stillbirth.

What we do sometimes we fail but we try to explain to them. Some will understand but others will not. So for us midwives, we don't go there we send doctors who are firm because she will start asking now what happened? So if you are a midwife who is a bit timid, you will start saying things which are not true. **(PNFP\_Hosp\_002\_IC\_Mat)**

## **Discussion**

### ***Main findings***

This study aimed to describe how frontline health workers implemented strategies to address stillbirth risks at the subnational-level final point of service delivery. Our results found that frontline health workers prioritised policy aspects in alignment with the available resources to suit service delivery through offering differentiated care to mothers and by packaging appropriate information and services based on context (14). Through these strategies, it emerged that frontline health workers played an important role in determining which policy aspects got implemented. A key lesson observed across the health facilities was that translation of policy objectives to address stillbirth risk did not come as a single standalone package but rather as the overall pursuit of policy goals expressed by the Ministry of Health. Strategies were instead integrated into ongoing policy alternatives currently running in reproductive maternal, adolescent, newborn and child health services. Where cases fitted into the available resources, health workers proceeded to manage them as part of the routine services they offered. As seen from the results, although it was not an “either-or” scenario while

translating policy recommendations, some aspects were prioritised more than others. Specifically, interventions that were already grounded in ongoing activities were easily adopted compared to those that were being introduced in the system specifically to respond to stillbirth.

### **Prioritisation of health service delivery to address gaps**

From this study, the ability to identify gaps in the system that may contribute to inadequate care to avert stillbirth led health workers to devise strategies that saw the prioritisation of service delivery in response to identified gaps. This is in pursuit of the MoH policy priorities that are in line with the recommendations (5) for aligning health systems interventions to the available resources in an integrated approach along the continuum of care from pre-pregnancy to postnatal health. A systematic review of the subject has documented evidence in support of appropriate spacing between pregnancies, which is associated with better maternal and foetal outcomes (15). Regarding stillbirth, literature has documented the causal relationship between short and long birth intervals in connection with the risk of stillbirth(16). Interventions to address birth spacing in the country are delivered through family planning programmes. Besides, it was observed from this study that health workers in some facilities opted to introduce family planning at all entry points into care. This was in line with the MoH strategy of the provision of reproductive maternal adolescent and child health services along the continuum of care (10). The same has been emphasised elsewhere as being crucial in linking service delivery since stillbirth causes overlap. When health workers adapt strategies to the health system context of limited resources, it can help maximise the available human resource and improve cost-effectiveness (5).

One interesting finding of this study was that prioritisation of service delivery aspects would sometimes extend beyond the formal policy provisions. This was particularly the case when frontline health workers thought it was in their best interest to deliver services while protecting their reputation. Examples included scenarios that reflected health workers conducting “mini-perinatal death audit meetings” ahead of the official one conducted by the facility MPDSR Committee. This was done as a quality improvement activity aimed at ensuring the identification of health systems gaps that led to a stillbirth and make adjustments for implementation to avoid similar instances in future. Perinatal death audits are policy objectives that have been reflected in national guidelines with procedures stipulated for conducting one (17). Cases were reported from this study where it was highly prioritised by the frontline health workers who held brainstorming sessions among those that handled a particular mother to establish the cause. Discussion of high-profile cases among staff outside formal proceedings is a universal practice around the world. Sometimes it occurs as a contribution to understanding the problem and coming up with solutions. This informal process is a key ingredient for quality and process improvement. It may also have occurred owing to fear of repercussions in case the cause fell on the health worker during the audit processes. This is understandable as a previous scoping review of the same attributed

the low uptake of MPDSR to fear of the potential for litigation from families (18). In the context of the study setting, not all health workers that handled the mother get invited during the audit committee meeting but, rather, representatives from the maternity unit, usually the officer-in-charge and the health worker that conducted the final delivery. The findings compare well with results from a study conducted in Jordan (19) that showed that health workers expressed a need to be part of the perinatal audits with reservations about the whole idea for fear of having a conflict with the bereaved family.

Improvements in data capture, a key element highlighted from the global campaigns, was also prioritised at the national level (20). Several strategies are identified in the national guidelines, such as the spatial distribution of the stillbirth burden (21), reflecting stillbirth as a district-level and hospital performance indicator(22), and perinatal mortality notification and review as a quality improvement indicator(17), among others. Another important finding of this study was that even at the facility level, health workers made efforts to ensure that stillbirths were among the indicators reported during daily handover reports from the maternity unit. Efforts were, in addition to notifications, review and District Health Information Systems (DHIS2) reporting procedures, recommended from policy. In turn, capacity gaps contributing to this trend would be identified and targeted skills-building initiated. The results re-echo similar sentiments from elsewhere (23) calling on actors to count stillbirth to improve care for women, which corroborates WHO's call for the same (24).

### **Differentiated care to align with existing resources**

Another important finding of this study was that, depending on the perceived risk of stillbirth in a mother, differential care was offered by frontline health workers during antenatal care. It is a universal practice to offer different packages to individual mothers depending on perceived risk. This is understandable, given that care during pregnancy is essential for identifying and modifying risk factors related to stillbirths, such as risky behaviours, for instance, alcohol consumption and cigarette smoking(25). Besides, it is during pregnancy care that micro-nutrient deficiencies can get addressed in addition to the identification and prevention of infections (26). In some facilities, mothers with elevated risk, such as hypertensive and diabetic disorders, were referred to continue services from medical officers while those with minimal risks received services from midwives during their routine visits. Lower-level facilities without such cadre-ship were referred to tertiary facilities to be seen by a doctor. Dialogue on birth preparedness included options for shorter return intervals, retention at a facility closer to due date or even delivery by caesarian section. These results are in agreement with findings of a modelling study that established the effect of managerial interventions in the reduction of stillbirth mortality (27, 28), reflecting high returns for delivery by caesarian section for mothers exceeding 42 weeks.

From the results, it emerged that emotional support through counselling mothers that had experienced a stillbirth was particularly challenging (29). More than additional resources, health workers informally recognise time as an essential element of

resolution for which no additional immediate resources, such as staffing, could probably substitute. This made health workers offer a differential package to mothers with a stillbirth and ones with a live baby. The former were encouraged to initiate family planning before discharge and the letter advised on appropriate spacing of approximately two years. Even among those that experienced a stillbirth, the packages depended on their levels of cooperation throughout the process, with the uncooperative ones receiving minimal emotional support. In addition to family planning counselling, they had to explain the circumstances surrounding the loss (30). The lack of trust and unfamiliarity between mothers and provider are certainly a handicap in determining grief comfort. One other reason given was the inadequate counselling skills which made it impossible to comfortably manage the grieving mothers who often blamed health workers for the loss (31). Similar results have been reported elsewhere (32), where difficulties were attributed to inadequate training. Health workers further noted that counselling was complicated by lack of space to conduct the sessions. As a result, the grieving mother ended up being counselled in the maternity wing among mothers with live babies. Our findings corroborate results from a systematic review (12) where midwives experienced stressful, emotionally challenging, uncomfortable and unprepared-to-care-for bereaved families (33).

### **Rationing of services in the context of resources**

Our findings show that in the absence of adequate resources to support the implementation of policy provisions to address stillbirth risks, services were rationed to fit existing resources. This was subject to their understanding and interpretation of policy requirements, given the resources at their disposal. The availability of specific family planning methods at particular points in time affected access to and utilisation of family planning services and yet it has the potential to reduce stillbirth (34). This was sometimes due to general stock-outs, partial stock-out of particular commodities on specific days, or the absence of health workers to administer certain methods. Prospects of a reduction in stillbirth rates, through fertility reduction leading to mortality reduction by scaling up family planning, have been documented (16). However, the observation from this study that commodities may not be readily available implies that such benefits cannot be realised under such conditions.

The level of demand for the available services made it challenging for health workers to accord each of the mothers adequate time to manage. Overwhelming demand which created high patient loads has been associated with compromised quality of the services delivered. To address this, mothers sometimes received services through group antenatal care where peer learning and counselling were encouraged (21). The same extended to the implementation of prioritised strategies to address stillbirths. Discretion, therefore, became one of the tools at the frontline health workers' disposal to get around the high volume, especially during the ANC clinics, which made them ration services. Rationing of information was common during these interactions, where the assessment of risk informed the amount of information to be provided and the mode



of delivery. Limited skills also influenced what aspects of the policy to prioritise, such as counselling skills, which are not optimal.

### **Limitation**

The main limitation of this study was that it was based on a single district case. However, we made attempts to have respondents from different implementation contexts such as levels of service provision, different cadreships and health facility ownership as these exert a greater influence on the influence of frontline health workers. We acknowledge that implementation contexts vary significantly and may lead to different outcomes when it comes to the influence of frontline health workers on policy implementation processes. Therefore, the results and conclusions from this study need to be interpreted with caution in other settings. We aimed at an in-depth understanding of how the frontline health workers translated policies at the frontline to respond to stillbirth mitigation measures. Maternal and child health policy implementation in Uganda at varying degrees depended on the service provision level and the capacities to offer the same. Although our sample represented all these service delivery levels, including a mix of public and private-for-profit entities, save for the regional and national referral hospitals, we are unable to account for the contextual factors that may influence the health workers' exercise of discretion in translating these policy intentions. Also, this study was unable to interview service users to get their perspectives with regard to the way frontline health workers exercised discretion while delivering services to them, which would have helped in the triangulation of views expressed by the latter. Besides, the adoption processes of the policy priorities to respond to stillbirth were still evolving and were likely to play out differently in different contexts by the time field data collection was conducted. Nonetheless, this study had some strengths. Specifically, it contributes to filling the knowledge gap with regard to the implementation experiences of frontline health workers following global campaigns which called upon governments to prioritise interventions aimed at addressing stillbirth by 2035. The provision of context and the contributing factors that are likely to have led frontline health workers to adjust aspects of policies at the final point of implementation will likely provide lessons on how best to inform policy implementation. It will provide policymakers and implementers with insights into what needs to be in place if policy intentions are to be realised. The results presented in this study are drawn from service provision following the routine standard of care and not pilot projects. Such a setting is not contaminated by external factors likely to sway outcomes and are, therefore, suitable to provide key implementation lessons in a real-life setting. Whereas some of the stillbirth global campaign priority areas had been implemented in a project mode with uncertain outcomes, by the time of the study they had been rolled out as a routine standard of care. Our results are from the real-world implementation context and are, therefore, likely to have practical implications since the context may not differ much.



## Conclusion

In light of the study findings and ensuing discussion, frontline health workers were seen to align resources tailored to the implementation of aspects from the policy provisions. It was influenced by their understanding of risk, the feasibility of implementation and the desire for optimal health systems performance. Our analysis indicated that the interplay of contextual factors at the final point of policy translation into service delivery, such as the health system capacities, the commitment to achieve policy objectives and alignment of available resources to policy targets in an integrated manner, ought to be considered while setting policy objectives.

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## CHAPTER FOUR

### Paper Three

#### **The role and attributes of social networks in the provision of support to women after stillbirth. Experiences from Uganda<sup>4</sup>.**

##### **Scope of the chapter**

This chapter investigated aspects of social support to women during pregnancy and after experiencing a stillbirth. Communities have been known to attach stigma to mothers and their families after they have experienced a stillbirth, which is at times detrimental to even seeking support that would go a long way in facilitating access to the needed care to address the stillbirth risk factors. This has also driven the direction of research investigating stillbirth at the community level. Maternal health care-seeking is socially constructed and decisions around the available care options and the means to access them is to a great extent influenced by the members of the social networks in which the women live. This paper explores the positive aspects of social support prevalent in the women's networks that can be harnessed to address some of the challenges impeding efforts to address stillbirth risk factors at the community level. Social support was operationalised into five different types where information about receipt of the same during pregnancy and after experiencing a stillbirth was collected from the women. This work was published in the journal BMC: Women's Health.

##### **List of tables**

Table 4.1: Respondents' demographics

Table 4.2: Alter characteristics

Table 4.3: Bivariate association of social support with alter characteristics

Table 4.4: Bivariate association of social support with network characteristics

Table 4.5: Predictors of social support during pregnancy

Table 4.6: Predictors of social support after experiencing a stillbirth

Table 4.7: Legend for the social network graphs

Table 4.8: Social support after stillbirth descriptive statistics at ego level

Table 4.9: Structural measures of personal networks for six scenarios

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<sup>4</sup> A slightly modified version of this article has been published in the journal BMC Women Health

## List of figures

Figure 4.1: Prevalence of social support during pregnancy and after experiencing stillbirth

Figure 4.2: Social support network visualisation for the six typical scenarios

## Data-sharing arrangements

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## Abstract

**Introduction:** Communities continue to exert pressure on mothers experiencing a stillbirth despite their potential to provide social support to the grieving parents. Maternal health care support-seeking behaviours are socially reinforced, rendering a social network approach vital to unveil the social support dynamics which, when tapped into, can improve community response to mothers experiencing stillbirth. However, it is not clear what type of social support and to whom women turn when in need of such support. The study sought to explore the role of women's social networks in the provision of support to mothers before and after experiencing a stillbirth in Uganda.

**Methods:** An exploratory cross-sectional study design adopting a social network approach was used. Data collection followed established procedures for conducting network interviews on a convenient sample of 17 mothers who had experienced a stillbirth within six months prior to the study and were recruited through their service providers at health facilities. Frequencies and bivariate analysis were conducted to determine the factors influencing the provision of social support from network members. We then performed a Poisson regression on each of the social support types and the



explanatory variables. Network structure variables were calculated using UCINET version 6 while Netdraw helped in the visualisation of networks.

**Results:** Overall, the findings revealed that social support was available from all network relations mentioned by the respondents. No major variations were observed between the two periods between pregnancy and after experiencing a stillbirth. The most common support that the respondents reported receiving was intangible and came in forms such as emotional and information support. Most of the social support which was reportedly received by the respondents came from females who were married and from the naturally occurring networks such as family and friends. We also observed that social support tended to follow certain patterns of network relational characteristics including trust, frequency of contact and counting on the alter for support.

**Conclusions:** Great potential for social support exists within women's social networks that can help them address stillbirth risk factors during pregnancy and cope after experiencing a stillbirth. Alter characteristics such as being female, married and from naturally occurring networks, and relational characteristics like trust, frequency of contact and counting on the alter for support were predictors of eventual social support. Interventions aiming at addressing stillbirth risk factors at community level and those targeting supporting women after experiencing one sought to harness these network characteristics for better returns to the mothers.

**Keywords:** social support, social network, stillbirth

### **Background**

Social support for mothers during pregnancy is associated with a general sense of psychological wellbeing and self-worth, and enables women to access resources for maternal health services, which all contribute to improved quality of life for mother-baby dyad (1). Similarly, a display of depressive symptoms and anxiety postpartum has been associated with a lack of social support from the social environment (2, 3), with a lack of emotional and information support being the leading contributor to postpartum anxiety (3). Social support is a modifiable risk factor and is measured as part of a comprehensive maternal health care assessment. Social support refers to the perceived and enacted care one receives from being part of a supportive social network (4), while social capital is the actual value embedded within the social relations that demonstrates the quality and quantity of such relationships. It manifests through the connections among network actors who demonstrate care by providing the different types of support to mothers in need (5). At the community level where the relationships are embedded, the support has the potential to aid pregnant women in seeking the required care to avert a potential stillbirth risk and enhance adjustment to cope with life afterwards for those that have experienced one.

Two mechanisms for social network influence through which social support manifests exist; these are connection and contagion. They trigger social capital among network actors to provide social support to a member in need. Connection is the individual's

standing within the wider network that attracts social support because of their position, while contagion is the spread of perceived and enacted reciprocal behaviours to offer social support to members in need from one individual to another (6). The network effect hypothesis that is related to contagion postulates that similarities in lifestyle and health behaviours, emotions and cultural norms among individuals are a product of diffusion and influence within networks, while the self-selection hypothesis, which is synonymous with connection, suggests that the ties among members are driven by predisposing beliefs and attitudes which may influence the formation and sustenance of the networks (7). Interventions utilising network approaches to strengthen or build capacities within existing community relationships and connections are known to reinforce social support and are more sustainable compared to ones that either introduce new nodes or links to existing social networks due to their overreliance on external social support (8). Understanding existing social networks and how they respond with support to women experiencing a stillbirth is important in informing community-level interventions and policy response.

On the one hand, community-level interventions targeting improved social support for better maternal and child health outcomes have deployed social network approaches in varying ways (8). On the one hand, strengthening existing networks through identification of the most influential persons by nominations or mathematical algorithm to engage them for behavioural change impact was behind the creation of mentor mothers to support Prevention of Mother-to-Child Transmission (PMTCT) programmes (9). Similarly, the involvement of male partners and mothers-in-law in maternal health, especially in rural areas where such traditional norms and beliefs are held in high regard, was intended to avoid unnecessary community delays due to maternal health care-seeking decision-making dynamics (10-12). Additionally, other interventions have used induction approaches where peer-to-peer interaction is stimulated between links of existing networks as witnessed when group antenatal care (ANC) counselling sessions (13, 14) and women's savings groups are initiated for birth preparedness plans (15, 16).

On the other hand, the segmentation approach to network interventions seeks to change a group of people at the same time for improved maternal health behaviours. The inclusion of maternal health and family planning services in the package delivered by community health workers on top of managing childhood illnesses was specifically intended to infiltrate pregnant women's networks with reliable maternal-related information and services (17). Relatedly, programmes that alter pregnant women's social networks, such as a ban on traditional birth attendants (TBAs) in Uganda and discouragement of the same thereof, was intended to eliminate a critical network node characterised by community delays and late referrals in a bid to improve facility deliveries under skilled birth attendants (18). Similarly, the inclusion of motorcycle riders through a transport voucher scheme in Eastern Uganda served to reduce redundancy while increasing communication and access to community resources to improve the referral system for improved maternal health outcomes (19).

Global campaigns to address stillbirth were embraced at national level, with Uganda prioritising interventions addressing fresh stillbirth through health systems strengthening to respond to risk factors. The country registered a steady decline in fresh stillbirth from 16/1,000 in 2013 to 9/1,000 by 2019, which was ahead of the Every Newborn Action Plan(ENAP) and Health Sector Development Plan (HSDP) targets (20, 21). While a number of interventions have focused on the health systems level, more remains to be done at community level (22). The strategy for a community intervention at scale with support from the World Bank's Global Financing Facility (GFF) is yet to be rolled out. This trajectory falls short of achieving the global objective of reducing stillbirth (23, 24), especially in Sub-Saharan Africa where many community cases occur and go unnoticed, coupled with late reporting for ANC and low completion rates, which would have addressed the macerated cases through interventions during ANC (22). It is then those interventions targeting social support to facilitate linkage into care that promise a viable option to contribute to addressing the stillbirth burden in low-resource settings.

For stillbirth prevention, a great deal of research into the community factors has focused on negative reactions from the community members to mothers and families experiencing a stillbirth, which amplifies stigma (25, 26). This masks the potential role that communities can play as active partners in addressing the problem. Given that a number of stillbirth cases still occur at community level, adequate social support can help in averting some of the risk factors when support networks are strengthened and purposed for this. Interventions with a potential optimal effect on stillbirth reduction are those that respond to equity in reaching the poor and marginalised as well as those dealing with behavioural practices (27). Access to the right maternal health information can redirect mothers to appropriate service providers, while the provision of transport can lead to timely referral. The major challenge has been that the potential to tap into social support from the social networks to avert stillbirth risks remains underexplored. Interventions that have attempted to address this have predominantly adopted singular community approaches that do not view community as a complete social ecosystem and focus more on health systems factors.

The value of understanding the dynamics around social support from network members is crucial to the national response in addressing the stillbirth burden at community level. This study aimed to explore the role and attributes of social networks in providing support to women before and after experiencing a stillbirth in Mukono district of Uganda. Elsewhere, kinship, trust, education, age, wealth and neighbourhood context have been shown to influence social support for maternal health care service-seeking and access (28-30). Within Uganda, studies have demonstrated the role of social support in helping patients access HIV services and act as agents for prevention (31, 32). None has examined the role of women's social networks in the provision of social support before and after experiencing a stillbirth. The expected outcome of this study was to document the nature of the available social support within existing networks for women experiencing a stillbirth and to characterise providers and recipients as well as the

networks they belonged so as to inform how best these can be strengthened to enhance community-level stillbirth prevention strategies.

## **Methods**

### ***Design and study setting***

This was an exploratory cross-sectional study design that adopted a social network approach as part of a larger mixed methods study conducted in Mukono district, located in central Uganda, and which has a high fertility rate. The district has both peri-urban and rural characteristics and borders Kampala, the capital of Uganda. It consists of four health sub-districts and, according to the 2016 population and housing census, it had a total population of 599, 817, of whom 51.3% were female, with 20% (121,163) being in their reproductive age. It has characteristics of a pluralistic health system with public, private not-for-profit and private-for-profit health facilities offering maternal and child health services. There are a total of 51 health facilities, of which only four are at Health Centre IV (HCIV) level and above, offering comprehensive emergency obstetric (CEMONIC) care services. These are led by medical doctors. One of the HCIVs is reported as conducting the highest number of deliveries and C-sections among facilities at the same level year on year in Uganda. At the time of conceptualising the study, the district was among those with the highest stillbirth burdens as reported in the Annual Health Sector Performance Report of the Ministry of Health. A number of mothers accessing maternal health services in the health facilities come from the neighbouring districts due to its central location, proximity to the city and access to the great East African Highway, a major transport route in the country and region

### ***Participants' characteristics***

The participants enrolled in this study included women in their reproductive age (18 years or older), with eligibility criteria of having experienced a stillbirth within six months prior to the study and having consented to be interviewed. The women had delivered the index pregnancy in one of the health facilities in the district, specifically Health Centre III (HCIII) and above, because they offer emergency obstetric care services. Exclusion criteria included not being available for interview during the study period. The results reported here are for only 17 respondents out of the 20 that were targeted from the 23 who were approached.

### ***Definitions***

*Emotional support:* Behaviours that foster a feeling of comfort, which leads to a person believing that they are being admired, respected and loved and that others are available to provide care and safety.

*Information support:* Knowledge, advice or information that helps an individual to understand their world and adapt to change that comes with it.



*Instrumental support:* The help from other people in terms of activities that the ego is unable to perform or for which others are required to help solve a problem (help with household chores, accompany one to hospital). We separate instrumental from material, as one refers to services while the other refers to tangible goods.

*Financial support:* Assistance in terms of money to help buy a good or facilitate a service.

*Material support:* This refers to tangible goods received to help solve a particular problem.

### **Description of the processes**

Data was collected by the first author between January and May 2019, where a convenient sampling technique was used to access potential participants who were identified from facility records. They were approached by the health workers from the maternity unit where they had the delivery. The health workers were first oriented about the study and received information, training and support to make them comfortable while explaining the objectives of the study to potential participants. Health workers would first speak to the potential participants and inform them about the study and thereafter request them if they would be willing to take part in the study after explaining to them the study objectives. A study team member verified information with health providers to ascertain eligibility before contacting the mothers. Those that agreed to participate were then approached by the study team member using information provided from the facility records to access them via mobile telephone. Thereafter a convenient place and time for conducting the interview would be agreed upon with the potential respondent. Interviews were face-to-face interviewer-administered. On the day of the interview, the objectives and procedures to be followed would be repeated for the participant and thereafter consent to participate obtained. Although the study did not set out to collect data on refusal to participate, it later emerged that three of the potential respondents that had been approached declined to participate and at that point no further contact was made.

The tool used was developed by the first author based on literature and standard procedures for conducting social network interviews. It contained five sections. The first section elicited information on social demographics, household characteristics, maternal health and obstetric history characteristics collected from each respondent through self-report. The second section included the name generator where an egocentric network approach was used to guide respondents to recall at least 15 to 20 of their social network members. The criteria included giving names of those people they could recall to have had contact or interacted with in the course of pregnancy and after experiencing a stillbirth. This followed established processes for conducting social network interviews (33-35).

To assess network composition, the third section asked respondents to provide information about each of the network members they had earlier listed. The information



included demographic data such as age, education, gender, marital status and relationship type. The level of trust, emotional closeness with network member, frequency in seeking advice from network member and whether that particular network member could be relied on for support were assessed on a three-point Likert scale including “Not at all”, “A little bit” or “Very much”. The frequency of interaction with a network member was assessed on a five-point Likert scale which reflected 1=never; 2=once a month; 3=once a week; 4=several times a week; and 5=about every day.

The fourth section covered the different aspects of social support that were explored between the respondent and network members. Specifically, following guidance from literature (28, 36), social support was conceptualised as consisting of five types, including financial, information, material, emotional and instrumental support. The questions were repeated for each of the categories where the respondents were asked if they had sought and received support from the network member during pregnancy and after experiencing a stillbirth. The responses were assessed on a three-point Likert scale which included 1) “Not at all”; 2) “A little bit”; and 3) “Very much”. The last section (five) assessed the network structure where participants were asked if a particular network member knew each of the other alters mentioned, with response options including “Yes”, “No” and “Don’t know”. Where the answer was in the affirmative, the participants were asked about the nature of the relationship in terms of trust and counting on the alter for support, which were assessed on a three-point Likert scale including 1) “Not at all”; 2) “A little bit”; or 3) “Very much”. Frequency of contact was assessed on a five-point Likert scale with 1) once in six months; 2) once in three months; 3) once in a month; 4) once a week; and 5) about every day. Emotional closeness was assessed on a three-point Likert scale with 1) not at all, 2) somewhat, 3) very close.

### **Data analysis**

Because the study adopted an exploratory approach, the results presented use descriptive statistics to characterise the study respondents and network alters who were the primary providers of social support before and after experiencing a stillbirth. Descriptive analysis was conducted for respondent and alter characteristics using frequencies and proportions. The prevalence of social support was calculated using frequencies, proportions and chi-square tests with 95% confidence intervals. Alter characteristics and network relational characteristics reflecting quality were considered as explanatory variables. A bivariate analysis was conducted on both the alter and network characteristics to explore the association both during pregnancy and after experiencing a stillbirth. We then performed a Poisson regression on each of the social support types and the explanatory variables. Statistical analyses were conducted using statistical analysis software (SAS) version 14 (SAS Institute Inc., Cary, NC, USA) with a significant level set at  $p < 0.005$ , while UCINET version 6 was used to calculate network structure measures for each of the respondents. The network graphs were drawn using Netdraw.

## Results

The data presented is from 17 respondents, although 20 had initially participated in the study. Three cases were removed at analysis because they provided fewer alters during the name generation exercise.

### **Respondent characteristics**

Overall, the respondents reported the mean age at first pregnancy as 20.5 years (range:14-30), with 66% reporting a parity of three or more at the time of the interview. Less than a quarter of the respondents (22.2%) indicated a history of a negative pregnancy outcome such as a stillbirth. More than half of the index pregnancies (55.6%) that resulted in the stillbirth were referrals-in, with the first point of care-seeking being mainly the lower-level health facilities (22.2%). Very few (16.7%) reported using any family planning method at the time, with more than half (66.6%) reporting intentions to have another child within the next one to three years.

According to the respondents' demographics, the mean age was 29.4 years (range 21-41), the majority (44.4%) had some secondary-level education, and many of them (88.8%) were Christians. The majority (83.3%) were married, with more than half (61%) living with four members or fewer in the households and staying in a nuclear family arrangement (66.6%). The details are presented in Table 4.1 below:

**Table 4.1: Respondents demographics (N=17)**

<b>Respondent Characteristics</b>	<b>Percentage</b>	<b>Mean</b>	<b>Range</b>
<b>Age</b>		29.4	21-41
<b>Education</b>			
No education	5.56		
Primary	22.22		
Some Secondary	44.44		
Completed Secondary	27.8		
<b>Religious affiliation</b>			
Christian	88.8		
Muslim	22.22		
<b>Marital status (married)</b>	83.33		
<b>Mean age at first pregnancy</b>		20.5	14-30
<b>Total pregnancies (3 and over)</b>	66.6	3.7	
<b>History of a miscarriage/stillbirth (yes)</b>	22.2		
<b>Stillbirth pregnancy order</b>			
First	16.7		
Second	11.1		
Third	11.1		
Forth	16.7		

Fifth	33.3		
Sixth	11.1		
<b>Place of SB delivery</b>			
Facility	44.4		
Referral-in	55.6		
<b>First point of care-seeking</b>			
TBA	11.1		
Clinic	22.2		
Lower-level health facility	22.2		
<b>Current use of family planning (yes)</b>	16.7		
<b>Intend to have more children (yes)</b>	66.7		1-4
<b>When intend to have child</b>		1 year	1-3 years
<b>People living in the HH ( four and below)</b>	61.11		
<b>Family type (nuclear)</b>	66.67		

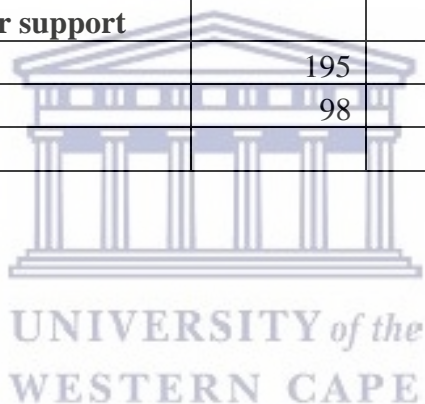
### ***Network members (alter) characteristics***

Network member characteristics reflected diversity, where 70.6% were females, the majority (64.8%) with some secondary-level education or more, and more than half (67.6%) were married. By composition, more than half (58.4%) were from naturally occurring network members, of whom 62.6% were family members. The majority (80.9%) of the alters were trusted by the respondents, while 78.5% were in frequent contact with the respondents and 72% were emotionally close to the respondents. The alters who would be counted on to offer support were 66.6%, with 65.5% maintaining or improving their relationship with the respondent following a stillbirth. The details are presented in Table 4.2 below:

**Table 4.2: Alter characteristics (N=293)**

<b>Respondent Characteristics</b>	<b>Frequency</b>	<b>Percentage</b>	<b>Range</b>
<b>Age (26&gt;)</b>	249	85	
<b>Gender (Female)</b>	207	70.6	
<b>Education</b>			
No education – primary	103	35.2	
Secondary and above	190	64.8	
<b>Marital Status (Married)</b>	198	67.6	
<b>Network member type</b>			
Naturally occurring network	171	58.4	
Community role network	122	41.6	
<b>Naturally occurring network member type</b>	<b>N=171</b>		
Spouse	16	9.1	

Family	107	62.6	
Friend	48	28.1	
<b>Trust (yes)</b>	237	80.9	
<b>Frequency of contact (frequent)</b>	230	78.5	
<b>Emotional closeness (close)</b>	211	72	
<b>Alter knows about SB incident (yes)</b>	287	98	
<b>How alter got to know</b>			
Told by respondent	80	27.3	
Knew by themselves	69	23.5	
Through network members	143	48.8	
Through other means	1	.3	
<b>Relationship with alter after SB incident</b>			
As before or better	192	65.5	
Worse than before	101	34.5	
<b>Count on network member for support</b>			
Yes	195	66.6	
No	98	33.4	
<b>Average network size</b>			16.1



**Table 4.3: Bivariate association of social support with alter characteristics**

<b>Variable</b>	<b>Total</b>	<b>Material</b>	<b>P-Value</b>	<b>Financial</b>	<b>P-Value</b>	<b>Emotional</b>	<b>P-Value</b>	<b>Instrumental</b>	<b>P-Value</b>	<b>Information</b>	<b>P-Value</b>
<b>During pregnancy</b>											
Age Group in Years											
Less than 18	9 (3%)	0 (0%)	0.199	0 (0%)	0.082	8 (3%)	0.669	7 (7%)	0.036	0 (0%)	0.001
19 to 25	35 (12%)	9 (10%)	0.199	10 (10%)	0.082	34 (13%)	0.669	15 (14%)	0.036	16 (8%)	0.001
26 to 45	183 (62%)	59 (66%)	0.199	68 (70%)	0.082	170 (63%)	0.669	64 (60%)	0.036	130 (66%)	0.001
46 and above	66 (23%)	21 (24%)	0.199	19 (20%)	0.082	60 (22%)	0.669	20 (19%)	0.036	52 (26%)	0.001
Gender											
Male	86 (29%)	33 (37%)	0.055	35 (36%)	0.075	76 (28%)	0.056	25 (24%)	0.103	36 (18%)	0.001
Female	207 (71%)	56 (63%)	0.055	62 (64%)	0.075	196 (72%)	0.056	81 (76%)	0.103	162 (82%)	0.001
Education Level											
None	16 (5%)	4 (4%)	0.486	3 (3%)	0.557	15 (6%)	0.038	4 (4%)	0.136	12 (6%)	0.008
Primary	87 (30%)	31 (35%)	0.486	29 (30%)	0.557	84 (31%)	0.038	40 (38%)	0.136	59 (30%)	0.008
Secondary	103 (35%)	32 (36%)	0.486	33 (34%)	0.557	98 (36%)	0.038	33 (31%)	0.136	58 (29%)	0.008
Tertiary	87 (30%)	22 (25%)	0.486	32 (33%)	0.557	75 (28%)	0.038	29 (27%)	0.136	69 (35%)	0.008
Marital Status											
Not married	95 (32%)	18 (20%)	0.003	17 (18%)	0.001	90 (33%)	0.381	37 (35%)	0.494	62 (31%)	0.558
Married	198 (68%)	71 (80%)	0.003	80 (82%)	0.001	182 (67%)	0.381	69 (65%)	0.494	136 (69%)	0.558
Network Type											
Community	122 (42%)	17 (19%)	0.001	24 (25%)	0.001	112 (41%)	0.564	35 (33%)	0.024	84 (42%)	0.694
Naturally	171 (58%)	72 (81%)	0.001	73 (75%)	0.001	160 (59%)	0.564	71 (67%)	0.024	114 (58%)	0.694
	293	89		97		272		106		198	
<b>After stillbirth</b>											
Age group in years											
Less than 18	9 (3%)	0 (0%)	0.078	0 (0%)	0.109	9 (3%)	0.042	8 (5%)	0.030	0 (0%)	0.001
19 to 25	35 (12%)	9 (9%)	0.078	11 (11%)	0.109	35 (13%)	0.042	25 (15%)	0.030	13 (7%)	0.001
26 to 45	183 (62%)	69 (68%)	0.078	65 (63%)	0.109	172 (63%)	0.042	100 (61%)	0.030	133 (68%)	0.001
46 and above	66 (23%)	24 (24%)	0.078	27 (26%)	0.109	57 (21%)	0.042	32 (19%)	0.030	49 (25%)	0.001



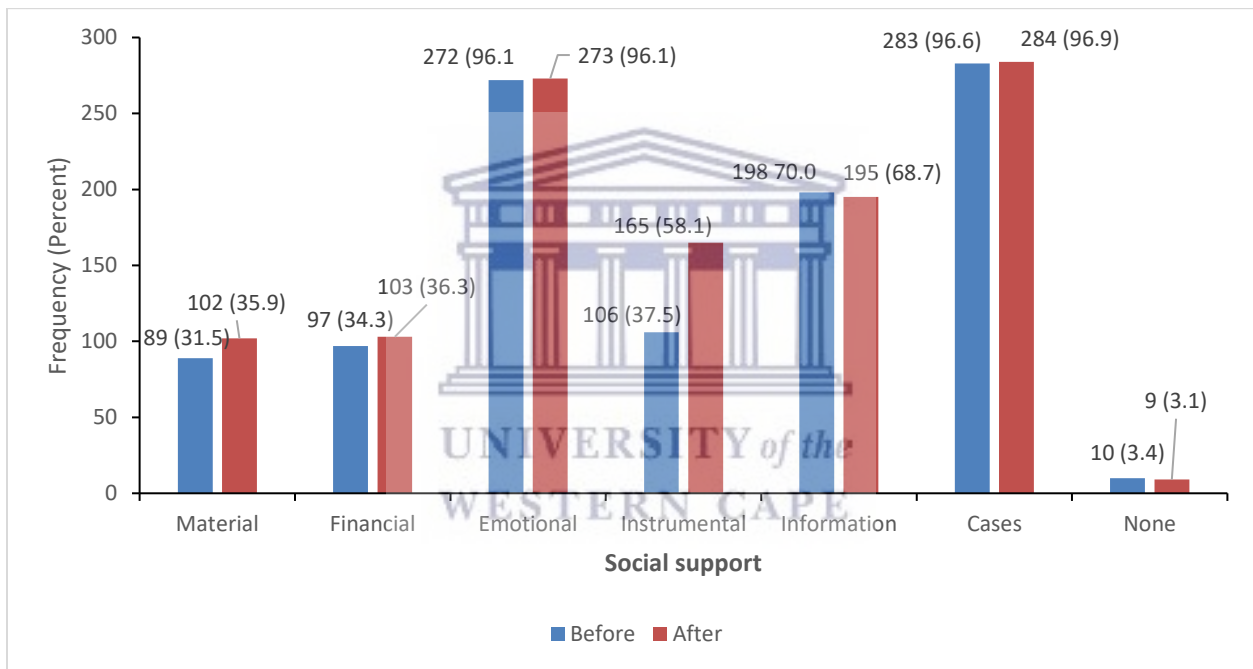
<b>Variable</b>	<b>Total</b>	<b>Material</b>	<b>P-Value</b>	<b>Financial</b>	<b>P-Value</b>	<b>Emotional</b>	<b>P-Value</b>	<b>Instrumental</b>	<b>P-Value</b>	<b>Information</b>	<b>P-Value</b>
<b>Gender</b>											
Male	86 (29%)	33 (32%)	0.410	39 (38%)	0.018	79 (29%)	0.566	44 (27%)	0.252	39 (20%)	0.001
Female	207 (71%)	69 (68%)	0.410	64 (62%)	0.018	194 (71%)	0.566	121 (73%)	0.252	156 (80%)	0.001
<b>Education Level</b>											
None	16 (5%)	4 (4%)	0.398	2 (2%)	0.192	14 (5%)	0.238	8 (5%)	0.127	13 (7%)	0.078
Primary	87 (30%)	32 (31%)	0.398	29 (28%)	0.192	84 (31%)	0.238	56 (34%)	0.127	56 (29%)	0.078
Secondary	103 (35%)	31 (30%)	0.398	37 (36%)	0.192	97 (36%)	0.238	60 (36%)	0.127	61 (31%)	0.078
Tertiary	87 (30%)	35 (34%)	0.398	35 (34%)	0.192	78 (29%)	0.238	41 (25%)	0.127	65 (33%)	0.078
<b>Marital Status</b>											
Not married	95 (32%)	23 (23%)	0.008	19 (18%)	0.001	89 (33%)	0.810	62 (38%)	0.032	53 (27%)	0.007
Married	198 (68%)	79 (77%)	0.008	84 (82%)	0.001	184 (67%)	0.810	103 (62%)	0.032	142 (73%)	0.007
<b>Network Type</b>											
Community	122 (42%)	40 (39%)	0.539	33 (32%)	0.014	110 (40%)	0.084	60 (36%)	0.038	78 (40%)	0.422
Naturally	171 (58%)	62 (61%)	0.539	70 (68%)	0.014	163 (60%)	0.084	105 (64%)	0.038	117 (60%)	0.422
	293	102		103		273		165		195	

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## Prevalence of social support among network members

Overall, the results revealed that emotional support was the most prevalent among network members both during pregnancy and after experiencing a stillbirth. There were no differences between emotional support received during pregnancy (96.1% CI 89.23 - 95.29) and after experiencing a stillbirth (96.1% CI 89.63 - 95.57). Material support was the least offered from network members both during pregnancy (31.5% CI 25.35 - 35.92) and when respondents experienced a stillbirth (35.9 CI 29.54 - 40.48). Details are reflected in Figure 4.1 below:

**Figure 4.1: Prevalence of social support (during pregnancy and after experiencing a stillbirth)**



## Social support and alter composition variables of personal networks

### Material support

According to alter characteristics, material support was reported to come from alters who were female 63% ( $p=0.05$ ), married 80% ( $p=0.003$ ) and from naturally occurring network members such as family and friends 81% ( $p=0.001$ ) during pregnancy. After experiencing a stillbirth, material support was reported to mainly come from alters who were 26-45 years 68% ( $p=0.078$ ) and were married 77% ( $p=0.008$ ).

### Financial support

Financial support was reported to come from alters who were married 82% ( $p=0.001$ ) and from naturally occurring network members 75% ( $p=0.001$ ) during pregnancy. After

experiencing a stillbirth, material support was reported to mainly come from alters who were female 62% ( $p=0.018$ ), married 82% ( $p=0.001$ ) and were from naturally occurring network members 68% ( $p=0.014$ ).

### ***Emotional support***

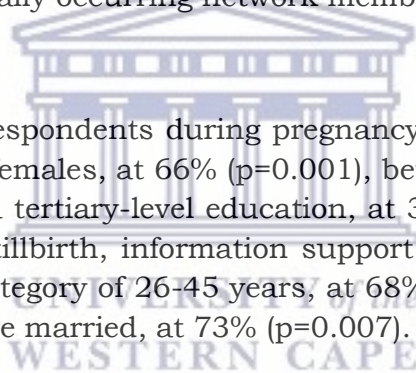
Emotional support was reported to come from alters who were male 72% ( $p=0.05$ ) and with a secondary-level education 36% ( $p=0.03$ ) during pregnancy and after experiencing a stillbirth; while emotional support was reported to come from respondents whose age ranged from 26 to 45 years, at 63% ( $p=0.04$ ).

### ***Instrumental support***

During pregnancy, instrumental support was reported to come from alters aged 26-45 years, at 60% ( $p=0.03$ ), and from naturally occurring network members, at 67% ( $p=0.02$ ); while after experiencing a stillbirth, instrumental support was reported to mainly come from alters who were aged 26-45 years, at 61% ( $p=0.03$ ), married, at 62% ( $p=0.032$ ) and from the naturally occurring network members, at 64% ( $p=0.038$ ).

### ***Information support***

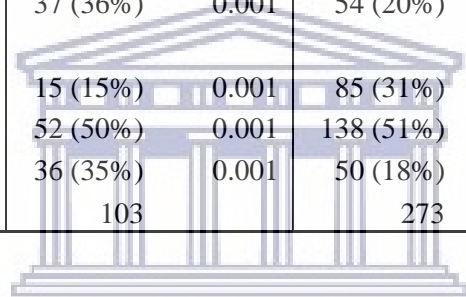
Information support to the respondents during pregnancy was reported to come from network members who were females, at 66% ( $p=0.001$ ), between ages 26 and 45 years, at 82% ( $p=0.001$ ), and with a tertiary-level education, at 35% ( $p=0.008$ ). On the other hand, after experiencing a stillbirth, information support was reported to come from alters who were in the age category of 26-45 years, at 68% ( $p=0.001$ ), females, at 80% ( $p=0.001$ ), and those who were married, at 73% ( $p=0.007$ ).



**Table 4.4: Bivariate association of social support with network characteristics**

<b>Variable</b>	<b>Total</b>	<b>Material</b>	<b>P-Value</b>	<b>Financial</b>	<b>P-Value</b>	<b>Emotional</b>	<b>P-Value</b>	<b>Instrumental</b>	<b>P-Value</b>	<b>Information</b>	<b>P-Value</b>
<b>During pregnancy</b>											
Trust the Alter											
Not at all	56 (19%)	7 (8%)	0.001	6 (6%)	0.001	46 (17%)	0.001	18 (17%)	0.001	20 (10%)	0.001
A little bit	157 (54%)	32 (36%)	0.001	42 (43%)	0.001	147 (54%)	0.001	43 (41%)	0.001	109 (55%)	0.001
Very much	80 (27%)	50 (56%)	0.001	49 (51%)	0.001	79 (29%)	0.001	45 (42%)	0.001	69 (35%)	0.001
Frequency of Contact											
Once in six months	14 (5%)	3 (3%)	0.006	2 (2%)	0.003	14 (5%)	0.078	3 (3%)	0.001	8 (4%)	0.062
Once in three months	49 (17%)	5 (6%)	0.006	10 (10%)	0.003	41 (15%)	0.078	3 (3%)	0.001	25 (13%)	0.062
Once a month	69 (24%)	21 (24%)	0.006	20 (21%)	0.003	66 (24%)	0.078	23 (22%)	0.001	51 (26%)	0.062
Once a week	72 (25%)	24 (27%)	0.006	22 (23%)	0.003	67 (25%)	0.078	24 (23%)	0.001	50 (25%)	0.062
About every day	89 (30%)	36 (40%)	0.006	43 (44%)	0.003	84 (31%)	0.078	53 (50%)	0.001	64 (32%)	0.062
Emotional Closeness											
Not at all	82 (28%)	6 (7%)	0.001	9 (9%)	0.001	67 (25%)	0.001	17 (16%)	0.001	40 (20%)	0.001
A little bit	155 (53%)	41 (46%)	0.001	49 (51%)	0.001	150 (55%)	0.001	51 (48%)	0.001	108 (55%)	0.001
Very much	56 (19%)	42 (47%)	0.001	39 (40%)	0.001	55 (20%)	0.001	38 (36%)	0.001	50 (25%)	0.001
Count on Alter for Support											
Not at all	98 (33%)	9 (10%)	0.001	10 (10%)	0.001	85 (31%)	0.016	22 (21%)	0.001	48 (24%)	0.001
A little bit	142 (48%)	35 (39%)	0.001	43 (44%)	0.001	136 (50%)	0.016	48 (45%)	0.001	105 (53%)	0.001
Very much	53 (18%)	45 (51%)	0.001	44 (45%)	0.001	51 (19%)	0.016	36 (34%)	0.001	45 (23%)	0.001
	293	89		97		272		106		198	
<b>After stillbirth</b>											
Trust the Alter											
Not at all	56 (19%)	13 (13%)	0.001	11 (11%)	0.001	48 (18%)	0.041	31 (19%)	0.052	17 (9%)	0.001
A little bit	157 (54%)	41 (40%)	0.001	51 (50%)	0.001	148 (54%)	0.041	80 (48%)	0.052	108 (55%)	0.001
Very much	80 (27%)	48 (47%)	0.001	41 (40%)	0.001	77 (28%)	0.041	54 (33%)	0.052	70 (36%)	0.001
Frequency of contact											
Once in six months	14 (5%)	2 (2%)	0.001	1 (1%)	0.003	9 (3%)	0.001	2 (1%)	0.001	8 (4%)	0.054

<b>Variable</b>	<b>Total</b>	<b>Material</b>	<b>P-Value</b>	<b>Financial</b>	<b>P-Value</b>	<b>Emotional</b>	<b>P-Value</b>	<b>Instrumental</b>	<b>P-Value</b>	<b>Information</b>	<b>P-Value</b>
Once in three months	49 (17%)	2 (2%)	0.001	11 (11%)	0.003	44 (16%)	0.001	17 (10%)	0.001	24 (12%)	0.054
Once a month	69 (24%)	23 (23%)	0.001	21 (20%)	0.003	63 (23%)	0.001	35 (21%)	0.001	49 (25%)	0.054
Once a week	72 (25%)	35 (34%)	0.001	36 (35%)	0.003	71 (26%)	0.001	42 (25%)	0.001	51 (26%)	0.054
About every day	89 (30%)	40 (39%)	0.001	34 (33%)	0.003	86 (32%)	0.001	69 (42%)	0.001	63 (32%)	0.054
<b>Emotional Closeness</b>											
Not at all	82 (28%)	18 (18%)	0.001	16 (16%)	0.001	67 (25%)	0.001	35 (21%)	0.001	35 (18%)	0.001
A little bit	155 (53%)	39 (38%)	0.001	50 (49%)	0.001	152 (56%)	0.001	87 (53%)	0.001	108 (55%)	0.001
Very much	56 (19%)	45 (44%)	0.001	37 (36%)	0.001	54 (20%)	0.001	43 (26%)	0.001	52 (27%)	0.001
<b>Count on Alter for Support</b>											
Not at all	98 (33%)	17 (17%)	0.001	15 (15%)	0.001	85 (31%)	0.006	38 (23%)	0.001	48 (25%)	0.001
A little bit	142 (48%)	45 (44%)	0.001	52 (50%)	0.001	138 (51%)	0.006	85 (52%)	0.001	99 (51%)	0.001
Very much	53 (18%)	40 (39%)	0.001	36 (35%)	0.001	50 (18%)	0.006	42 (25%)	0.001	48 (25%)	0.001
	293	102		103		273		165		195	



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## **Social support and network characteristics of personal networks.**

Network characteristics, such as trust in the alter, emotional closeness with the alter, frequency of contact with the alter and counting on the alter for support, were found to be significantly associated with all types of social support, such as material, emotional, financial, instrumental and information support, which was reported to come from alters both during pregnancy and after experiencing a stillbirth, as revealed in Table 4.4 above.

### **Predictors of social support**

During pregnancy the predictors for the provision of material support from the alters were being female ( $p=0.05$ ), being married ( $p=0.006$ ), coming from a naturally occurring network ( $p=0.00$ ), trusting the alter ( $p=0.00$ ), being very close emotionally ( $p=0.00$ ) and very much counting on alter for support ( $p=0.00$ ). The predictors for the provision of financial support from the alter were being married ( $p=0.001$ ), coming from a naturally occurring network ( $p=0.00$ ), having much trust in the alter ( $p=0.001$ ), meeting the alter at least once a week ( $p=0.045$ ), being very close emotionally ( $p=0.00$ ) and very much counting on the alter for support ( $p=0.00$ ). The predictors for the provision of emotional support from the alter were having much trust in the alter ( $p=0.049$ ), being emotionally very close to the alter ( $p=0.005$ ), and counting on the alter for support a little bit ( $p=0.007$ ). The predictors for instrumental support during pregnancy were being aged 25 years and above ( $p=0.049$ ), coming from a naturally occurring network ( $p=0.029$ ), meeting with the alter about every day ( $p=0.010$ ), being very close to alter emotionally ( $p=0.000$ ), and counting on the alter for support ( $p=0.000$ ). The predictors for information support during pregnancy were being 46 years and over ( $p=0.000$ ), being female ( $p=0.000$ ), having much trust in the alter ( $p=0.000$ ), being emotionally very close to the alter ( $p=0.000$ ), and very much counting on the alter for support ( $p=0.000$ ).

After experiencing a stillbirth, the predictors for the provision of material support were: the alter being married ( $p=0.020$ ), coming from a naturally occurring network ( $p=0.000$ ) and among those alters whom the respondent would count on to provide support ( $p=0.019$ ). For the provision of financial support after experiencing a stillbirth, the predictors were being married ( $p=0.004$ ), coming from a naturally occurring network ( $p=0.000$ ), and being counted on by the respondent to offer support whenever in need ( $p=0.000$ ). Regarding the provision of emotional support, the predictors were frequency of contact from once a week ( $p=0.046$ ) to about every day ( $p=0.058$ ), being emotionally close from somewhat ( $p=0.006$ ) to very close ( $p=0.015$ ). The predictors for the provision of instrumental support were being female ( $p=0.029$ ), coming from a naturally occurring networks ( $p=0.013$ ), having trust in the network member ( $p=0.002$ ), frequency of contact of about every day ( $p=0.023$ ) and ability to count on the alter to provide support anytime it is needed ( $p=0.010$ ). Lastly, the predictors for the provision of information support to mothers after experiencing a stillbirth were: the alter being older than 46 years or more ( $p=0.000$ ), being female ( $p=0.000$ ), having a tertiary level of education ( $p=0.028$ ), coming

from a naturally occurring network ( $p=0.029$ ) and having trust in the alter very much ( $p=0.001$ ).





	c.PR (95%CI	P-Value	c.PR (95%CI	P-Value	c.PR (95%CI	P-Value	c.PR (95%CI	P-Value	c.PR (95%CI	P-Value
<b>Trust levels</b>										
Not at all	1		1		1		1		1	
A little bit	1.1 (0.65 - 1.94)	0.672	1.7 (0.93 - 2.94)	0.087	1.1 (0.98 - 1.23)	0.102	0.9 (0.69 - 1.22)	0.564	2.3 (1.5 - 3.42)	0.000
Very much	2.6 (1.55 - 4.3)	0.000	2.6 (1.47 - 4.62)	0.001	1.1 (1 - 1.26)	0.049	1.2 (0.92 - 1.61)	0.166	2.9 (1.92 - 4.33)	0.000
<b>Contact Frequency</b>										
Once in six months	1		1		1		1		1	
Once in three months	0.3 (0.04 - 1.86)	0.189	3.1 (0.44 - 22.37)	0.253	1.4 (0.93 - 2.09)	0.104	2.4 (0.63 - 9.29)	0.195	0.9 (0.5 - 1.47)	0.574
Once a month	2.3 (0.62 - 8.81)	0.211	4.3 (0.62 - 29.22)	0.140	1.4 (0.95 - 2.11)	0.084	3.6 (0.96 - 13.11)	0.057	1.2 (0.77 - 2.01)	0.374
Once a week	3.4 (0.92 - 12.58)	0.066	7 (1.04 - 47.08)	0.045	1.5 (1.04 - 2.27)	0.032	4.1 (1.11 - 14.98)	0.034	1.2 (0.77 - 2)	0.379
About every day	3.1 (0.85 - 11.61)	0.085	5.3 (0.79 - 36.13)	0.085	1.5 (1.01 - 2.23)	0.042	5.4 (1.49 - 19.72)	0.010	1.2 (0.77 - 1.99)	0.376
<b>Emotional Closeness</b>										
Not at all	1		1		1		1		1	
Somewhat	1.1 (0.7 - 1.87)	0.586	1.7 (1.01 - 2.72)	0.047	1.2 (1.08 - 1.33)	0.001	1.3 (0.99 - 1.75)	0.062	1.6 (1.24 - 2.14)	0.000
Very close	3.7 (2.38 - 5.62)	0.000	3.4 (2.1 - 5.47)	0.000	1.2 (1.05 - 1.32)	0.005	1.8 (1.35 - 2.4)	0.000	2.2 (1.67 - 2.83)	0.000
<b>Support from alter</b>										
Not at all	1		1		1		1		1	
A little bit	1.8 (1.11 - 3)	0.017	2.4 (1.43 - 4)	0.001	1.1 (1.03 - 1.22)	0.007	1.5 (1.16 - 2.05)	0.003	1.4 (1.13 - 1.79)	0.003
Very much	4.4 (2.75 - 6.89)	0.000	4.4 (2.69 - 7.33)	0.000	1.1 (0.98 - 1.2)	0.106	2 (1.54 - 2.72)	0.000	1.8 (1.48 - 2.3)	0.000

**Table 4.6: Predictors of social support after experiencing a stillbirth**

Variable	Material		Financial		Emotional		Instrumental		Information	
	a.PR (95%CI	P-Value	a.PR (95%CI	P-Value	a.PR (95%CI	P-Value	a.PR (95%CI	P-Value	a.PR (95%CI	P-Value
Age										
18 to 25	1		1		1		1		1	
26 to 45	1.3 (0.67 - 2.65)	0.412	1.1 (0.58 - 2.19)	0.725	1 (0.93 - 1.09)	0.812	0.7 (0.45 - 1.04)	0.078	1.9 (1.25 - 2.75)	0.002
46 and above	1.4 (0.69 - 3.03)	0.330	1 (0.45 - 2.19)	0.982	1 (0.9 - 1.07)	0.687	0.6 (0.36 - 1.03)	0.063	2.1 (1.42 - 3.12)	0.000
Gender										
Male	1		1		1		1		1	
Female	0.9 (0.67 - 1.24)	0.573	1 (0.73 - 1.28)	0.803	1.1 (0.98 - 1.16)	0.145	1.5 (1.04 - 2.09)	0.029	2 (1.52 - 2.51)	0.000
Educ level										
None	1		1		1		1		1	
Primary	1.2 (0.53 - 2.95)	0.613	1.3 (0.42 - 4.31)	0.615	1 (0.9 - 1.19)	0.636	1.8 (0.71 - 4.35)	0.225	1.1 (0.88 - 1.45)	0.335
Secondary	1 (0.43 - 2.46)	0.950	1.2 (0.38 - 3.92)	0.745	1 (0.89 - 1.17)	0.800	1.1 (0.44 - 2.86)	0.811	1 (0.78 - 1.34)	0.879
Tertiary	1.1 (0.43 - 2.59)	0.906	1.7 (0.54 - 5.31)	0.367	0.9 (0.79 - 1.09)	0.344	1.5 (0.6 - 3.97)	0.372	1.3 (1.03 - 1.76)	0.028
Marital status										
Not married	1		1		1		1		1	
Married	1.9 (1.1 - 3.14)	0.020	2.2 (1.28 - 3.74)	0.004	1 (0.92 - 1.06)	0.753	1.1 (0.74 - 1.54)	0.737	1 (0.87 - 1.18)	0.862
Network Type										
Community role	1		1		1		1		1	
Naturally occurring	3.2 (1.95 - 5.21)	0.000	2.5 (1.68 - 3.77)	0.000	1 (0.93 - 1.07)	0.928	1.5 (1.09 - 2.17)	0.013	1.2 (1.02 - 1.37)	0.029



Variable	Material		Financial		Emotional		Instrumental		Information	
	a.PR (95%CI	P-Value	a.PR (95%CI	P-Value	a.PR (95%CI	P-Value	a.PR (95%CI	P-Value	a.PR (95%CI	P-Value
Trust levels										
Not at all	1		1		1		1		1	
A little bit	0.9 (0.46 - 1.76)	0.764	1 (0.46 - 2.07)	0.955	0.9 (0.81 - 1.09)	0.413	0.6 (0.39 - 0.81)	0.002	2.1 (1.31 - 3.37)	0.002
Very much	0.9 (0.42 - 2.12)	0.881	0.8 (0.32 - 1.87)	0.566	1 (0.82 - 1.11)	0.559	0.5 (0.34 - 0.81)	0.003	2.3 (1.4 - 3.88)	0.001
Contact frequency										
Once in six months	1		1		1		1		1	
Once in three months	0.2 (0.04 - 1.42)	0.113	2.2 (0.33 - 14.92)	0.410	1.4 (0.94 - 2.01)	0.105	2.3 (0.61 - 8.51)	0.223	0.7 (0.46 - 1.03)	0.073
Once a month	1.4 (0.39 - 5.28)	0.593	2.4 (0.37 - 15.78)	0.352	1.4 (0.93 - 1.98)	0.116	3 (0.81 - 10.96)	0.099	0.9 (0.62 - 1.26)	0.492
Once a week	2.2 (0.59 - 7.97)	0.246	4 (0.62 - 26.19)	0.144	1.5 (1.01 - 2.1)	0.046	3.5 (0.97 - 12.89)	0.055	0.9 (0.61 - 1.23)	0.416
About every day	1.9 (0.52 - 7.07)	0.326	2.9 (0.45 - 18.9)	0.263	1.4 (0.99 - 2.08)	0.058	4.5 (1.23 - 16.1)	0.023	0.9 (0.63 - 1.24)	0.480
Emotional Closeness										
Not at all	1		1		1		1		1	
Somewhat	0.7 (0.37 - 1.33)	0.282	0.9 (0.47 - 1.9)	0.874	1.2 (1.05 - 1.37)	0.006	1.3 (0.9 - 1.96)	0.154	1.1 (0.77 - 1.48)	0.704
Very close	1.5 (0.69 - 3.16)	0.318	1.4 (0.6 - 3.09)	0.456	1.2 (1.04 - 1.43)	0.015	1.5 (0.86 - 2.51)	0.156	1.2 (0.85 - 1.75)	0.274
Support from alter										
Not at all	1		1		1		1		1	
A little bit	1.8 (1.06 - 3.19)	0.030	2.3 (1.32 - 4.14)	0.004	1 (0.94 - 1.08)	0.857	1.5 (1.09 - 2.04)	0.014	1.1 (0.83 - 1.38)	0.622
Very much	2.3 (1.15 - 4.77)	0.019	3.7 (1.79 - 7.61)	0.000	0.9 (0.82 - 1.06)	0.293	1.8 (1.16 - 2.94)	0.010	1.1 (0.81 - 1.49)	0.548

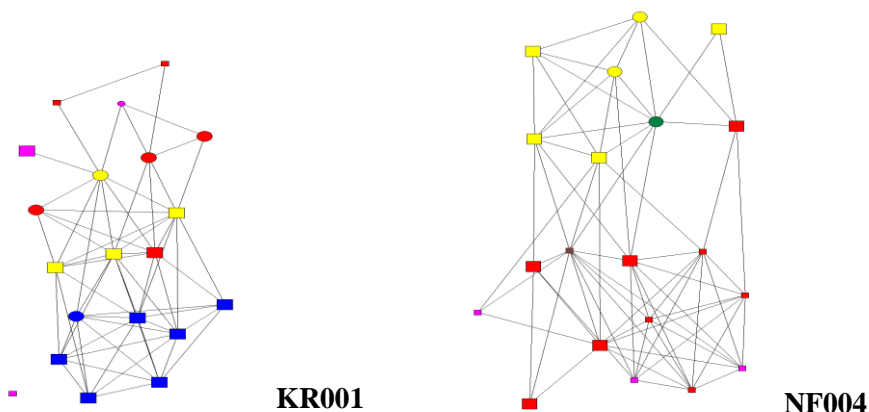
## Social support visualisation at individual network level

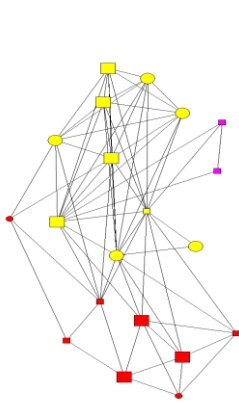
Support is visualised through graphs at individual network level as perceived by the respondents' reflecting actors as nodes and relations connecting the actors as lines. Typical scenarios are picked from six respondents that reflect the different examples of actors and social support relational data with the respondent. The visuals below represent social networks, with health workers being integral (KR001, NF004, NH005), while (NF004, NKE008, NJ009) shows a network with spousal support and (NF004, NH005, NJ009) reflecting a highly dense network and (KR001, NE007) shows crucial network members as isolates. Table 4.8 shows results of the social support variables reported by each of the respondents per support type and the quality of relationship that exists between them and the alters.

**Table 4.7: Legend for the social network graphs**

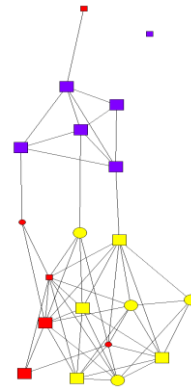
Node shape: Gender	Node size: support	Node colour: Relationship
Circle: Men	Small: Rely less on alter for support	Spouse: Green
Squire: Women	Large: Count on alter for support	Family: Yellow
		Friend: Red
		Workmate: Blue
		Health worker: Pink
		Neighbour: Black

**Figure 4.2: Social support visualisation for six typical scenarios**

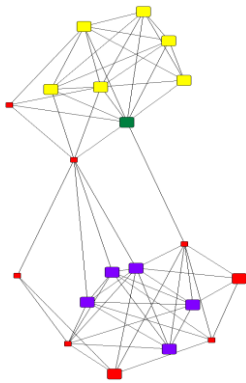




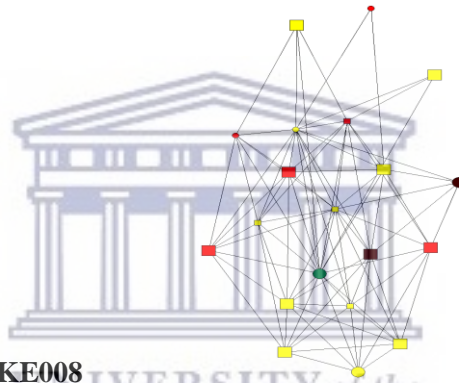
NH005



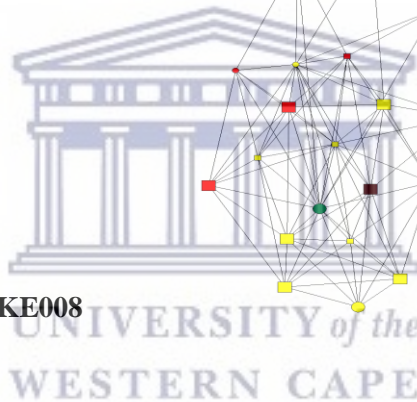
NE007



NKE008



NJ009



**Table 4.8: Social support after stillbirth descriptive statistics at ego level**

Variable	category	KR001	NF004	NH005	NE007	NK008	NJ009
Count on alter for support	Not at all	4(20)	8(40)	8(40)	5 (25)	6(30)	7 (35)
	A little bit	8(40)	6(30)	11(55)	10 (50)	12(60)	10 (50)
	Very much	8(40)	6(30)	1(5)	5(25)	2(10)	3(15)
Type of social support	Material (yes)	9(45)	8(40)	6(30)	17(85)	14(70)	2(10)
	Financial (yes)	4(20)	9(45)	8(40)	18(90)	17(85)	3(15)
	Emotional (yes)	17(85)	19(95)	20(100)	20(100)	19(95)	20(100)
	Instrumental (yes)	10 (50)	9 (45)	9(45)	18(90)	13(65)	6(30)

	Information(yes)	17(85)	20 (100)	14(70)	17(85)	15(75)	9(45)
	About every day	9(45)	2(10)	4(20)	6(30)	3(15)	6(30)
	Once a week	3(15)	13(65)	8(40)	6(30)	11(55)	4(20)
Frequency of contact	Once a month	4(20)	3(15)	7(35)	7(35)	4(20)	5(25)
	Once in three months	2(10)	2(10)	1(5)	1(5)	1(5)	5(25)
	Once in six months	2(10)	-	-	-	1(5)	-
	Not at all	6(30)	2(10)	10 (50)	5(25)	6(30)	4(20)
Emotional closeness	Somewhat close	7(35)	11(55)	8(40)	9(45)	12(60)	11(55)
	Very close	7(35)	7(35)	2(10)	6(30)	2(10)	5(25)
	Told them myself	8(40)	9(45)	5(25)	3(15)	3(15)	4(20)
How alter got to know about stillbirth news	Knew by themselves	2(10)	1(5)	2(10)	1(5)	6(30)	6(30)
	Through network members	7(35)	10 (50)	13(65)	16(80)	11(55)	10(50)
	Other means	3(15)	-	-	-	-	-
Change in friendship after stillbirth	As before	11(55)	11(55)	11(55)	7(35)	13(65)	18(90)
	Better now	8(40)	9(45)	8(40)	13(65)	7(35)	2(10)
	Worse than before	1(5)	-	1(5)	-	-	-

**Table 4.9: Structural measures of personal networks for six scenarios**

Variable	KR001	NF004	NH005	NE007	NK008	NJ009
1 Density	0.32	0.36	0.35	0.27	0.33	0.42
2 Degree centrality (mean)	6.1	6.9	6.8	5.3	6.3	8.05
3 Closeness centrality (mean)	41.3	33.6	34.9	47.8	38.1	30.5
4 Betweenness centrality (mean)	7.3	7.3	7.95	9.65	9.55	11.5
5 Eigenvector centrality	45.5	40.5	46.3	41.7	35.8	47.3
6 Number of ties	122	138	136	106	126	161

7	Isolates	1	0	0	1	0	0
8	Homophily	-0.27	-0.59	-0.05	-0.13	-0.04	-0.08

Table 4.9 above reports the structure of the network and, overall, the **degree centrality**, which denotes tie strength as reflected in the networks, with most direct ties showing that of the six cases presented, the degree centrality ranged from 5.3, 6.1, 6.3 to 6.8 and was highest in networks with spousal support 6.9 (NF004) and 8.05 (NJ009).

**Closeness centrality:** Results from the closeness centrality, which refers to a relationship traversing fewer degrees of separation or closest to other nodes in the network, show that the mean closeness centrality score of all the six cases presented here ranged from 30.05 to 47.8 and was highest among respondents' networks with workmates (KR001, NE007) and without spousal support.

**Betweenness centrality**, which refers to the extent to which a node lies on the shortest paths between other nodes on the main information pathway, had results revealing that the mean scores were highest among respondents that had health workers as integral actors in their networks (KR001, NF004 and NH005).

**Eigenvector centrality:** Overall, the Eigenvector centrality results show that fewer than half (50%) of all distances among the personal networks of the six actors reported here are reflective of the main pattern, demonstrating the complexity of relationships and social support after experiencing a stillbirth among this sample.

## Discussion

This study set out to explore the role of network members in the provision of social support to pregnant mothers before and after experiencing a stillbirth. It is perhaps the first of its kind to explore the community-level support structures available to women experiencing a stillbirth using the network approach. This is particularly important because whereas previous studies have investigated the role of social support among pregnant women, the outcomes of focus were on maternal wellbeing postpartum in general and not necessarily because they had experienced a stillbirth (28). Even where the focus seemed to be on pregnancy outcomes, having a stillbirth was not among those assessed (37).

The study explored whether network members' characteristics, network relational characteristics and the structure of the networks influenced the receipt and provision of various social support types. The dynamics between the individual, their alters and the structure of the networks have been explored among other population sub-groups and have been found to influence social support (37). Network characteristics specifically have previously been found to impact maternal health service utilisation (29). They can be key to routing community-level intervention support to help address stillbirth risk factors, support grieving mothers and families as well as facilitate access



to the available health care services to respond to utilisation challenges through network-based interventions that base their hypothesis on contagion and connection to impact network members(7).

### ***Availability of social support***

The findings revealed that social support was available from all network relations mentioned by the respondents. No major variations were observed between the two periods between pregnancy and after experiencing a stillbirth. During pregnancy only 10 (3.4%) relations (the network members mentioned) were noted not to have provided any form of support, while 9 (3.1%) were noted for the same after experiencing a stillbirth. All forms of support from network members increased slightly after experiencing a stillbirth compared to the same during pregnancy, save for information support, which reduced. This is expected since communities tend to empathise with grieving families and, as a result, will tend to offer any possible support available at that particular point in time. Another possible explanation could be that, given that the alters elicited during the study were perceived to have an already existing relationship with the respondent, provision of such support would be forthcoming. Targeting mothers at that point to engage them in postnatal counselling is key to guiding them in subsequent pregnancies since studies have long established that the desire for more children increases with the loss of a child and women tend to conceive immediately. Purposing the support at that point to one which will help the mother get out of the situation healthy is important. Such support can range from information to emotional support, since many women would like to be guided through their post-partum health care-seeking and emotional recovery.

The most common support that respondents reported receiving was intangible, such as emotional and information support. This form of support was reported from 96% of the alters throughout pregnancy and after experiencing a stillbirth. Similar results have been reported elsewhere (4, 38), where emotional support was found to be the most prevalent among network members. It provides a sense of empathy, accompaniment and understanding (39). This demonstrates that the quality of information shared with a pregnant mother or even after experiencing a stillbirth through emotional support is crucial. This ensures that quality information is offered in the context of averting stillbirth risk factors. One reason why emotional and information support was more prevalent could be that it is readily available, unlike other forms, such as material support (40). However, information support reduced slightly after experiencing a stillbirth, which was most likely a reflection of a sense of loss and fear of causing more sorrow and stigma to the affected woman. Mapping of network members likely to offer this kind of support and empower them through programmes identifying community peer supporters is one way to achieve this.

### ***Alter characteristics associated with social support***

Most of the social support which was reportedly received by the respondents came from females who were married and from the naturally occurring networks such as family and friends. These variables highlight the importance of gender and social status, such as marital status of the alter, in predicting social support both during pregnancy and after experiencing a stillbirth. These results add to the existing body of knowledge that has highlighted the importance of gender in provision of social support (41). Elsewhere studies have also identified marital status as being key to predicting the provision of social support (42). Regarding the relationships between the ego and the alter, our results show that much of the social support came from alters who were from the naturally occurring networks, such as family and friends. This observation builds on the existing body of knowledge where studies have previously reported the important contribution of family and friends in the provision of social support when in need (43). As previously reported elsewhere, the proportion of family members within the network might be a reflection of the group orientation around family, which is typical of many African settings, including Uganda (44). Also, this may serve to emphasise that family is a major factor in the decision-making dynamics surrounding maternal health and overall health (45, 46). The cohesive strength of family may work to influence maternal health care decision-making. For friends, they are an immediate point of reference whenever faced with a life challenge, including maternal health issues. They serve to cushion pregnant mothers from adverse life events and also help uplift them after they have experienced such dangers (47). Interventions aiming at addressing stillbirth reduction, therefore, ought not to look at the pregnant women in isolation of the settings they live in, especially the networks they interact with regularly.

### ***Social network relational characteristics associated with social support***

From our study, we also observed that social support tended to follow certain patterns of network relational characteristics. Trust, frequency of contact and alters that were counted on by respondents to offer support whenever in need were more likely to provide the same, as the results show. Trust builds confidence within individuals in a particular relation and they will tend to seek or receive support among those they feel have a certain level of trust (48). Frequency of contact resulted in a mutually reinforcing interaction. People in such relationships will tend to have a particular pattern of interaction with specific people and will inform who they are likely to fall back on for support whenever in need (49). Counting on an alter for support has a reassurance effect which may make support seekers alter behaviours to seek support where they are assured of getting it whenever in need. Therefore, when considering social support in terms of the quality of relations, it is important to note that trust in the alter, frequency of contact and perception of ability to provide support are important in predicting the actual support received when in need.

### ***Social network structure characteristics***

Previous studies have observed the role of network structure in predicting certain health outcomes, such as the transmission patterns of infectious diseases and sexual

behaviours in networks (50) or contagion of unhealthy behaviours within a network, such as obesity (51) and drug abuse (52). Another important finding of our study is that, in terms of network structure, the mean degree centrality scores ranged from 5.3 to 8.05 and were highest among networks who enjoyed spousal support. This means that spouses play a critical role in providing but also in galvanising support from other network members. Closeness centrality scores revealed themselves as dominant among women with networks that had workmates as major actors. The underlying assumption could be that workmates may act in other roles within the same network, thereby bridging the distance with other network actors, such as friends, neighbours and family members. The mean betweenness centrality scores revealed that it was highest where the network contained health workers as nodes within the pregnant woman's network. In our case, it may have facilitated the shortening of the distance between nodes, especially with regard to information related to pregnancy health. As established elsewhere, a higher betweenness can be important in presenting quality social support to the ego through tapping into other indirect relationships( 39). Lastly, the eigenvector scores revealed that less than 50% of the relations reported were reflective of the main pattern of the whole network. This meant that different actors within the networks carried different characteristics, which affected social support.

### **Limitations**

One limitation to this study, as is the case with social network studies, is the likelihood of overestimating or underreporting social support, given the prevailing circumstances. In this case, mothers that perceive themselves as having not received the expected support tend to underreport. Besides, the results for participants recruited from public health facilities and PNFP whose clients share similar characteristics, cannot be generalisable to whole populations, including mothers who seek care from private-for-profit facilities. They are perceived as being capable of meeting the health care costs and may deliberately not seek some support, such as financial and material support, from their network peers. Still, the results, discussion and conclusions are drawn from a study conducted in a single district with characteristics of a peri-urban livelihood context and, therefore, caution is called for when generalising these results outside this context with varying socio-cultural and economic contexts that are central to social network functioning. Further, this was a cross-sectional survey and, thus, the results may not be able to assess social support over time before and after experiencing a stillbirth. However, during design and data collection, efforts were made to recruit mothers from facilities at different levels of service provision for both public facilities and PNFP. We recommend a larger study covering more districts with varying characteristics that incorporate private-for-profit maternal health service users with a qualitative component to explore in depth the social support dynamics among these mothers.

### **Conclusions**

The paper highlights the variations in social support extended to mothers during pregnancy and after experiencing a stillbirth. There is urgent need for attention from programmes to innovatively work around tapping into these social support dynamics involving network members for optimal benefit to mothers experiencing a stillbirth. Further research is also needed on the best strategies to sustain this support within networks. Parents experiencing a stillbirth without proper support systems within their communities are already experiencing negative shocks from communities, such as stigma and discrimination, and will continue to experience the same if interventions continue to focus on the health systems level without involving the communities. Effective interventions that engage the social systems where the women are embedded and view maternal health care-seeking behaviours as socially constructed are crucial to stillbirth reduction efforts.

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## CHAPTER FIVE

### Paper Four

#### **Perceptions of stillbirth risk among women from a community sample in Uganda. A cross-sectional study<sup>5</sup>.**

##### **Scope of the chapter**

The chapter presents a research paper from this study entitled “Perceptions of stillbirth risk among women from a community sample in Uganda. A cross-sectional study”. It explores the women’s perception of stillbirth risks at the community level. Risk perceptions have been known to motivate health care-seeking behaviours and these vary significantly between laypeople and health workers, where laypeople understand risk based on the context in which it happens. When the risk is perceived as low, it will impact access to and utilisation of the available health services as they may possess the potential to address the risk factors. Many of the stillbirth risk factors are modifiable with available low-cost interventions once accessed on time. This study, therefore, had an interest in establishing the women’s perceptions of stillbirth risks and how that can be tapped into to create awareness of the same and stimulate utilisation of the available maternal health care services.

##### **List of tables**

Table 5.1: Social demographic, obstetric history and fertility intentions

Table 5.2: Descriptive statistics of risk perception score

Table 5.3: Logistic regression of social demographic, obstetric and fertility intentions and the average risk perception scores for maternal- and foetal-related outcome variables

Table 5.4: Logistic regression of social demographic, obstetric and fertility intentions and the average risk perception scores for social demographic, lifestyle and health systems-related outcome variables

##### **Data-sharing arrangements**

This article has been submitted to the journal BMC Public Health, an open access journal with free access to published manuscripts. The article will be licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as

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<sup>5</sup> A slightly modified version of this article has been submitted to the journal BMC Public Health and currently under review.

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### **Citation**

**Ssegujja E**, Mulumba Y, Guttmacher S and Andipatin M (**Forthcoming**): Perceptions of stillbirth risk among women from a community sample in Uganda. A cross-sectional study. BMC Public Health.

### **Abstract**

**Background:** Risk perception is a subjective belief and feeling of potential harm to health and is known to impact decision-making to seek care. Perceptions about stillbirths and the communication thereof are predominantly top-down, with pregnant women being recipients of health workers' assessment results. This study aimed to describe the women's perceptions of stillbirth risks at the community level.

**Methods:** A cross-sectional survey was conducted, where 431 women were interviewed in one of the stillbirth high-burden districts in Uganda. The data collection utilised a questionnaire that elicited information about the respondents' demographics, obstetric history, fertility intentions, stillbirth knowledge, and a stillbirth risk perception score was obtained for maternal medical conditions, foetal medical conditions, social demographic factors, lifestyle factors and health system-related factors. The analysis utilised frequencies and proportions to describe the respondents' characteristics. We used principal factor analysis to estimate variables that represented each of the risk factors from their respective items. Bivariate and multivariable linear regressions for each of the five categories of risk scenarios were estimated to examine the association between the grouped risk scenarios and demographic factors.

**Results:** Overall, women rated the risk of stillbirth due to foetal medical conditions and health system-related factors lowest while stillbirth due to maternal medical conditions, women's social demographic factors and lifestyle factors were scored highest. Among the foetal medical conditions, infections and reduced foetal movements were scored highest, while among the health systems factors the lack of skills and equipment to detect reduced foetal movements was scored highest. On the other hand, pregnancy-related medical conditions such as eclampsia were scored highest among the maternal factors, multiple gestations for social demographic factors and smoking for lifestyle-related factors. Perceptions varied by age, marital status, history of pregnancy complication, current use of family planning and intention to have more children.

**Conclusion:** Women scored factors that were perceived as out of their control the lowest and scored highest risk factors related to their lives, such as maternal factors, social demographic factors and lifestyle-related factors. Differences in risk perception scores existed according to the history of pregnancy complications, where those that experienced one tended to score risk highly while those who were currently using family planning with the intention of having more children scored and perceived the risk to be lower. This calls for tailored antenatal care messaging to cater to these variations while responding to potential stillbirth risk factors.

**Keywords:** stillbirth, risk perception, risk communication, community perceptions

## **Background**

Risk perception refers to the individual's subjective beliefs and feelings about the potential for a disease or harm to health to happen and has been observed to motivate health behaviour change (1). Drawing from the health belief model, two predictors – perceived susceptibility and perceived severity – trigger action towards health behaviours. It manifests in two ways. Beliefs about susceptibility to risk can affect the patient positively through pleasure about not belonging to the at-risk category or negatively through anxiety about potential risk. Variations exist between professional and laypeople while interpreting risks (2). Whereas professionals consider frequency formats and probabilities to estimate the magnitude of risk, this is not common among laypeople. Instead, laypeople use subjective perception to estimate risk. Emotions play a role in how risk is interpreted, with behavioural changes being linked to how people feel about the message than the message itself (3). According to laypeople, risk perception is informed by the social context, familiarity with the risk, beliefs, individual ability to act, trust in the source of information, experience, frequency of occurrence, packaging, framing and repetitive messaging, leading to social amplification (4, 5). Understanding the motivation to address stillbirth risk factors, therefore, calls for an understanding of women's perceptions of them.

Efforts to incorporate patients' perspectives, such as risk perceptions to inform health care responses, are aimed at improving service quality while enhancing patients' positive experiences when in care. Evidence of movements to achieve this has seen several deliberate efforts being made. Within human immune virus (HIV) and non-communicable diseases (NCD) management, patients' and caregivers' associations have long advocated for consideration of patient perspectives into disease management (6). Within clinical research, national organisations have advocated deliberate efforts to include patient voices, preferences and feedback in the conduct and management of research (7). In the policy arena, drafts of policy guidelines and patients' charters with consideration for their feedback and service responsiveness of the health care system to the same have been proposed and implemented (8-10). Non-state actors like CSOs have also contributed towards raising service users' voices and perspectives through awareness creation, advocacy and strategic litigation in cases where patients' input is



threatened (11, 12). To capture service users' perspectives, researchers have contributed through exit patient satisfaction surveys (13) while public health service providers strive for established patient and community feedback loops through representation that conveys service users' feedback on care experience (14, 15).

Acknowledging service users' perspectives on risk perception and health care services has necessitated the incorporation of their views to inform the design of appropriate response in what is termed as patient-centred care (16). Proposals for patient engagement have seen renewed calls being made for the engagement of service users' right from the beginning at every step as opposed to the tokenistic endorsement of actions at the end, with little consequence for service modifications/improvement (17). For stillbirths, the invisibility is loud albeit in relation to familiarity with the phenomenon within families. Substantial stigma and secret rituals are wrapped up in cultural beliefs and taboos (18). These differ significantly from medical practice and yet knowledge about the same is crucial for maximum health care benefit when applied to informing service modifications to suit mothers' expectations. While calling for attention to amplify parent voices (19, 20), understanding their perspectives to inform such responses is crucial in community-level efforts to reduce this burden. One deliberate effort to turn the course is the call to action to amplify patients' voices to address this invisibility (21, 22).

Understanding women's perceptions of stillbirth risk is important as it provides insights into barriers to and enablers of health care access and utilisation, especially where it concerns weighing the potential risks against the quality of the available services or the available alternatives thereof (23). It is also important because patients can raise ethical issues that may have eluded the service providers, such as gender preferences of the health service providers, discomfiting experiences while documenting pregnancy history or negative pregnancy outcomes or proper conduct of perinatal death reviews (24). Knowledge of patients' perspectives regarding stillbirth risks has the potential to improve adherence and cooperation with the health care system while utilising maternal health services (21, 22). In terms of risk communication, perceptions about risks are important in facilitating the identification of factors that people are more passionate about and how they respond to them (2). It can also facilitate proper communication of health care feedback through appropriate channels following consultations (25). Patients' perspectives have been integrated into quality of care improvement efforts that make health services provide a continuous learning and self-improvement experience (10, 13, 16). Interventions targeting social accountability have promoted patient exchanges regarding views which inform the expectations of the service providers' response (26). In addition, it constitutes an ethical requirement to engage and listen to patient feedback about the service and their anxieties while in care (27).

WHO defines stillbirth as the death of a fetus after 28 weeks of gestation and it is associated with the health systems, medical, psychological, economic and social effects that persist long after the event (28, 29). Currently, over 2.6 million stillbirths happen

every year and half of these are due to preventable causes (30). A disproportionate number occurs in low-income countries and after the onset of labour leads to fresh stillbirths (31). The sub-Saharan Africa region is disproportionately affected by many of the cases occurring at the community level and this is never reported due to the stigma attached to stillbirth and to poor registration systems. This is despite the availability of interventions to address most of the modifiable risk factors once accessed early. The limited maternal literacy about maternal conditions compounds the problem, thus limiting the identification of risk factors and timely response (32). Besides improved care around birth, the active engagement of mothers is a key avenue for averting cases with improved pregnancy monitoring, early detection and response, once what constitutes women's perception of risks is ascertained to inform care (33). For mothers that experienced a stillbirth, the grief and trauma become the defining feature of how they perceive the quality of care during subsequent interactions with the health systems (21). Experiences of parents who regret not having conducted an autopsy or having waited for perinatal death review results where such services exist have been documented (34, 35). This is especially true when mothers return to seek maternal health services during subsequent pregnancies in a bid to ascertain and address pre-existing conditions (36, 37). Understanding women's perceptions of risk to purpose prevention interventions and messaging has the potential to contribute towards the greatest return and improvement of care to address the stillbirth burden.

### ***Objective***

The study aimed to provide women's perspectives regarding stillbirth risk perceptions.

### **Methods**

#### ***Study design and setting***

The study adopted a cross-sectional quantitative design to capture community-level perceptions about stillbirth risk among women of reproductive age. It was conducted in Mukono, one of the districts in Uganda that was highlighted as one of the stillbirth high-burden districts, having been ranked in the second tier (stillbirth burden of 9-14.9/1,000 live births) at the time of conceptualising the study according to the Annual Health Sector Performance Report (AHSPR). The district is peri-urban and the 7<sup>th</sup> most highly populated district in the country with a total population of 1,019,575, of whom 509,594 are females. It had a high population growth rate of 2.1-2.9 between 2002 through 2014. Twenty per cent of the women were in their childbearing age, with the expected birth per year standing at 4.9% of the overall population. Of the 8,973 deliveries conducted at the main high-level public health facilities, 88 were stillborn (AHSPR 2014/15), and yet approximately half (49.4%) of the deliveries were conducted at public sector health facilities where routine data is collected. Many of the stillbirth risk factors are prevalent, for example, malaria rates during pregnancy were at 42.4%. Other risk factors included early initiation of childbearing, early marriages and higher levels of income inequality. In terms of the health systems, the district is served by four health sub-districts, one hospital and three facilities at Health Centre (HC) IV level, 15

facilities at HCIII, 33 at HCII and 2,615 Village Health Teams (VHTs). There was a strong presence of the private sector, which offered maternal health services and functioned at lower levels of the health systems, with the majority offering preventive and curative maternal and child health services.

### **Sample size and sampling procedure**

The study sample was comprised of women of reproductive age (18-50 years) drawn from the community. A total of 431 women were enrolled in the study after adjusting for a 2% design effect (38) and a 10% non-response rate. The Leslie Kish formula for sample size estimation based on a proportion was the preferred choice since the population of women of reproductive age in the study area was established. The application of the formula for the cross-sectional study was appropriate because of its ability to adjust for a finite population. A two-step sampling process was employed; first, we sampled sub-counties and, at the second step, parishes were sampled from which villages were drawn. At the household level, eligibility was based on respondents falling within the reproductive age and they were approached for possible participation in the study. Those that agreed were taken to a secure location by a research assistant from where written consent was obtained. Only one call-back was made to potential respondents who were not available at the time of the interview, after which replacements were made. The procedure involved following similar steps at household level for eligibility. Priority was given to the next household from where the potential index respondent had been identified. The study did not collect data on the non-response rate but, overall, less than five instances of refusal to participate were registered.

### **Data collection procedures**

Face-to-face interviews were conducted with a team of experienced graduate level research assistants. These included three females and three males who read each survey question to the respondents and answered any questions the respondents raised for clarity and interpretation of the question and thereafter recorded the respondents' answers to the questions raised. The data was collected over one month between April and May 2019. The tool used was developed by the first author following insights from reviewed literature and feedback from the second author and the pre-test feedback (supplementary file 1: questionnaire). It explored two main types of data: the respondents' characteristics such as social demographics, obstetric history and fertility intentions. The second set included questions which elicited risk perception scores for provided risk scenarios that are documented in literature as associated with stillbirths. They included maternal medical conditions, foetal medical conditions, social demographic and lifestyle factors as well as health systems-related factors. A Likert scale was used to score the responses (with 1=not at all serious, 5=very serious). The respondents were asked if they perceived a risk scenario that was serious enough to cause a stillbirth, or that was not at all serious, not serious, slightly serious, serious and very serious. The scores ranged from 1 to 5, with 5 indicating a more perceived seriousness in the scenario causing a stillbirth.

## Data analysis

The respondents' background characteristics were summarised using frequencies and percentages. For each of the risk scenarios, we calculated the mean and median of the perceived risk score using the 95% confidence intervals as well for the maternal medical conditions, foetal medical conditions, social demographic factors, lifestyle and health systems-related factors. We used principal factor analysis to estimate variables that represented each of the risk factors from their respective items. Bivariate and multivariable linear regressions for each of the five categories of risk scenarios were estimated to examine the association between the grouped risk scenarios while controlling for respondents' demographic, obstetric and fertility intention factors. A positive coefficient meant higher perception scores for the risk scenario while a negative coefficient meant a lower perception score for the risk scenario. Data analysis and corresponding p values were calculated using STATA, version 14 (StataCorp LP, College Station, TX).

## Results

Four hundred thirty-one respondents participated in the study (Table 5.1). The ages ranged between 18 and 50 years, where the majority were between 18-25 years (185/42%). The majority (226/52%) had attained a secondary level of education and were Catholics (124/28%). Seventy-one per cent (306) of the participants were married and most (63%) reported at least one pregnancy in their life, while up to 35% indicated never experiencing pregnancy complications. Sixty-eight per cent reported having the intention to have more children, while 36% were currently using a family planning method at the time of the study.

**Table 5.1: Social demographic, obstetric history and fertility intentions**

<b>Variable</b>	<b>Frequency (percent)</b>
Sample size	431 (100)
<i><b>Demographic</b></i>	
Age group in complete years	
18 to 25	185 (42.9)
26 to 30	106 (24.6)
31 to 35	63 (14.6)
36 to 50	77 (17.9)
Highest level of education attained	
Primary	163 (37.8)
Secondary	226 (52.4)
Tertiary	42 (9.7)
Religious affiliation	
Catholic	124 (28.8)
Protestant	117 (27.1)

Muslim	99 (23)
Pentecostal	69 (16)
Other	22 (5.1)
Marital status	
Not married	125 (29)
Married	306 (71)
<b>Obstetric history</b>	
Parity	
0	47 (10.9)
1	272 (63.1)
>2	112 (26)
Ever experienced pregnancy complications	
No	233 (54.1)
Yes	151 (35)
NA	47 (10.9)
<b>Fertility intentions</b>	
Currently using any family planning method	
No	272 (63.1)
Yes	159 (36.9)
Has plan for having more children	
No	134 (31.1)
Yes	297 (68.9)

Overall, women rated infections during pregnancy (aOR=4.3, 95% CI 4.2-4.37) and haemorrhage (aOR=3.7, 95% CI 3.5-3.77) with the highest perceived risk score of leading to a stillbirth among the maternal medical conditions. Infections (aOR=3.9, 95% CI 3.78-3.93) and reduced foetal movement (aOR=3.9, 95% CI 3.79-3.93) were perceived with the highest estimated risk score in causing stillbirths among the foetal medical risk factors. For the women's demographic risk factors, multiple gestations (aOR=2.9, 95% CI 2.7-2.97) were perceived as being high-risk in leading to a stillbirth while smoking (aOR=3.3, 95% CI 3.2-3.4) was also perceived as being high-risk for causing stillbirths. Poor care during childbirth was perceived as having a higher risk of causing a stillbirth among the health systems risk factors (aOR=4.1, 95% CI 4.0-4.2).



**Table 5.2: Descriptive statistics of risk perception score (n=431)**

<b>Variable - Risk Factors</b>	<b>Median</b>	<b>Mean</b>	<b>95% C.I</b>
<b>Maternal medical risk factors</b>			
1. NCDs (diabetes and hypertension)	4	3.6	3.4819 - 3.7014
2. Infections (syphilis, HIV, malaria)	4	4.3	4.2143 - 4.375
3. Mothers blood type (AB at high risk)	2	2.4	2.3154 - 2.5478
4. Antepartum haemorrhage	4	3.7	3.5581 - 3.7737
5. Maternal vesicular supply abnormalities (deficiency of blood supply)	4	3.5	3.3847 - 3.5805
6. Pregnancy-related medical conditions (pre-eclampsia, maternal jaundice)	4	3.8	3.6958 - 3.882
7. Mental health (mother's mental wellbeing)	3	2.7	2.5826 - 2.8466
8. Prolonged pregnancies	3	2.8	2.662 - 2.9204
9. Pregnancy traumas (abdominal trauma, domestic injuries from falls)	3	3.2	3.124 - 3.2565
10. Past history of miscarriage, a history of pregnancy complications	3	3.0	2.8283 - 3.0743
Maternal medical risk	0.05468	0.000000000069	-0.1497 - 0.1497
<b>Foetal medical risk factors</b>			
1. Congenital abnormalities	4	3.2	3.0572 - 3.2954
2. Infections	4	3.9	3.7826 - 3.9344
3. Foetal distress (reduced foetal movement)	4	3.9	3.795 - 3.9638
4. Hematological conditions (anemia)	4	3.4	3.2505 - 3.4688
Foetal medical risk	0.18115	-0.000000000802	-0.1192 - 0.1192
<b>Social demographic risk factors</b>			
1. Maternal age (<25/>35)	2	2.2	2.0514 - 2.3059
2. Pregnancy order (1st pregnancy with higher risk)	2	2.1	1.9879 - 2.207
3. Multiple gestations (placenta previa, short gestation period and LBW babies)	3	2.9	2.7438 - 2.9731
4. Income level (lower income = poor health seeking)	3	2.5	2.4135 - 2.6584
5. Literacy levels (lower level= non-comprehension of medical information)	2	2.2	2.0608 - 2.2919
6. Mother's place of residence (rural/urban)	2	2.4	2.2994 - 2.5684

Social demographic risk	-0.0356	0.0000000048	-0.1492 - 0.1492
<b>Lifestyle-related risk factors</b>			
1. Alcohol use	3	2.7	2.6016 - 2.8694
2. History of drug abuse	4	3.2	3.1171 - 3.3701
3. Smoking	4	3.3	3.2063 - 3.4526
4. Dietary habits (nutritional deficiencies)	3	3.1	2.9317 - 3.1704
5. Low physical activity	3	2.6	2.5304 - 2.7597
Lifestyle-related risk	0.06472	0.0000000097	-0.1562 - 0.1562
<b>Health systems risk factors</b>			
1. Quality ANC (preventive screening)	4	3.7	3.5952 - 3.8016
2. Quality ANC (counselling to modify mother's behaviours)	4	3.7	3.6127 - 3.8119
3. Lack of diagnostic capacity to detect foetal complications	4	3.9	3.8239 - 3.9997
4. Poor care during labour	4	4.1	4.0638 - 4.2286
5. Post-partum care	3	2.7	2.5653 - 2.8036
Health systems risk	0.27802	-0.0000000094	-0.1531 - 0.1531



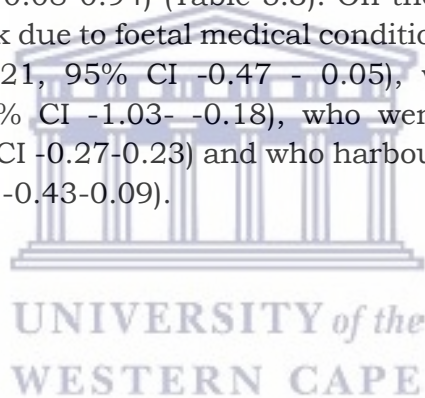
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### **Perception of stillbirth risks of maternal medical conditions**

The estimated perception of stillbirth risk for maternal medical conditions was highest among women aged between 31 and 35 years and with a tertiary level of education. Their estimated risk perception score was (aOR=0.27, 95% CI -0.19-0.72) and (aOR=0.54, 95% CI 0-1.07). Married women, currently using a family planning method and with plans to have more children, had a lower perception of stillbirth risk of maternal medical conditions. Women with two or more pregnancies who had not experienced any pregnancy complications reported a higher perception of stillbirth risk due to maternal medical conditions (Table 5.3). Their estimated risk perception score was (aOR=0.08, 95% CI -0.46-0.62) and (aOR=0.11, 95% CI -0.22-0.43).

### **Perception of stillbirth risks of foetal medical conditions**

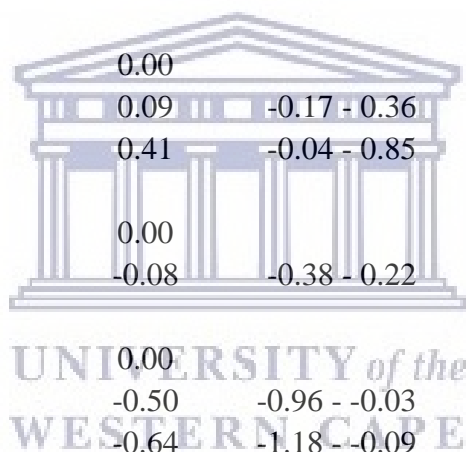
The estimated stillbirth risk perception score for foetal medical conditions was higher among women of 31 to 35 years (aOR=0.31, 95% CI -0.05-0.67), with a tertiary level of education (aOR=0.51, 95% CI 0.08-0.94) (Table 5.3). On the other hand, the scores for the perception of stillbirth risk due to foetal medical conditions was lower among women who were married (aOR=-0.21, 95% CI -0.47 - 0.05), who reported two or more pregnancies (aOR=-0.60, 95% CI -1.03- -0.18), who were currently using a family planning method -0.02 (95% CI -0.27-0.23) and who harboured intentions to have more children (aOR=-0.17, 95% CI -0.43-0.09).



**Table 5.3: Logistic regression of social demographic, obstetric and fertility intentions and the average risk perception scores**

<b>Maternal medical risk factor</b>							
<b>Variable</b>	<b>unadjusted</b>			<b>adjusted</b>			
	<b>a.Coeff.</b>	<b>95% C.I</b>	<b>P-Value</b>	<b>c.Coeff.</b>	<b>95% C.I</b>	<b>P-Value</b>	
Age group in complete years							
18 to 25	0.00			0.00			
26 to 30	0.01	-0.39 - 0.41	0.973	0.04	-0.34 - 0.42	0.851	
31 to 35	0.18	-0.32 - 0.68	0.475	0.27	-0.19 - 0.72	0.249	
36 to 50	0.04	-0.49 - 0.58	0.873	0.17	-0.25 - 0.59	0.431	
Highest level of education attained							
Primary	0.00			0.00			
Secondary	0.26	-0.07 - 0.6	0.120	0.20	-0.12 - 0.52	0.221	
Tertiary	0.65	0.09 - 1.21	0.024	0.54	0 - 1.07	0.050	
Marital status							
Not married	0.00			0.00			
Married	-0.22	-0.6 - 0.16	0.263	-0.16	-0.49 - 0.17	0.329	
Number of pregnancies							
0	0.00			0.00			
1	0.23	-0.36 - 0.82	0.436	-0.01	-0.5 - 0.49	0.979	
2	0.24	-0.45 - 0.94	0.489	0.08	-0.46 - 0.62	0.775	
Ever experienced pregnancy complications							
No	0.00			0.00			
Yes	0.11	-0.22 - 0.44	0.524	0.11	-0.22 - 0.43	0.517	
NA	0.00			0.02	-0.47 - 0.52	0.924	
Currently using any family planning method							
No	0.00			0.00			
Yes	-0.03	-0.36 - 0.3	0.851	-0.07	-0.38 - 0.24	0.641	
Has plan for having more children							

No	0.00			0.00		
Yes	-0.23	-0.62 - 0.15	0.238	-0.21	-0.54 - 0.11	0.196
<b>Foetal medical risk factor</b>						
Age group in complete years						
18 to 25	0.00			0.00		
26 to 30	-0.03	-0.35 - 0.28	0.846	-0.09	-0.4 - 0.21	0.535
31 to 35	0.40	0.01 - 0.79	0.043	0.31	-0.05 - 0.67	0.087
36 to 50	-0.04	-0.46 - 0.38	0.846	-0.09	-0.43 - 0.24	0.583
Highest level of education attained						
Primary	0.00			0.00		
Secondary	0.09	-0.17 - 0.36	0.475	0.13	-0.12 - 0.38	0.316
Tertiary	0.41	-0.04 - 0.85	0.072	0.51	0.08 - 0.94	0.019
Marital status						
Not married	0.00			0.00		
Married	-0.08	-0.38 - 0.22	0.593	-0.21	-0.47 - 0.05	0.120
Number of pregnancies						
0	0.00			0.00		
1	-0.50	-0.96 - -0.03	0.035	-0.56	-0.95 - -0.17	0.005
2	-0.64	-1.18 - -0.09	0.022	-0.60	-1.03 - -0.18	0.006
Ever experienced pregnancy complications						
No	0.00			0.00		
Yes	0.06	-0.2 - 0.31	0.672	0.06	-0.19 - 0.32	0.630
NA	0.00			0.60	0.21 - 0.99	0.003
Currently using any family planning method						
No	0.00			0.00		
Yes	0.10	-0.16 - 0.36	0.442	-0.02	-0.27 - 0.23	0.878
Has plan for having more children						
No	0.00			0.00		
Yes	-0.23	-0.53 - 0.08	0.145	-0.17	-0.43 - 0.09	0.200





### **Risk perception of stillbirth for the social demographic factors**

Regarding the social demographic risk factors of stillbirth, respondents aged 26 years and above, with a secondary-level education and above, and with past experiences of a pregnancy complication had a higher perception score for stillbirth risk due to social demographic risk factors than women aged 18-25 years, with primary-level education and who had never experienced a pregnancy complication (Table 5.4 – attached as supplementary material). The estimated risk perception score for women aged 26-30 years was (aOR=0.14, 95% CI -0.24-0.52) compared to women aged 18-25 years (reference category). Similarly, the estimated risk perception score for women who had ever experienced a pregnancy complication (aOR=0.16, 95% CI-0.16 - 0.48) compared to those who had never experienced a pregnancy complication before the study (reference category). On the other hand, women who were married, with two or more pregnancies and currently using family planning reported a lower perception of stillbirth risk.

### **Risk perception of the stillbirth of the lifestyle-related factors**

Regarding the lifestyle-related factors, women aged 31-35 years, with a tertiary level of education perceived these factors as riskier in contributing to a stillbirth relative to women aged 26-30 years and who had never experienced a pregnancy complication (Table 5.4). On the other hand, women who reported being married, with two or more pregnancies, and who were currently using a family planning method, and with the intention of having more children had a lower perception score for stillbirth risk. The estimated risk perception score for married women was (aOR=-0.39, 95% CI-0.74 - -0.05), for women with two or more pregnancies was (aOR=-1.03, 95% CI-1.58 - -0.47), for women using family planning was (aOR=-0.04, 95% CI-0.36 - 0.29) and for women with the intention of having more children was (aOR=-0.13, 95% CI-0.47 - 0.2).

### **Risk perception of the stillbirth of the health systems-related factors**

The estimated perception score for stillbirth risk due to health systems-related factors was higher among women aged 36-50 years (aOR=0.21, 95% CI-0.23 - 0.64), of secondary-level education (aOR=0.29, 95% CI--0.03 - 0.62), and who reported no pregnancy history (aOR=0.16, 95% CI-0.35 - 0.67). On the other hand, women who were married, who reported two or more pregnancies, who were currently using a family planning method and who had the intention have more children had a lower estimated risk perception score for health systems-related factors compared to women in the reference categories (Table 5.4).

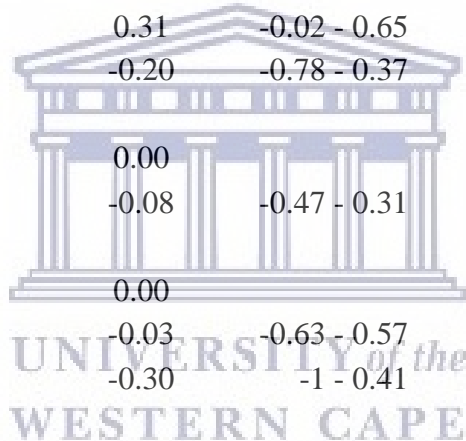
**Table 5.4: Logistic regression of social demographic, obstetric and fertility intentions and the average risk perception scores for social demographic, lifestyle and health systems-related outcome variables**

<b>Social Demographic Risk factor</b>						
<b>Variable</b>	<b>a.Coeff.</b>	<b>95% C.I</b>	<b>P-Value</b>	<b>c.Coeff.</b>	<b>95% C.I</b>	<b>P-Value</b>
Age group in complete years						
18 to 25	0.00			0.00		
26 to 30	0.13	-0.26 - 0.53	0.505	0.14	-0.24 - 0.52	0.460
31 to 35	0.18	-0.3 - 0.67	0.462	0.26	-0.2 - 0.71	0.265
36 to 50	-0.04	-0.56 - 0.48	0.880	0.25	-0.17 - 0.67	0.248
Highest level of education attained						
Primary	0.00			0.00		
Secondary	0.28	-0.05 - 0.6	0.094	0.22	-0.09 - 0.54	0.169
Tertiary	0.42	-0.13 - 0.97	0.134	0.35	-0.19 - 0.88	0.200
Marital status						
Not married	0.00			0.00		
Married	-0.19	-0.57 - 0.18	0.315	-0.33	-0.66 - -0.01	0.045
Number of pregnancies						
0	0.00			0.00		
1	-0.23	-0.81 - 0.35	0.432	-0.54	-1.03 - -0.05	0.029
2	-0.32	-0.99 - 0.36	0.359	-0.36	-0.9 - 0.18	0.189
Ever experienced pregnancy complications						
No	0.00			0.00		
Yes	0.17	-0.15 - 0.49	0.308	0.16	-0.16 - 0.48	0.331
NA	0.00			0.55	0.06 - 1.05	0.029
Currently using any family planning method						
No	0.00			0.00		
Yes	-0.14	-0.46 - 0.18	0.384	-0.27	-0.58 - 0.04	0.087
Has plan for having more children						
No	0.00			0.00		

Yes	-0.67	-1.05 - -0.29	0.001	-0.62	-0.94 - -0.31	0.000
<b>Lifestyle-related risk factor</b>						
Age group in complete years						
18 to 25	0.00			0.00		
26 to 30	0.22	-0.19 - 0.63	0.291	0.03	-0.36 - 0.43	0.874
31 to 35	0.48	-0.02 - 0.98	0.061	0.24	-0.23 - 0.72	0.314
36 to 50	0.39	-0.15 - 0.93	0.159	0.05	-0.39 - 0.49	0.810
Highest level of education attained						
Primary	0.00			0.00		
Secondary	0.45	0.11 - 0.78	0.010	0.50	0.17 - 0.83	0.003
Tertiary	0.72	0.15 - 1.29	0.014	0.87	0.32 - 1.43	0.002
Marital status						
Not married	0.00			0.00		
Married	-0.23	-0.62 - 0.15	0.235	-0.39	-0.74 - -0.05	0.025
Number of pregnancies						
0	0.00			0.00		
1	-0.79	-1.39 - -0.2	0.009	-0.82	-1.32 - -0.31	0.002
2	-1.17	-1.88 - -0.47	0.001	-1.03	-1.58 - -0.47	0.000
Ever experienced pregnancy complications						
No	0.00			0.00		
Yes	0.36	0.03 - 0.69	0.034	0.34	0.01 - 0.68	0.043
NA	0.00			1.01	0.5 - 1.52	0.000
Currently using any family planning method						
No	0.00			0.00		
Yes	0.17	-0.17 - 0.5	0.325	-0.04	-0.36 - 0.29	0.821
Has plan for having more children						
No	0.00			0.00		
Yes	-0.18	-0.57 - 0.22	0.382	-0.13	-0.47 - 0.2	0.438

**Health systems risk factors**

Age group in complete years						
18 to 25	0.00			0.00		
26 to 30	0.20	-0.21 - 0.61	0.343	0.17	-0.21 - 0.56	0.376
31 to 35	0.21	-0.29 - 0.72	0.407	0.17	-0.29 - 0.64	0.467
36 to 50	0.18	-0.37 - 0.72	0.527	0.21	-0.23 - 0.64	0.349
Highest level of education attained						
Primary	0.00			0.00		
Secondary	0.31	-0.02 - 0.65	0.069	0.29	-0.03 - 0.62	0.078
Tertiary	-0.20	-0.78 - 0.37	0.486	-0.22	-0.77 - 0.33	0.429
Marital status						
Not married	0.00			0.00		
Married	-0.08	-0.47 - 0.31	0.700	-0.14	-0.47 - 0.2	0.427
Number of pregnancies						
0	0.00			0.00		
1	-0.03	-0.63 - 0.57	0.925	-0.11	-0.61 - 0.39	0.672
2	-0.30	-1 - 0.41	0.407	-0.13	-0.68 - 0.42	0.647
Ever experienced pregnancy complications						
No	0.00			0.00		
Yes	0.13	-0.21 - 0.46	0.450	0.12	-0.21 - 0.46	0.466
NA	0.00			0.16	-0.35 - 0.67	0.530
Currently using any family planning method						
No	0.00			0.00		
Yes	-0.08	-0.41 - 0.26	0.654	-0.13	-0.45 - 0.19	0.421
Has plan for having more children						
No	0.00			0.00		
Yes	-0.39	-0.79 - 0	0.052	-0.34	-0.67 - -0.01	0.041



## **Discussion**

### ***Summary of key findings***

The study set out to investigate the perceptions of stillbirth risk among women of reproductive age at the community level. To the best of our knowledge, this is the first study to be conducted in such a setting. We explored the women's stillbirth risk perception scores on several variables, including maternal medical conditions, foetal medical conditions, women's social demographics, lifestyle and health system-related risk factors. Previous studies investigated the magnitude of these risk factors but primarily from a biomedical perspective (30, 39). A few of the studies that explored the subject from the women's own standpoint were primarily conducted in different contexts, such as high-income country settings where the stillbirth burden is lower, and from a health facility setting where efforts to reach the facility tends to lower the perceived risk due to the ability to address the initial delays (40). Some studies investigated single risk factors such as reduced foetal movements and not necessarily its association with stillbirth (41), while others focused on only high-risk pregnancies (42). Overall, the perceived risk of stillbirth as reported from the risk perception score by the respondents indicated that foetal medical conditions and health system-related factors were scored lowest while maternal medical conditions, maternal social demographics and lifestyle-related factors were scored highest. The implications of this are that perhaps those factors that were not directly attributable to them were scored the highest, while the ones that affected them directly were scored the lowest.

### ***Perceptions of maternal medical stillbirth risk factors***

The notion that maternal medical conditions are directly related to pregnancy outcomes is widely observed across maternal and pregnancy health literature. As such, interventions aiming at modifying potential maternal medical conditions related to stillbirths have been the mainstay within the response to improve and provide quality maternal and delivery services (19, 33, 43). Consequently, women are advised to seek antenatal care services during which maternal conditions can be identified early and with the necessary interventions modified to avert potential stillbirth risk. Nonetheless, cases of perinatal and maternal deaths continue to happen due to these factors. The results from this study revealed that respondents within the age range of 31-35 years reported a higher perception score for maternal medical risk factors for stillbirth. The same scores increased with an increase in educational level and the total number of pregnancies reported by the respondents. The observation within that age category can be explained by the acquired experience regarding maternal health, while education level can be explained by its association with improved knowledge and information about maternal health as well as the ability to comprehend medical explanations. As is borne out by studies conducted elsewhere, educational level plays a role in comprehension alongside the health information provided (44, 45), hence gives rise to the ability to perceive maternal medical conditions as high-risk in causing stillbirths.



### ***Perceptions of foetal medical stillbirth risk factors***

Previous studies established an association between foetal conditions and the risk of stillbirth (46). As such, recommendations are made for women to initiate antenatal care early and, if conditions allow, to go for the first visit during the first trimester of their pregnancies (47). Our findings show that higher perception scores for foetal medical conditions and the risk of stillbirth were registered among women aged 31-35 years with a tertiary-level education and women who report never having experienced a pregnancy complication. This may be explained by the acquired maternal health experience at the intersection of still being active with their reproductive health lives, hence the registered reduction in risk perception among those aged 36 years and older. On the other hand, having a tertiary level of education may explain the ability to comprehend medical explanations surrounding stillbirths due to foetal conditions. Women reporting never having experienced a pregnancy complication and attaching a higher perception score to foetal medical conditions can be explained by the risk subjectivities prevalent among people. Similar to findings from elsewhere, women make risk judgements not based on what they think about a particular risk but how they feel about that risk (48). Consequently, women who have never experienced a pregnancy complication may present anxieties about the same based on fear of the unknown and will amplify the potential of that risk happening.

### ***Perceptions of social demographic related stillbirth risk factors***

Women are advised not to initiate childbearing either too early or later in their reproductive life cycles as that in itself could increase the risks of negative pregnancy outcomes such as stillbirth as well as risk to the mother, which might result in mortality (49). The findings of this study show that risk perception scores increased with an increase in the age of respondents as well as an increase in the educational level of the respondents. Women from age 26 years or older and with a secondary-level education or more were more likely to record a higher risk perception score for stillbirth due to social demographic factors. This observation was the same for respondents who indicated having ever experienced a history of pregnancy complications. Results from other studies reported these risk factors (50, 51), and women attending antenatal care are sensitised to these risk factors to create awareness and advance plans and adequate preparations for childbirth (52). By echoing similar sentiments about these risk factors, the respondents may have been expressing inherent anxieties about negative pregnancy outcomes, which is consistent with results elsewhere (53).

Our findings also reveal that risk perception scores attributed to social demographic factors were lower among married women, those reporting two or more pregnancies, those currently using family planning and those with the intention of having more children. This observation could potentially be explained by risk homeostasis, which refers to an individual's acceptance of a certain level of subjective or perceived risk to their health or that of the developing fetus in exchange for benefits they expect to receive, which has been established in studies conducted elsewhere in maternal health

settings (54-56). In line with these findings, women tend to maintain a certain set risk point which is often lower, but it does not stop them from going ahead with certain behaviours or sets of behaviours (57). Hence women who were active in their reproductive life tended to downplay or attach lower perception scores because they would not wish to associate it with their pregnancies.

### ***Perception of lifestyle-related to stillbirth risk factors***

Lifestyle-related behaviours during pregnancy have been reported elsewhere as modifiable risk factors with negative effects on both the mother and fetus, including negative pregnancy outcomes such as miscarriage, pre-term birth and stillbirth, with women expressing worry over the same (58). Specifically, alcohol consumption during pregnancy has been reported to have harmful effects on both mother and foetus (59). However, the debate continues on the threshold for minimum allowable alcohol consumption during pregnancy (60). The findings of our study revealed that concerns about lifestyle-related factors such as alcohol consumption, drug abuse and cigarette smoking during pregnancy registered a higher risk perception score in relation to stillbirth risk with an increase in respondents' education and higher scores among relatively older respondents (31-35 years). Alcohol consumption, cigarette smoking and drug abuse are harmful not only to pregnant women but also among the general population where non-communicable diseases have been attributed to the intake of these substances. This partly explains why it is not common among women, which results from negative societal judgement when they are seen consuming any of the above. Besides, smoking was generally not found to be a common practice among women in the study setting and especially among pregnant women, while drug abuse continues to happen illicitly, with those using substances unlikely to admit it in public. Similarly, the harmful effects of poor dietary habits and low physical activity have been reported among pregnant women but also in the developing foetus(61). Therefore, a higher risk perception score registered among respondents with tertiary-level education may have been due to exposure to such information, while among those who reported ever experiencing a pregnancy complication this may have been due to explanations provided by the health workers regarding the previous pregnancy complication.

### ***Perceptions of health systems related to stillbirth risk factors***

A properly functioning health system has been attributed to the ability to reduce the risk of stillbirths and, in fact, among the global calls to action to reduce the stillbirth burden was the imperative to ensure that health systems can respond to high-risk pregnancies by equipping facilities to offer quality antenatal and delivery services such as comprehensive emergency obstetric care services (19, 30, 33, 43). Our findings revealed that higher perception scores for stillbirth risks attributed to health systems-related factors increased with the respondent's age. This could be explained by familiarity with the health systems context attained over time and by interaction with them. First-time mothers and those that never used such services may not be familiar with the health systems functionality with regard to maternal health services during

pregnancy and childbirth. The results also revealed that the stillbirth risk perception scores reduced among respondents with tertiary education, reflecting the possibility of knowing the health systems capability and ability well enough to negotiate it for better options for maternal health service delivery, given the direct link between educational attainment and income level. Quality maternal health services, especially during antenatal care and around the time of birth, has been attributed to a reduction in negative pregnancy outcomes, hence a reduction in stillbirth risks (62). Our finding that older women who are familiar with health system functionality tended to score health systems-related risk factors high is in line with the more general perception that the health system plays a great role in reducing stillbirth-related risk factors (19, 30, 33).

### ***Implications for policy***

The global campaigns drew attention to stillbirth as a major public health challenge and made strides in calling upon nations to prioritise interventions within the health systems and the general social determinants of health to address the stillbirth burden (33). Of particular importance was the call to countries where the burden was highest, such as sub-Saharan Africa (19). Specifically, the global campaigns observed a need to amplify community voices as the invisibility of stillbirth within the health systems and at the community level was attributed to the negative cultural norms and practices that promoted secretive burial practices, hence causing stigma and discrimination against the affected families (19, 30, 33). However, the community response is not strong despite efforts to adapt and integrate global recommendations into the health systems response. The official health systems response involving the integration of community aspects through the Community Health Extension Workers (CHEW)/Village Health Teams (VHTs) has not yet led to enough empowerment to respond to these unique challenges regarding stillbirth prevention. Variations exist within the women's perceptions of stillbirth risk from the different risk factors, as revealed by their perception scores. Reflecting on the ideal scenario for a countrywide scale-up of prevention interventions, there is, therefore, a need to tailor interventions responsive to women's perceptions and concerns. Innovative approaches to differentiated care within the community arm that responds to the earlier challenges of focused antenatal care can go a long way in identifying and responding to pregnant women's anxieties and risk perceptions. Fast-tracking the CHEW strategy followed by the requisite funding for its functionality is crucial to the community response as it will go a long way in ensuring uniform implementation and sustainability.

### **Limitations**

This study is not without limitations. The results reported are from a hypothetical scenario. Despite being of reproductive age, the women interviewed were drawn from a community sample and data on current pregnancy status was not collected. Therefore, the responses are based on perceived risk without due consideration for current pregnancy status. However, we defined stillbirth, contextual factors and burden in Uganda to create respondent familiarity with the problem. Further, the study was

conducted in a single district that is peri-urban with a relatively even distribution of health facilities and a blend of public and private service providers to increase respondent provider preference. Hence the results need to be interpreted with caution in order not to generalise outside contexts which are slightly different from where the data collection occurred. Finally, the sample was drawn from the community and the results may vary when the sample is drawn from a facility setting such as antenatal care clinics. More research is needed on perceived stillbirth risk among women who are currently receiving services since some perceptions arise from the experience and quality of antenatal care services received.

### **Conclusions**

Within maternal health care service provision, stillbirth risk assessments and judgements are often based on clinical judgements and policy guidelines and algorithms that utilise standard assessment procedures and tools which quantify medical and obstetric factors to predict a potential stillbirth. This approach leaves little room for the experiences of the mother to be integrated into the service care package of the expectant women. Within the context of shared responsibilities and decision-making between the expectant mothers and service providers, women's perception of stillbirth risks must be incorporated into the tailored package if the stillbirth burden is to be reduce, especially in regions bearing the highest burden. Our study presents perceptions from women's point of view within a community-level setting, which provides insights into how they feel about potential risk factors which, once tapped into, can be a good resource to tailor antenatal care packages which may be practical and suitable in this context during clinical encounters.

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## CHAPTER SIX

### **Accounting for variations in implementing interventions to address stillbirth from national to subnational levels. Experiences from Uganda<sup>6</sup>.**

#### **Abstract**

**Introduction:** Of the 2.6 million global stillbirths happening annually, many happen in regions with the highest burden, such as sub-Saharan Africa where Uganda is located. To respond to this burden, policies made at national level were diffused from the centre and translated into service delivery at the district level, which is charged with implementation under the decentralisation of health services arrangement. Variations emerge whenever policy recommendations are moved from the national to the subnational level, with some aspects often getting lost along the way. However, the extent to which implementation varied from the policy provision for national stillbirth reduction strategies remains unclear. This article aims to present an understanding of variations in the implementation of interventions to address the stillbirth burden at the national and subnational health systems levels in Uganda.

**Methods:** The study adopted a qualitative cross-sectional study design. Data was collected from a purposively selected sample of key informants drawn from both the national and subnational levels using digital audio-recorders. All interviews were conducted in English and transcribed verbatim. Atlas.ti was used to guide the coding process which adopted a codebook developed following the Consolidated Framework for Implementation Research (CFIR) domains as codes and constructs as sub-codes. Analysis followed the content analysis technique.

**Results:** National-level factors that favoured the implementation of interventions to address stillbirth included the desire to comply with global norms, incentives to improve performance for stillbirth reduction indicators for better comparison with global peers, and clear policy alternatives as process implementation advanced by champions. Variations at subnational level revealed aspirations to address service delivery gaps which fell within maternal health routine standards of care and ongoing health systems strengthening endeavours. Coalescing existing networks around maternal and child health was a key mobilisation factor for advocacy and programming with the promise that the set targets would be operationalised at the subnational level. The key champions were defined by their official roles within the district health systems, which enhanced accountability. Feedback and reflection were distinguished from the national to subnational level through joint assemblies and formal audit reviews, respectively.

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**Conclusion:** Heavy influence of the global events directed national-level adaptation of interventions to address stillbirth. The implementation context at subnational level led to the local adaptation and translation of policy provisions from the national level to suit the context, which, to a greater extent, explains the variations in the final content of policy provisions delivered.

**Keywords:** stillbirth, policy translation, implementation context, policy adaptation

## **Background**

Of the close to 2.6 million stillbirths that occur every year, the majority of the cases happen around the time of delivery (1, 2). Low-income countries typically constrained by resource limitations are disproportionately affected. Within Uganda, the stillbirth burden stands at 9/1,000 live births, with many categorised as fresh stillbirths, reflecting deficiencies in the quality of maternal health care, especially around the time of delivery (3). To address the challenge, tremendous progress stemming from the Millennium Development Goals (MDG) era has registered success in reducing perinatal mortality and continues to be pursued under the Sustainable Development Goals (SDGs), specifically goal 3.2(4). Some of the key success areas have been policy changes to improve health facility service delivery, health workforce education and training, community demand-side factors, drugs and essential commodities that have witnessed an increase in the number of facility deliveries (5, 6). However, birth attendants have been reported to inconsistently perform practices known to reduce mortality rates (6). Despite these efforts, the rates of stillbirth reduction have continued to be slow, posing threats to the possibility of achieving the set targets. Nonetheless, access to skilled birth attendance is increasingly being seen as inadequate in addressing maternal and perinatal mortality. This has accelerated calls for consideration of the quality of services delivered at the health facilities. Currently, innovative interventions to improve the quality of maternal health care, especially around the time of delivery, are being promoted in different parts across the globe. This is due to many of the maternal deaths and stillbirths being registered around the time of delivery and yet known evidence-based interventions delivered around this time provide the greatest opportunity to save many lives (7).

The targeted national-level efforts to address stillbirth reduction were prioritised in policy with the hope that transfer processes would see them translated into service delivery at the subnational level. Policy recommendations highlighted several evidence-based interventions, such as scale-up of basic and comprehensive emergency obstetric care services, periconceptional folic acid supplementation, the prevention of malaria during pregnancy, and improved detection and management of syphilis during pregnancy, among others, to address the known stillbirth risk factors (8, 9). Many of the proposed interventions have been or continue to be piloted in different parts of the world involving both low-cost and resource-intensive interventions (10, 11). As pilot results start to trickle in, so do the concerns over their effectiveness in reducing the stillbirth burden. The UK trial that piloted interventions responding to known stillbirth risks through the



creation of awareness among pregnant women regarding foetal movements revealed that despite controlling, for now, the risk factors, the intervention did not affect stillbirth occurrence (12). Relatedly, the baby birth trial conducted in the Indian province of Uttar Pradesh that aimed at piloting a World Health Organisation (WHO) safe childbirth checklist (SCC), another known evidence-based tool, revealed that despite the adoption of positive essential birth practices, it did not have an effect on stillbirth reduction, both in intervention and control (13). Experience of piloting the same in Uganda showed that although the SCC was piloted in both control and intervention sites, most reductions in stillbirth were registered among intervention sites where additional evidence-based tools were implemented reflecting the low effect on SCC in reducing stillbirth (14). Application of the same tools in another Indian context of Rajasthan revealed that application of the SCC was an effective intervention with the potential to avert intrapartum deaths, with most reductions occurring in the prevention of stillbirths (10).

Whereas most of these experiences are from controlled settings, the results point to the importance of contextual factors in influencing the implementation outcomes (15). It is not yet known how such initiatives can play out when delivered through routine standard care services. Experiences of variations in the package from design to implementation, especially in maternal and child health (MCH) interventions, have long been established (16). The implementation context has been advanced as one of the factors that can account for this. Detailed information on the exact contextual factors that make it difficult or influence implementation outcomes, however, remains scanty. Drawing on experiences from elsewhere, contextual factors that are general to the health system and specific to context have been advanced as reasons behind the observed differences in outcomes (17, 18). These include the limited resources, which lead to a lack of inputs and infrastructural shortcomings, which, in turn, make it difficult to implement policies according to plan as they move from national to subnational levels. Earlier work from Uganda revealed that the narrow decision space was an impediment to implementation (19), coupled with the managerial behaviours and practices of some of the health systems managers (17). Even where implementation goes as per plan and behavioural change is successfully impacted, complexity issues may inhibit positive outcomes on intended indicators such as stillbirth (13).

Uganda adopted a mix of policy options to address maternal mortality and subsequently stillbirth reduction. These cover a wide array of the health systems building blocks in a bid to realign them to address the risk factors (16). The policies targeting human resource for health improvements included the prioritisation of recruitment and deployment of rare cadres such as anaesthesiologists, having a physician as officers-in-charge at HCIV level, designating a senior nurse as the Assistant District Health Officer (ADHO) to oversee the implementation of maternal and child health services within the districts as well as prioritisation and recruitment of midwives as officers-in-charge for HCII to oversee the delivery of maternal health services at that level. Policy options targeting health systems efficiency included the addition of another layer (health sub-district) below the district level under the decentralisation arrangement specifically to

oversee the delivery of maternal health services. In addition, HCIVs were to be operationalised to deliver comprehensive emergency obstetric and neonatal intensive care (CEmONIC), which necessitated equipping them with a functional operational theatre complete with blood transfusion services, while HCIIIs were equipped to deliver basic emergency obstetric care (BEmOC) (20). Policies targeted at service delivery improvement involved boosting of antenatal care attendance, the promotion of facility deliveries under skilled attendants, the delivery of services along the Reproductive Maternal Newborn Child and Adolescent Health (RMNCAH) continuum of care, and an improved referral system (21). A number of initiatives to address demand-side barriers, such as male involvement in reproductive and maternal health, addressing distance to health facilities and discouraging delivery by traditional birth attendants (TBAs), were also being prioritised. Other policy options were in the areas of improving the availability of reproductive maternal health medical commodities as well as data capture to improve the visibility of the stillbirth burden. This was reflected in the inclusion of stillbirth as a notifiable condition within the surveillance systems, and stillbirth as a quality of care and performance indicator for health facilities and districts, respectively, among others. However, translation of all these interventions at the final points of service delivery varied depending on the prevailing contexts.

The above experiences reflect variations in implementation as policies move from the national to the subnational level. This calls for a critical review of the process factors likely to account for this observation. Although the influence of contextual factors more than the intervention package in determining the observed outcomes is acknowledged, a consensus is yet to be reached regarding the exact contextual factors that may exert the most influence over outcomes (22). This falls short of the premise underpinned by the diffusion of innovation theory. Policy transfer theories follow these underpinnings where it postulates that once an idea or policy aspect is introduced into a new setting, actors, through their actions and relational networks, will facilitate its adoption across the different levels of implementation. Hence, to answer these questions, this study was conducted among national-level policymakers, policy implementers and health partners. At the subnational level, the target study population comprised district health managers, health facility managers and frontline health workers. Using the CFIR framework, the objective of this study was to examine the factors that accounted for variations in the implementation of interventions to address stillbirth at both national and subnational levels of implementation. Information from the study, when applied by programme planners and implementers, is better able to inform strategies to respond to the factors likely to derail intended results.

## **Methods**

### ***Study design***

Details about the study design have been explained elsewhere (3, 23) but, briefly, we adopted a cross-sectional qualitative approach. A qualitative approach was preferred

because of its exploratory nature that provides an in-depth understanding of the “how” and “why”, which facilitate a deeper understanding of the phenomena and context. It was conducted both at the national and subnational levels, with one district acting as a case study for subnational-level implementation. The CFIR framework was utilised at both national and subnational levels to assess the implementation of interventions to address stillbirth. It was applied as a deductive codebook for content analysis and as a guide to facilitate the interpretation of results.

### *Study setting and population*

The study was conducted in Uganda. At the time of the study, components of the recommended interventions to address stillbirth were at varying levels of implementation and adaptation. For example, operationalisation of birth and death registration which, was targeted at recording all stillbirths happening at community level, had not been fully realised by the National Identification and Registration Authority (NIRA). Similarly, the Community Health Extension Worker (CHEW) strategy meant to operationalise the minimum recommended eight antenatal care contacts during pregnancy had not become fully operational. On the other hand, the country was in full operational mode for other policy components such as stillbirth notification, operationalisation of CEmONIC and BEmOC, as well as conducting the Maternal and Perinatal Death Surveillance and Response (MPDSR) at health facility levels, albeit with some challenges. The country opted for a stepwise approach towards the implementation of these recommended interventions, rather than adopting everything at once. At the subnational level, the study was conducted in Mukono district, located in central Uganda and bordering Kampala, the main commercial city and the capital city of the country. At the time of conceptualising this study, it was one of the districts with the highest burden of stillbirth, as reflected in the Annual Health Sector Performance Report (AHSPR) 2015/16. The study population at the national level included key informants drawn from the maternal and child health policy communities. At the subnational level, the study population comprised frontline health workers and health managers at different levels of health system functioning, including facility level, sub-district level and the district health office, where members of the District Health Management Team (DHMT) were targeted.

### *Sample and sampling procedure*

The final study sample comprised 36 respondents, with 20 drawn from the national level and 16 respondents drawn from the subnational level. Within the results section, national-level interviews are labelled with the initials “NLI” while interviews conducted at subnational-level were labelled with the initials “SNLI”. National-level respondents were purposively identified through a consultative process with the help of an informant familiar with national-level maternal health policymaking processes. The aim was to target national-level maternal and child health policy communities. Thereafter, the identified potential respondents were approached through telephone contacts. A snowball criterion was also applied to arrive at additional respondents after

commencement of the study, where respondents would be asked at the end of each interview to identify and recommend potential respondents that were familiar with the study subject. A total of 23 respondents were approached for participation, out of whom 20 were interviewed. We did not pursue further interviews since no new data was emerging after the 20 respondent had been interviewed. At the subnational level, a step-wise process was employed to arrive at the final potential respondents. This involved drawing up a list of all health facilities in the district from which potential respondents, particularly those working in the maternity units of each health facility, were identified. The telephone numbers of potential respondents were then obtained from the district, whereupon each contact was initiated, study objectives explained and a request to participate extended with a potential day of interview requested. On the day of interview at the health facility, further explanations were made and informed consent was obtained. Further consultations were then done to identify more potential respondents in cases where we found that the pre-identified potential respondent was not available in the course of the study.

#### *Characteristics of the study sample*

Overall, 17/20 national-level respondents were female drawn from the Ministry of Health (5); non-governmental organisations (4); professional associations (6); private not-for-profit health facilities (2); academia (2); and private-for-profit entities (1). Their places of work were not mutually exclusive as some doubled as working in academia, being affiliated to professional associations and being linked to either private-not-for-profit or private-for-profit entities. Subnational-level respondents included members of the district Health Management Teams (3), hospital (6), HCIV (5), and HCIII (2). These varied by cadreship to include medical officers, nurses and midwives.

#### *Data collection*

Prior arrangements were made where potential respondents, particularly those at the national level, were first approached by telephone and the aims and objectives of the study were explained. The process involved conducting key informant interviews using semi-structured interview guides to collect data at both the national and subnational levels of the health systems. Different tools were used for both national- and subnational-level interviews. Their development was guided theoretically by policy translation and diffusion by literature. The national-level tool explored national-level political prioritisation of global health campaigns while the subnational-level tool explored policy translation experiences reflected in health workers' experiences, the role of facility management and individual health workers in the translation of policy aspirations, workplace context and service users' characteristics. Interviews were conducted face-to-face from March to June 2019 at the respondents' places of work following agreement on the day and time when the interview could be conducted. Interviews were recorded using a digital audio-recorder with field notes taken during the interviews. Overall, the interviews lasted between 45 minutes and one hour and the interview guides used to conduct the interviews have been explained elsewhere (3, 23).



At the national level, two callbacks would be made before a potential respondent would be replaced, while at the subnational level, none of the contacted potential respondents declined to participate.

### *Conceptual framework*

The study utilised a Consolidated Framework for Implementation Research (CFIR), one of the most commonly used implementation science frameworks (24). The framework was applied deductively to analyse and understand the underlying factors for variations in implementation at both national and subnational levels. It consists of five domains that interact iteratively in complex settings to influence implementation effectiveness. The five domains include 1) the intervention characteristics; 2) the outer setting; 3) the inner settings; 4) characteristics of the individuals involved; and 5) process implementation. Within each domain, several constructs explain different assumptions, expectations, beliefs, factors and theories behind the effective implementation of the intervention. The framework postulates that the implementation of interventions is influenced by the different domains working through multiple constructs to determine outcomes. Conceptual frameworks are ideal for analysing complex interventions, for they explain variables either graphically or in narrative form that influence a phenomenon of interest, thereby increasing the generalisability and interpretability of results (25-27). The CFIR was preferred for its flexibility to be tailored to the context for this study and its ability to explain the non-linear complexities surrounding the translation of interventions from the national to the subnational level of the health systems. Details of the domains, their definitions and specific constructs are explained further in Table 6.1 below:



**Table 6.1: CFIR framework(24)**

	<b>Domain</b>	<b>Definition</b>	<b>Related constructs</b>
1	Intervention characteristics	Features of the intervention that might influence its implementation	8 constructs denote this domain, e.g. 1) intervention source which refers to perceptions of whether intervention is internally or externally developed; 2) evidence strength – perception of quality and validity of evidence; 3) relative advantage – perception of advantage of implementing intervention vs available alternatives; 4) adaptability – degree to which intervention can be tailored or refined to meet local needs; 5) trialability – ability to test intervention; 6) complexity–perceived difficulty of implementation; 7) design quality – perceived excellence in how intervention is packaged; and 8) cost – expenses associated with implementation.
2	Outer setting	Features of external context and environment that might influence implementation	4 constructs form this domain, e.g.; 1) Patient needs; extent to which patient requirements and barriers are known and addressed, 2) Cosmopolitanism; extent to which organisation is networked with other organisations, 3) peer pressure; competitive pressure to implement from peers, 4) external policies and incentives; external strategies to spread intervention.
3	Inner settings	Features of the implementing organisations that might influence implementation	12 constructs relate to this domain e.g. 1)structural characteristics – social architecture and size of organization; 2)networks and communication – webs of interlinkages within an organisation; 3) culture – norms, values within an organization; 4)implementation climate – absorptive capacity for change; 5) tension to change – extent to which stakeholders perceive current situation as intolerable; 6) compatibility – tangible fit between meaning and value of intervention; 7) relative priority – shared perception of importance of implementing intervention; 8) organisational incentive – extrinsic value of implementing intervention; 9) goals and feedback – communication of goals to staff with feedback aligned to the goals; 10) learning climate – individuals feel safe to try new methods with sufficient time for reflective thinking and evaluation; 11) readiness to implement – tangible and immediate indicators for organisational commitment to implement intervention; and 12) leadership engagement – commitment, involvement and accountability of leaders for implementation.

4	Characteristics of individuals involved	Characteristics of individuals involved in implementation that might influence implementation	5 constructs form this domain, e.g. 1) knowledge and beliefs about intervention – attitudes and values placed on the intervention; 2) self-efficacy – individual beliefs in their own capacity to execute the intervention; 3) individual stage of change – phase of progress towards skilled, enthusiastic use of intervention; 4) individual identification with organization – individual’s degree of commitment and relationship to the organisation; and 5) other personal attributes – broad enough to include other personal traits such as intellectual ability, tolerance of ambiguity etc.
5	Process implementation	Strategies and tactics employed that might influence implementation	8 constructs form this domain, e.g. 1) planning and execution; developing tasks for implementing intervention; 2) engaging – involving appropriate individuals; 3) opinion leaders – individuals within organisation with formal and informal influence over attitudes of others; 4) formally appointed internal implementation leaders – individuals with formal responsibility for implementing intervention; 5) champions – individuals who dedicate themselves to supporting and marketing intervention; 6) external change agents – individuals affiliated with external entity who formally influence intervention; 7) executing – accomplishing the implementation according to plan; and 8) reflecting and evaluation – quantitative and qualitative feedback about the implementation process.

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## **Data analysis**

To facilitate the analysis of variations in implementation between the national and subnational levels, transcripts from the national-level sub-study (3) and the subnational-level sub-study (23) were integrated. The national-level context involved the translation of policy recommendations from the global campaigns into national-level policy provisions, while the subnational context involved the translation of national policies into maternal health care service provision. This was followed by a codebook development exercise which followed domains and constructs from the CFIR framework. Specifically, each of the domains was adopted as a code with constructs adopted as sub-codes. Thereafter, transcripts were exported into Atlas.ti, a qualitative data management software (28). A framework analysis technique was adopted as an analytical approach. It was preferred for its ease of configuration with a deductive coding technique (29, 30). After familiarisation with the data, coding was deductively conducted following these CFIR domains and specific constructs under each domain. A coder would identify textual data relating to specific constructs, highlight it and then attach it to a specific sub-code corresponding to a particular construct. The team then developed an analytical framework, having familiarised themselves with data during the coding process (31). At the end of this process, query reports were produced for each of the constructs, followed by a manual pile sorting exercise, leading to the grouping of text with similar meaning under unique piles in a data charting exercise guided by the applied analytical framework. The team then read through each of the textual data once more to identify underlying meaning in a data interpretation exercise which led to the identification of factors related to variations in the implementation of specific policy recommendations between national and subnational levels. Typical quotes have been used while presenting the final results under each domain and construct. We present the results based on underlying meaning as it related to the identified constructs within the applied CFIR framework. Finally, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) while reporting the qualitative results (32). Detailed information about the study team has already been reported elsewhere (3, 23).

## **Results**

### ***Intervention characteristics domain***

#### *Intervention source*

From the national perspective, a desire to comply with global MCH targets appears to explain the national efforts to address the stillbirth burden. This motivation was not exclusive to stillbirth reduction but it can also be traced across several other Reproductive Maternal Newborn and Child Health (RMNCH) indicators. Within this context, a focus on stillbirth reduction was an extension of national strategies to address the low-performing RMNCH indicators. Acknowledgment of external support to tailor national objectives was a common theme across the respondents:

When we adopt or get guidance from let's say the World Health Organisation on how to manage newborns or maternal health issues, we through the Ministry, partners,

professional medical association bodies can sit down and comb through and see how to contextualise these guidelines. **(NLI019)**

At the subnational level, the likely causes and burden of stillbirth were familiar to the service managers and providers. These were addressed through already existing interventions delivered through the routine standard of care. There was a general feeling that efforts to provide support in addressing stillbirth reduction were welcome and long overdue. Tailoring national efforts to fit the local context is what was adopted on a case-by-case basis at the final point of service delivery. A widely held perception was that triggers for most stillbirth risks originated from the community and were due to delayed or late referrals. This knowledge of the causes was a common observation among the respondents.

### *Evidence strength and quality*

The global connection of the intervention source had an influence on the nature of the evidence presented. The observation that an exclusive stillbirth indicator was omitted in national-level statistics seemed to have created discomfort among advocates. A feeling that the high rates of perinatal deaths were being disproportionately skewed by stillbirth was another point of concern. The adoption of evidence from the global campaign found fertile ground to galvanise national-level support to join the efforts in addressing the problem at the national level. Nonetheless, thoughts of insufficient data persisted, prompting support for the existing deliberate efforts to improve data systems.

We are making sure that that is part of the strengthening we are talking about. So we are making sure that once these partners are also working with the districts; and we are reporting through District Health Information Software 2 (DHIS2), and so once we do that we are strengthening the DHIS 2. The annual reports that people talk about have much better data than what has been previously happening so we are seeing that as a chance in the activities that we have. **(NLI008)**

Variations at the subnational level with regard to evidence strength were reflected in the way that most health workers involved in the delivery of maternal and child health services were familiar with and had recent experiences of encounters with and management of mothers with stillbirths. The belief that addressing stillbirth was long overdue was widely shared. National-level prioritisation found a familiar context contributing to its acceptance at the subnational level.

My experience with stillbirth is that it has been on the rise, especially the fresh stillbirth because for the macerated we have been able to teach the mothers what causes it and now at least they have improved. Then for the fresh stillbirth, it has been rising in our hospital because in Mukono this is the only big hospital around and we get many referrals in. **(SNLI025)**

### *Relative advantage*

Closely related to the relative advantage was the evidence used, which reflected an interconnectedness between the maternal mortality risk factors and stillbirth risk factors. From the national perspective, prioritising stillbirth meant boosting maternal and child health systems and service delivery improvement efforts since they shared similar risks and possible interventions to address risks. Besides, these global campaigns were attracting funding, something the government embraced to reinforce

its strategic objective of systems strengthening. This would, in turn, respond to the persistent challenges of demand-side bottlenecks which had inhibited optimal utilisation of the available maternal health services to encourage facility deliveries under skilled attendants.

We are talking of strengthening the system like in our most districts we have substantive District Health Officer (DHOs) who are the health managers in the district, we have the ADHO who manages maternal and child health and is also responsible for immunisation so through that angle most of the systems are okay and then you look at the facilities where they are delivering. Now the Ministry of Health through a project called Expand on Maternity Wards in Health Centre IIIs and strengthen them and also skill through mentorship and courses. **(NLI007)**

Maternal health was already a prioritised intervention at the subnational level, with utmost caution being exercised to avert any maternal death. Since many of the strategies to address stillbirth were similar to those for maternal mortality, it presented a relative advantage for embracing stillbirth reduction within the ongoing MCH standard of care.

#### *Adaptability*

Maternal mortality was already a notifiable condition captured within the surveillance systems. This made the inclusion of stillbirth in the same surveillance system less complex. Besides, maternal death reviews were already an area of focus in national policies; therefore, adapting perinatal death reviews seemed to have made its prioritisation much easier. At the subnational level already, the district had a designated officer in charge of MCH, stillbirth reduction was added onto the indicators the officer had to prioritise at the facility level. The health workers followed national guidelines to notify any stillbirth within 24 hours. Besides, it did not require the setting of separate guidelines for perinatal death reviews but rather stillbirth inclusion among the cases to be reviewed:

You see, the Ministry says that if you get a maternal death they must be notified within 24 hours. Normally we notify them and we also notify the office of the DHO but the most important thing is for us to find out the gap and address it. **(SNLI029)**

#### *Trialability*

Stillbirth reduction efforts benefited immensely from evidence generated from maternal health projects implementing neonatal components. This is evident from these interventions that were later used to support advocacy, inform policy revisions and support the national-level rollout. Other evidence-based tools, such as the WHO Safe Childbirth Checklist (SCC) piloted by the East Africa Preterm Birth Initiative (PTBi-EA), had their results ready to inform policy modifications. More recently, during the adoption of WHO quality-of-care guidelines, the country selected 11 districts for trial purposes, as explained in one of the interviews:

Currently, under the WHO, we have Quality of Care Improvement for Maternal and New Born and we have adopted the WHO guidelines where we are emphasising quality in maternal and newborn care as one of the strategies of reducing both maternal and newborn deaths. So we rolled out the guidelines, we have identified 11 planning districts that are going to represent those standards. **(NLI007)**



Evidence of trial flexibility was observed in the study district. Previous maternal and child health quality improvement interventions, for example the Helping Babies Breathe (HBB) project, was piloted in the area. This partly informed the health workers' capacity-building in areas such as resuscitation skills to avert stillbirth. In addition, evidence from other within-country project pilots, such as Saving Mothers Giving Lives (SMGL) which was piloted in other districts, reinforced and informed district-level strategies to address stillbirth risks. These were adopted into routine MCH services offered at the respective levels.

### *Complexity*

Adopting strategies to address stillbirth at the national level was viewed as a complex process. Initiatives targeted at improving the quality of Reproductive Maternal Newborn and Child Health (RMNCH) services were intertwined with chronic health systems challenges impeding quality service delivery. Therefore, planning to address stillbirth had resource implications for which attention to outstanding challenges was needed. To streamline prioritisation, the MoH opted to first respond to facility-based fresh stillbirth as they confronted other chronic health systems challenges:

To tackle these issues, you also need to address the deep-seated health system bottlenecks. For instance, we know that for one to handle these mothers and babies well you need to have a skilled midwife or doctor who is available on site. So, over the years the Ministry has been doing its best to see how they can increase the staffing, especially of midwives at the public facilities. **(NLI019)**

Contextual complexities inherent at the subnational level often played out in efforts to address stillbirth. Supply-side bottlenecks such as inadequate staffing affected demand-side factors; for instance, it had a negative effect on care-seeking. The demand-side barriers to service access over which health workers had little influence continued to persist. These included delays in health care-seeking and dysfunctional referral systems, among others.

You see, the Ministry even abolished traditional birth attendants (TBAs) but they are still operating and they are taking a lot of mothers when compared to the number of mothers coming to our health facilities, the numbers are still big. And among the reasons is the issue of understaffing ... we need to address the knowledge gaps in the communities and also among the health workers. **(SNLI021)**

### *Design quality and packaging*

The rollout of some interventions was preceded by streamlining misaligned aspects within the policy. Many of the fresh stillbirths happening within the health facilities were due to late referrals. Addressing policy gaps became important in responding to these cases, as explained in one of the interviews, quoted below:

The second thing that is happening now is that we are revising some areas in policy that are going to help streamline referrals. So, the referral hospitals policy is going to be critical. The third one is the ambulance system. The new ambulance policy is also going to help in the new referral policy, so in a way certain things are more in line to improve at least in the policy arena. **(NLI008)**

The subnational-level challenges reported included those arising from design quality and packaging incompatibilities. A case in point was the conduct of perinatal death reviews amidst the scarcity of tools/forms with low appreciation as compared to maternal death reviews. The subnational response targeted this amidst challenges, as reflected in an interview with a respondent:

Even when we were going to do this result-based financing evaluation, among the aspects they are looking at was that Maternal and Perinatal Death Reviews (MPDR). They were looking at whether the facility has the form and whether the committee sits. So, we are just even struggling to download the forms and put them in the files. That one is not well appreciated. **(SNLI027)**

### *Cost*

Country-level efforts were boosted with the availability of funds to support different pilots with a neonatal health component. Later, this was an important resource in informing policies responsive to stillbirth reduction.

To realise this vision, the Ministry has also adopted certain programmes like the results-based financing which is focusing on maternal-child health issues. So that is a focused effort by the Ministry which understands that this is a problem and we need to have some kind of focused effort to address it. **(NLI016)**

No differences were observed between the national and subnational levels where similar resource opportunities enabled rollout. The World Bank provided support to national-level maternal and child health improvement goals through the Uganda Reproductive Maternal and Child Health Improvement Project (URMCHIP). It operationalised results-based financing (RBF) that compensated outputs for pre-selected indicators, some of which related directly to the country's efforts to address stillbirth. These included the conduct of Maternal and Perinatal Death Surveillance and Response (MPDSR), among others.

### **Outer settings**

#### *Patient needs and resources*

Demand-side barriers impeding facility deliveries had been at the core of the MoH strategies to address maternal mortality. Stillbirth campaigns were ushered in to address the distance to health facilities and to improve the quality of maternal health care services through the operationalisation of basic and comprehensive emergency obstetric care and improved referral systems.

A lot of effort has been done to encourage mothers to come and deliver in health facilities but when they come they are losing their children. Antenatal coverage we are saying has gone up but when you look at the fourth antenatal care (ANC) coverage is far below compared to the first ANC and is still below standard, so all those are factors that are leading to the death of our newborns. **(NLI007)**

There was a need to bring services closer to the users, including comprehensive emergency obstetric care, with linked services to improve the referral system at the subnational level. It emerged that challenges of referring high-risk mothers for delivery in tertiary facilities with the ability to transfuse blood were often not welcomed by such mothers, who preferred to deliver at nearby facilities.

Looking at the stillbirths alone, most of the cases we get here are fresh stillbirths and those are mothers that are usually been referred from the community ... And when we assess, they were being referred from these clinics. And one that came with a ruptured uterus at 28 weeks and we could not save the baby. **(SNLIO21)**

### *Cosmopolitanism*

At the national level, Uganda was actively involved in and was part of the global efforts to address maternal mortality. These events date back to the beginning of the MDG era during the early 2000s, which triggered off campaigns to reduce maternal and neonatal mortality by the agreed indicators by 2015. Cumulative efforts translated into national acceleration of implementation to achieve the MDG set targets. The post-MDG era witnessed the extension of similar efforts, with Uganda being a signatory to several global commitments. Maternal health prioritisation was a beneficiary, which had to be reflected in the ways the interventions were implemented. At the subnational level, aggregated stillbirth numbers were part of indicators for monitoring health facility and district-level performance within the Annual Health Sector Performance Reports. A high stillbirth burden would reflect poor performance, which would be compared in relation to other health facilities and districts. Health facilities were networked through a localised referral system which in outlook appeared interest-driven. Strategies to reduce stillbirth were communicated through these existing relations.

### *Peer pressure*

The desire to keep pace with the set Every Newborn Action Plan (ENAP) targets by 2020, 2030 and 2035 alongside other countries where Uganda was one of the ENAP countdown countries, necessitated close monitoring of the set indicators to signal progress towards these targets. At the regional level, related obligations were arising from the regional treaties that exerted pressure on the country to act to improve maternal health services in which stillbirth reduction was embedded:

There are certain things that the East African region has asked for which I think are good but for the implementation, it's up to the Ministry to decide. They are implementing some of these regional approaches, for example there is a scorecard and we all contribute to that scorecard. Then there are regional issues around how training doctors should be done. **(NLIO08)**

At the district level, high numbers of stillbirth signalled poor performance compared to peers. At the facility level, the same high numbers of stillbirth signalled poor quality of MCH service when compared to other health facilities within the district. This was complicated by the MoH's request that facilities register all stillbirth cases even when they originated from the community but were reported to the health facility when the affected mothers presented for management of delivery complications or postpartum care. This would be irrespective of whether they occurred within the health facility, so long as they were within the catchment area and managed to reach the health facility. Some health workers from the affected facilities expressed dissatisfaction with this decision.

Yes, you can have the high numbers but the Ministry says when the mother comes to you start from there but by the time they come we have nothing to do and you have to admit that this is an FSB...what I can say if it is a fresh stillbirth (FSB), they should not

put it in our book at least let them get a way of reporting such say “referral in-FSB” so that they don’t pin the hospital. **(SNLI025)**

### *External policy incentives*

Global appraisal of evidence regarding interventions with the highest impact coupled with mapping of policy areas that required realignment to address the problem appear to have given direction to national-level processes. Pivoting resources from global initiatives in support of intervention implementation for programmes with neonatal components contributed to incentives directed at favouring national stillbirth reduction action plans. Evidence for policy was handled at the ministry level during steering committee meetings wherein different players, including representatives of bilateral and multilateral agencies, got an opportunity to present and deliberate on the evidence available before it could inform and be adopted into policy. Despite these contextual factors at the time, reservations were expressed with regard to the influential role of partners directing the national response:

The major way they have done it is through the steering committee meetings that they have at the Ministry level where they bring all key players, people who are doing the work. If I would just mention a bit of a challenge in my opinion that I think should be improved is that sometimes it is partner-driven where a partner will front support [to] have these meetings and so if the partner runs out of funds or he is no longer existing, then the meetings kind of stagger. **(NLI020)**

At the subnational level, the performance rewards through the Uganda Reproductive Maternal and Child Health Improvement Project (URMCHIP) led to rapid scale-up of some interventions. Efforts to improve stillbirth data quality to give visibility to the hidden burden partly informed the Ministry of Health’s decision to set out the requirement for all health facilities and districts to have all stillbirths captured through the surveillance system and notified within 24 hours. This in itself added another accountability layer to improve reporting and adherence to set guidelines such as perinatal death reviews and documentation.

### ***Inner settings***

#### *Structural characteristics*

Maternal health services within which stillbirth reduction strategies were embedded were a mobilising factor among multiple stakeholders, including donor agencies, researchers and professional associations. Their working relationships and networks were further strengthened during the MDGs and in pursuit of the national ENAP targets. MoH then guides the policy direction and overall stewardship while moving these targets from the national to the subnational level. Similar networks exist at the subnational level through which service delivery is managed:

The District Health Officer who is in charge of the health issues that happen in their respective districts and it is through that channel that districts can get clear communication and feedback on those issues that are implemented at the Ministry level and also at the district level because through the DHO and his team where the Ministry has a structure. Among the district team members there is a maternal-child health focal person and we know that through our experience that having a focal person to take lead



on a particular programme issue helps to drive the process in a catalytic manner. **(NLI019)**

### *Networks and communication*

Established networks at the national level coalescing around the MCH cluster and other sub-committees, such as the Newborn Steering Committee, with shared ENAP goals operationalised through the RMNCH investment case existed. These networks included multi-representation from stakeholder networks like professional associations with direct access to policymakers. The strong working relationships were embraced within the MoH systems strengthening efforts to address the chronic challenges identified and advocated by partners for a long time.

We know that the Ministry of Health is the overseer, is the team lead, is the driving force that ensures we comply with the existing policies and guidelines and how they manage to see that this is being done through support supervision and these are done directly by the headquarters staff, people who sit at the Reproductive Health Division here in Kampala but since they are few, they also work through channels like regional level structures. **(NLI018)**

At the subnational level, tertiary facilities already had established working relationships through which they reached out to lower-level public health facilities, private facilities, and TBAs within their catchment areas. At this level, the MCH service provision ecosystem was contextually different, as a result of which they had to adjust service provision. Contextual challenges included private providers withholding mothers far too long before referrals, TBAs remaining active and major players in the referral system suffering some delays attributed to their role. Facilities initiated call-backs for lower-level service providers to follow up on referred cases to establish how they were responding to identified gaps. At the top were the district management teams that ensured that all aspects are well coordinated to streamline communication and avoid duplication.

One thing that the districts over time have been strengthening is the clear stakeholder engagement in their respective Districts to ensure that they at least don't have a lot of duplication or things happening under their nose that they are not aware of because they are the gatekeepers and are responsible to give feedback at Ministry level as well. **(NLI015)**

### *Culture*

This construct was not explored in-depth for both the national and subnational levels.

### *Implementation climate*

Maternal and child health still held very strong norms originating from the MDG era which were further reinforced within the post-MDG development agenda, such as the SDGs and universal health coverage (UHC) that looks at comprehensive coverage. Already, improving specific MCH indicators, including stillbirth reduction, was a felt need. Stillbirth reduction benefited from this and since similar interventions had the potential for triple return on investment, its acceptance met with little resistance. Support from global bodies and MCH stakeholders was another aspect that made the



implementation climate favourable, with country offices being engaged in direct national-level rollout:

Globally we maybe adopt standards having done a lot of research and benchmarking, then as a country we customise. We have a Country Office here and so it is their role to come to the Ministry of Health and they adopt those standards and roll them over to the implementing sites and those are the districts and all facilities and like for this case, the quality of care we have to scale up into the entire country other than having learning districts. **(NLI007)**

Stillbirth remained a sensitive issue even at the subnational level, where the MoH engaged in spot checks when numbers exceeded the regular threshold from what was routinely reported. Sharing similar strategies with maternal mortality reduction efforts made addressing stillbirths compatible in the context of a limited resource setting and the existing policy environment.

We got feedback when we sent our Health Management Information Systems (HMIS) report and we indicated that we had three to four fresh stillbirths that month. We had a team from the Ministry that came to find out what the problem was. And that was about eight months ago. But from the perinatal death audits we send, we don't get feedback. **(SNLI021)**

## ***Process implementation***

### *Planning*

Clear policy alternatives at the national level with strategic objectives highlighted in national policies, particularly the RMNCAH investment case as the overall guiding policy, were evident. The Reproductive Health Division within the MoH oversees and coordinates planning at the ministry level. The national strategy to deliver stillbirth reduction was through the routine standard of maternal and child health services. The consensus of delivery as reflected in policy guidelines took up the integrated approach where services were delivered along the continuum of care with service quality being enhanced through health systems strengthening.

We plan together with the districts. We have our new plans and then the Department of Planning has regional plan meetings to look at issues of budgeting for health and budgeting for all resources. We coordinate the partners, we also earmark resources to the district but more so for a partnership. We look into the policy and the implementer is the Government. We set the guidelines and the protocols through maybe institutions like Mulago [national referral hospital] and the academia may help us come out with standards and protocols which we distribute. **(NLI007)**

The feeling that current plans were not commensurate with population growth rates and the resulting pressures on existing maternal health services emerged. Proponents of this view argued that current maternal health challenges, including the stillbirth burden, stemmed from poor planning that did not match the current demand for services. This view is represented by the interview below:

The problem is the systems and not responding to our population growth. And because of that our current system, our population is outstripping the services that we currently have and so until we make sure that our population growth and our health system can balance out, we shall still have a lot of problems. So, I know there are approximately 1.7

million pregnancies every year but our facilities are not designed to provide services for the 1.7 million. So, we need more functional facilities to be able to provide the high-quality services that they should be providing. We also know that our MBChB numbers every year if we continue with our training at the moment; we are at 3% annual population growth and we are nowhere near being able to reach the numbers that WHO recommended. So until we see that, it is going to be very hard. **(NLI008)**

Suggestions were advanced regarding the need for holistic implementation since most bottlenecks were already known and efforts to deal with them were only impeded by the disjointed implementation of interventions.

I feel we have the answers to what the problem is and where the problem is. The thing is reinforcing efforts to do these interventions holistically; [by] holistic I mean we know the three delays and I really feel that covers and encompasses everything where if the mother does not know when and how quickly to seek that care, and if at all she goes to the facility and does not get the quality of that care then that is the beginning of all these problems. **(NLI019)**

Subnational-level efforts were characterised by joint planning for the district-level stillbirth response, which was embedded in strategies to address maternal mortality. The DHMT planned for the execution of strategies through the respective sub-districts, while at the facility level, the officer-in-charge and the maternity unit officer-in-charge together with the staff made plans during staff meetings.

But we always talk during meetings and they will talk about the quick referral here. When we go for the district meetings, we encourage them to refer quickly and monitor mothers well but still, I don't think I have any other thing because apart from saying that we refer those very complicated cases which will also be a problem to the mother. **(SNLI026)**

### *Engaging champions*

Enthusiastic national-level champions were more defined by their passion for maternal health. Interest in stillbirth reduction appeared more to be a spin-off from earlier efforts in maternal health advocacy and intervention implementation. More of the maternal health champions that took on stillbirth advocacy. These oscillated between advocating stillbirth reduction and going back to their dockets of maternal and child health service improvement. The concept of patient advocates in maternal and child health is still very weak in the context outside HIV services. Influential subnational champions were more defined by their official positions held in career and professional ranks as understood through their job expectations. The Assistant DHO in-charge of maternal and child health is responsible for championing maternal and child health causes, sub-district in-charges stewarding health systems strengthening at that level while facility in-charges, maternity unit in-charges and midwives were the champions at the facility level. These are supported by health workers attached to the maternal health unit.

Our health workers do everything if I may say and ours (management) is to support their decisions and being able to implement them and support them in logistics, consumables and supplies. So they do a lot, especially in ensuring that the treatment is given, those pre-terms are reported to us, and doctors are called in to review. And also ensuring that when death has occurred, they convene a meeting and look through the gaps and address them. **(SNLI024)**

### *Executing*

Strategies to address the national-level stillbirth burden were adopted into policy for the subnational administration to translate. Policy alternatives reflected in the annual district league tables, including the addition of stillbirth to the list of notifiable conditions, a focus on fresh stillbirths, incorporating perinatal death reviews within existing maternal death reviews and adopting stillbirth as a district performance indicator, among others, were considered. These were very clear national-level strategies with targets expected at specific time points. Extension of coverage for emergency obstetric care services was another clear policy direction for the overall maternal health quality with stillbirth reduction benefits, as revealed during the interview below:

Needless to say, we need to look at strengthening emergency obstetric care because once you are doing emergency obstetric care then you are going to reduce the fresh stillbirths. So those are the key areas that we are kind of trying to address. **(NLI008)**

Interventions to address stillbirth at the subnational level were embedded within the routine MCH services. Execution of identified strategies in the study area benefited more from the daily experiences and feedback from meetings as well as guidance from the MoH policies. Health workers implementing interventions to address stillbirth did so within their routine standard of maternal and child health care.

You know, the MS would call for internal meetings. What we do is that we divide up and the doctor would say that today give as a CME topic. Still, there are daily reporting where we have a person in this department who is the focal person for children. I [also] keep checking on them and if there is a loophole somewhere we always give a general CME. **(SNLI026)**

### *Reflection and evaluating*

Platforms for reflection and evaluation existed at the national level where participation varied. The annual joint review mission, an accountability platform for the health sector as a performance review mechanism, is conducted every year. Similarly, the Annual National Assembly on RMNCAH sets thematic targets for the government and partners to pursue and support their implementation such as strengthening accountability mechanisms. Other platforms included the Newborn Steering Committee with a mandate from the MoH to advise on newborn survival, the MCH cluster, and the Health Policy Advisory Committee (HPAC) meetings, among others. Specifically, the Annual National Assembly on RMNCAH offers a distinct platform where implementation feedback is shared with national and subnational-level key stakeholders. Monitoring of district performance indicators is a platform for reflection and the evaluation of policy effects on the burden.

... and we have an Annual Assembly where we sit and evaluate that [during] the first period, how have we performed and how can we make commitments to the coming year. This includes the Ministries of Gender and others because there are many contributors other than the health sector to health. **(NLI007)**

I know we do monitor because we have like at the Ministry level the Annual Performance Report that brings out districts that have issues with either maternal deaths or stillbirths. So, there is a system that we are monitoring. **(NLI019)**

Subnational-level platforms established from the centre such as Maternal and Perinatal Death Surveillance and Response (MPDSR), together with localised initiatives, including Continuous Medical Education (CMEs) and staff meetings, existed to support reflection and evaluation. These are forums for discussing facility performance with regard to the stillbirth burden in addition to district-level initiatives. They have evolved to include not only documented stillbirths but also near-miss cases. Results from formal reviews offered spaces for reflection on the service quality to identify gaps and tailor response.

We have daily reminders and guidelines because we have senior people here so they keep reviewing and reminding and then getting results to identify individual weaknesses and try to correct them. **(SNLI030)**

We take monthly and whenever we finish the reports we give the feedback to our staff every Wednesday we have a meeting so if we finish the report on Monday on Wednesday we have to give them a report. Someone can ask what happened? then you tell them that we got a referral with a ruptured uterus. **(SNLI025)**

### **Discussion**

This paper investigated possible explanations for variations in the implementation of interventions to address stillbirth at both national and subnational levels in Uganda that happened between 2010 and 2018 when the fieldwork for this study was conducted. The timelines reflect a period when global campaigns to address the stillbirth burden eclipsed, especially after the launch of the 2011 Lancet Stillbirth Series which, to date, stand out as a landmark in the global stillbirth reduction campaigns. Specifically, the authors wanted to identify the differences and similarities in strategies adopted at both levels. The paper presents this anchoring discussion based on the emerging salient issues on four domains of the applied CFIR framework, excluding one framework domain (characteristics of individuals involved). This domain can be influential in policy direction to suit particular stakeholder interests, such as NGO actors and the undue influence of politicians during policy decision-making. However, it was not explored in depth during the analysis of the current manuscript since it had been covered extensively in two earlier publications from the same study preceding this paper (3, 23). Outstanding features of the constructs are expounded, and these include patient needs, intervention complexities and contextual factors, as well as the role of champions.

An important finding of our study as applied from the CFIR framework was the importance of considering patient needs at both national and subnational levels, which made resultant maternal health services more responsive. Integration of care was adopted with varying dimensions at the final point of maternal health care. This involved patient-centred care and respectful maternal care, among others, within the delivery of maternal and child health services. The findings revealed that national-level efforts were responsive towards improving facility delivery experiences through improved quality of maternal health services by rolling out the RMNCH quality-of-care guidelines and operationalising basic and comprehensive emergency obstetric care at different levels. This resonates well with recent findings, which reflect that focus on intervention components alone without much regard for contextual factors may not be enough to address the stillbirth burden (12, 13). More efforts in addressing contextual factors such as referral systems can be an important aspect in responding to stillbirth. Another



aspect of maternal health to respond to women's needs is improvement in the quality of the available emergency obstetric care services to minimise the possibilities of referrals out.

Another key finding was the variations and influence of complexity at both levels in directing the response. The quality of available MCH services was a thorny issue for planners and implementers. At the national level, there was a tendency to over-focus on policy failures, which occasioned facility-level fresh stillbirth to anchor national response. And yet at the subnational level, intertwined layers of complex issues may have accounted for stillbirth rates, such as cases of demand-side bottlenecks beyond the referral systems that were observed. Choosing to respond to known complex issues was a strategic move in anticipation of better outcomes, rather than focusing entirely on recommended "magic bullets". For example, the Ministry of Health opted to prioritise responding to risk factors for fresh stillbirths which were happening at health facilities. In addition, the fact that many of the cases were happening owing to complications during delivery called for scale-up of comprehensive emergency obstetric care services while equipping the available human resource with the required skills and revising staffing norms to include the recruitment of rare cadres such as anaesthesiologists. This observation compares well with results from the better birth trial conducted in Uttar Pradesh that established that despite the adoption of recommended practices, improved quality of facility-based childbirth, and a change in provider behaviours, no impact was achieved on a composite outcome, including stillbirth between intervention and control sites (13, 33, 34). This reflects the amount of influence that context can exert on known high-impact interventions in determining the intervention outcomes.

In our work published earlier (23), we have reported about implementation-level contexts such as late referral and maternal continuum of delivery care-seeking, which place the facility at the tail end of all available alternatives and this, to health workers, accounted for the majority of facility-level fresh stillbirths. Whereas women seek care early, some tend to start from other alternatives, including unskilled providers, and report very late to the facility. These scenarios present an important aspect to reflect on while designing interventions to address stillbirth. It is also key to reflect on them regarding whether pursuing proven high-impact intervention effectiveness is enough and how to position context within this design thinking. Elsewhere, studies have established that context appeared to be stronger than the proposed interventions in influencing barriers and mortality outcomes (13, 33). Planning implementation, therefore, goes beyond intervention adherence to focus on the contextual complexities surrounding such initiatives, especially where it impacts the quality of care. It also highlights the limitations of implementing potential strategies within controlled settings which may appear different from the routine standard-of-care settings where change is expected.

Our study also established variations in national and subnational-level champions. This could perhaps explain variations in the implementation of interventions at the same levels. At the national level, these were driven by their passion for MCH and influence among peers, and were drawn from different MCH stakeholder groups, including development partners, professional associations, implementers, and top government



bureaucrats, among others. One common feature among all was that representation was driven by interests from each of the stakeholders. This is important because the ability to influence other stakeholders becomes a rationale for choosing who to represent the group at the negotiation table. This can perhaps explain why adaptation at the national level appeared quicker – the different stakeholder representatives were top-level decision-makers within their groups. At the subnational level, our results revealed that the champions were in most cases defined by their official positions and the roles they played in addressing MCH challenges within the districts. At the final point of delivery, some of the champions were lower-level cadres, like nurses and midwives, with no authority to make decisions in response to chronic health systems challenges. Within health, most policy issues requiring major decision-taking are a preserve of the centre, signifying that some role bearers at best provide policy feedback from the subnational to the national level. These findings echo earlier observations that challenges of limited decision spaces were not uncommon(19).

### **Limitations**

This study is not without limitations. First, the purposive sampling may have left out perspectives of other key actors and, therefore, the results reported here may have represented a one-sided story, especially from health workers directly involved in the implementation of MCH. Secondly, the study design was cross-sectional, and such studies have a limitation of predominantly considering views possibly connected to occurrences around the time of data collection and hence missing out on the range of experiences that may have happened sometime before the study was conducted. Third, the study relied on information provided by the respondents, and in a context where a lot goes on in the implementation of maternal and child health programmes, views may be subject to recall bias. Therefore, in the absence of documented experiences, we were unable to triangulate respondents' information. Fourth, there was a risk of social desirability associated with research related to programme implementation experiences where respondents may systematically edit out views that may appear to reflect the poor performance of the health facilities they represent. A key strength of this study is that the analysis and discussion draw on perspectives from multiple sources of data, including both national-level and subnational-level key actors in the implementation of maternal and child health policy in the country. This enabled the triangulation of information provided from more than one source, which ensured reliability of the information collected. Besides, the analysis was conducted deductively, drawing on the main constructs of the applied framework, and where particular text fitting into a particular theme of the framework was not applied, it does not reflect the weakness of the framework but the inability to access that data during the study period.

### **Conclusion**

Analysing interview data from both national and subnational levels following the CFIR framework facilitated the identification of variations in the implementation of similar strategies at different levels. This framework has the potential to be used in identifying gaps that lead to variations in implementation, which may account for the inability to realise the different policy aspects and objectives across varying implementation contexts within the country. Applying an implementation science lens is key to providing

useful feedback to government programmes implemented at scale across the country which would otherwise not benefit from such feedback in the context of limited resources with inadequate finances to commission full-blown evaluation. In particular, regarding stillbirth reduction efforts, a lot is being rolled out and the country can benefit from early implementation experiences to identify gaps and devise solutions to address them in time for optimal results. Application of the CFIR framework enabled the study team to break down complex implementation processes to analyse the experiences and variations from national to subnational levels. The framework has the potential for enhanced utility while planning for interventions like this that are implemented at scale and later during monitoring to adjust the strategies found to be unfit to achieve the intended results.

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## CHAPTER SEVEN

### **Health workers' social networks and their influence in the adoption of strategies to address the stillbirth burden at a subnational-level health system in Uganda<sup>7</sup>.**

#### **Abstract**

**Background:** Health workers' peer networks are essential in influencing health worker behaviours and practices while translating policies into service delivery. However, it remains an under-researched area within maternal and child health (MCH) interventions aimed at addressing the stillbirth burden. This article aimed to explore the influence of health worker social networks on the adoption and implementation of strategies to address the stillbirth burden at subnational-level health systems in Uganda.

**Methods:** To explore how health worker peer exposure influenced their adoption of strategies to address the stillbirth burden, we conducted a study adopting a cross-sectional qualitative design. It was conducted in Mukono district where 16 key informants drawn from the local health system were identified and interviewed using a digital audio-recorder. After transcription, the analysis adopted a thematic content technique using the Atlas.ti qualitative software.

**Results:** More than anything, workplace social networks were found to have the greatest influence on health workers' implementation of policies to address stillbirth. From the lower- to upper-level health facilities the influence exerted by network members was in the form of linkages to other services. From network members among the private providers, the influence mechanisms were in terms of advice and caution regarding the strict adherence to policy provisions, which was perhaps reflective of the level of trust in private providers' ability to adhere to policy provisions. Among network members from the district health management and non-state actors, the influence was in terms of support in areas of weakness in policy implementation; while for the referral system it reflected the initiation of contact and eventual transportation of expectant mothers.

**Conclusion:** Social network relationships among peers within a local health system supported the implementation of interventions to address the stillbirth burden through different mechanisms. This reflects the potential of social influence over the direction and success of policy implementation at the subnational level. Opportunities to strengthen these exposures through communication exist, hence providing insights into underlying factors for policy adoption, which ought to be harnessed for optimal policy outcomes.

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<sup>7</sup> A slightly modified version of this manuscript has been submitted to the journal BMC Global Health Research and Policy



**Keywords:** stillbirth, social network, peer influence, health worker practices, subnational health systems, policy adoption.

### **Contribution to the literature**

- Health workers form relationships among peers who, in turn, influence the way they translate policies into service delivery.
- The contribution of these networks has been explored elsewhere but rarely researched in maternal and child health service delivery and particularly as it related to stillbirth reduction strategies.
- The results show that workplace networks exerted the most influence through peer learning while hierarchical relationships, through linkage to other services, and private sector networks, through caution and reminders about policy implementation requirements, as mechanisms of influence.
- These results highlight critical areas of focus to prioritise for optimal policy implementation benefits.

### **Background**

Subnational health systems are formal structural collaborations between health workers and other health service providers which aim for a strong service delivery structure (1-3). The intertwined web of relationships brings together public facilities, private providers, health systems managers, professional associations, civil society, political leaders and referral systems actors. Health workers interact regularly and rely on their relationships with peers to share patients, and to effect referrals, policy and professional advice while attending to service delivery bottlenecks (4, 5). Physician peer networks have already been highlighted as essential in influencing health worker behaviours (6, 7). Belonging to a network may influence the pace of adoption of new policies through social influence, a process by which network members are impacted by the medical practices of their peers through imitation, role modelling and persuasion (1, 8, 9). Successful policy diffusion is essential for the adoption of new policy modifications.

Peer influence is a key factor in policy diffusion and adoption arising from network members. Social contagion theory postulates that social networks have a greater impact on provider-related behaviours and practices among health workers and their peers (6, 10). Health workers turn to peers as reference points for policy advice and the adoption of new guidelines (11). Elsewhere peers' adoption of new treatment technology led to the subsequent adoption of the same in a different setting (12). Furthermore, uptake of medical practice was noted to be influenced by network connections among physicians (3, 13). At the subnational level in Uganda, these relationships can support policy implementation through the enforcement of procedural aspects such as support supervision, referral patterns and sharing of clinical advice. When explored, these patterns can uncover channels through which policy diffusion informally occurs between providers. By sharing patients, adoption of policy recommendations will likely

be accelerated following social contagion either because they are directly influenced or because they are in a similar position within the network (9, 14). Health workers often call colleagues for clinical advice, effect referrals, administrative requirements, second-opinion policy guidelines backstopping are key sources of evidence of complexities surrounding policy translation at the final point of service delivery (5, 10, 11). Understanding the nature of such relationships is important in generating evidence of how local practice patterns support interventions to address stillbirth at the subnational level.

Translation of policies to address the stillbirth burden provides a good case study. For comparisons, stillbirth refers to foetal loss after 28 weeks of gestation(15). Following global campaigns(16), Uganda took drastic measures to translate ENAP targets into the RMNCAH investment case which is the flagship national MCH umbrella policy guideline. Subsequent efforts saw the translation of these at the subnational level into actual service delivery. National stillbirth rates stood at 21/1,000 by 2013/5 and with the ENAP target for countries to aim at a reduction of at least 12/1,000 or less by 2030, it has been reduced to 9/1,000 facility-level live births(17, 18). Despite this positive trajectory, emerging evidence also suggests that most stillbirths are currently occurring within health facilities. This reflects the poor quality of MCH services delivered and the important role that subnational health systems can play in addressing the pattern. With the 2030 target around the corner, a lot needs to be done to address all possible bottlenecks that are likely to obstruct the achievement of set targets.

Despite studies conducted elsewhere suggesting peer influence in provider practices and patterns (5, 6, 11, 14), little is known about how the same plays out in the adoption of strategies to mitigate the stillbirth burden. To address this gap, we explored the role of subnational health workers' social networks in supporting strategies to address the stillbirth burden. In this study, we considered the relationship to exist when health workers shared the provision of maternal health care to mothers and exchanged policy or professional advice in efforts to mitigate the stillbirth burden. The objective of this study was to explore experiences and processes through which health workers' social networks contributed to strategies to address the stillbirth burden at the subnational level in Uganda. To our knowledge, this article is the first to document the influence of health worker social networks in addressing stillbirths, thus it contributes to the current evidence regarding factors that underlie the translation of stillbirth reduction strategies at the subnational level.

## **Methods**

### ***Study design***

The detailed methodology has been published elsewhere (18, 19) but, briefly, the study adopted a cross-sectional qualitative design.

### **Setting**

The national health sector aspirations are reflected in the National Health Policy II and the five-year Health Sector Strategic and Investment Plan (HSSIP 2021-2026). The national health system is organised around a tiered health structure whereby at the top is the MoH, followed by the national referral hospitals, regional referral hospitals, district health management teams, district hospitals, HCIV, HCIII and HCII, which is the first level of clinical care, and the Village Health Teams (VHT) structure that operates as the community arm of the health system. They are interlinked through a detailed referral system which has been enhanced through the recent introduction of the referral policy and national ambulatory policy.

The country operates a pluralistic health system with multiple actors, including the public sector and the private providers. Among the private providers are private-not-for-profit (PNFP) under the different religious medical bureaus and the private-for-profit (PFP) that include high-level corporate hospitals and lower-level clinics. These are guided through the Public-Private Partnership Policy for Health (PPPPH). Overall, the public sector constitutes 55% of care facilities, with PFP accounting for 29% and PNFP for 16%. At the macro level, the MoH leads the stewardship, taking on the policy formulation functions in addition to planning, coordination, quality assurance and resource mobilisation. It is at this level that global stillbirth campaigns were translated into national policy objectives and reflected in the different MCH policy documents. Under the decentralisation for health arrangement adopted in 1997 as part of the comprehensive decentralised system in Uganda, decentralisation responsibilities are vested at the subnational level, with the district political leadership (LCV) responsible for providing oversight to the health service delivery in the district. Something unique to health services, a health sub-district level was introduced.

Maternal and child health services at the subnational level are delivered through the routine standard of care under the direct supervision of the District Health Office (DHO) where the Assistant DHO, a post usually designated for a senior nurse, acts as the focal person for MCH in the district. Following efforts for interventions to achieve MDG goals, particularly those related to MDGs 4 and 5, the health sub-district was staffed with a physician as the officer-in-charge to operationalise comprehensive emergency obstetric and neonatal intensive care (CEmONIC). Following a recommendation by Every Newborn Action Plan (ENAP) (17), targets were translated into national policies where strategies to address stillbirths are implemented at all levels of service provision. Currently, the stillbirth rate is one of the indicators considered for assessing the annual district performance and a quality-of-care indicator at the health facility level.

It is within this context that this study was conducted in the peri-urban district of Mukono that was at the time of the study considered among districts with a high stillbirth burden.

### **Population and sample**

Details about the study participants are described elsewhere (19). The process involved identifying six health facilities and the district health management team from where potential respondents were identified. Sixteen respondents were included in the final sample, with some occupying more than one position of responsibility, that was a target for our interviews. Overall, all had spent two years or more in their current positions. For example, some midwives acted as maternity unit in-charges, while the sub-district heads also doubled as health facility in-charges.

### **Data collection and analysis**

After introducing the study to the District Health Office, consultations were done on potential respondents. This led to the compilation of a list of people with contacts to be approached later by the study team. The same process was repeated at each of the health facilities that were visited during the study. Potential respondents were then approached and the purpose of the study explained. For those that expressed willingness to take part, a date and venue for the interview were agreed upon. On the day of the interview, a consent process was administered before the actual interviews were conducted with a study team. The tool had eight questions that explored the health worker's experiences as well as the role of both facility management and individual health workers in ensuring that stillbirth risk factors were responded to appropriately. It further explored the influence of the workplace context and mothers' characteristics on translating guidelines at the frontline. All interviews were audio-recorded with a digital recorder and at the end of each field day, field notes were expanded and recorded data downloaded and saved on computer.

Analysis followed a thematic content technique after a verbatim transcription process which saw the typing out of all audio interviews into Microsoft Office Word and uploaded them into Atlas.ti, a qualitative data analysis software. A codebook was developed and the coding exercise had all textual data relating to a particular code highlighted and attached to that particular code. Query reports were produced for each of the codes and a manual pile sorting process saw quotes with related meaning grouped into separate piles of text. These were further analysed for emerging sub-themes and this is what has been used in the presentation of results, with representative quotes used in some instances to bring out the participants' voices.

### **Results**

#### ***Within the health workers' places of work***

Relationships among health workers within the same physical workplace formed the most pronounced level where network members interacted regularly to improve the delivery of services to address stillbirth risk. It involved both formal and informal engagements through which network members influenced the adoption of strategies to address stillbirth. The mechanisms of influence included coaching, which embraced "learning by doing", expert consultations from senior colleagues, occasional reminders



about guidelines enforcement and peer learning through organised sessions during CMEs, as reflected in the quotation below:

We go and look for those particular sessions that maybe need urgent attention. So, through CMES are general to everyone sometimes we ensure that CMEs are particular to the midwives so that we can maximise their attention. **(PNFP\_Hosp\_001\_IC\_Mat)**

Other formal mechanisms involved the implementation of quality assurance measures, skills-building to address identified gaps, support supervision and the different interfaces through which staff feedback meetings were held, as reflected in the quote below:

During the meetings, we discuss some of those things and in case you are managing a condition and you need to consult on something, you can refer to the guidelines and come back and manage the cases. **(PF\_HCIII\_005\_IC\_Mat)**

### ***Lower-level to upper-level health facilities***

Health workers' social networks were reported to support the identification and recommendation for appropriate service providers according to mothers' conditions, which informed the referral decision. These ranged from requirements for foetal evacuation, C-section and blood transfusion services. Existing relationships from network members were used to initiate advance contact before effecting referrals to save time, especially in response to addressing the second and third delays while managing mothers, as reflected in the quotation below:

Some of the facilities around we know them and the staff working there we know them... Sometimes the midwife can tell you that this mother was referred at such and such a time and we can compare the time of referral and time of arrival at the facility. If I fail on the phone sometimes, we meet and discuss, that you know what you sent us a mother with such and such a condition and the outcome was this. So if it was her negligence she changes if she has a positive attitude. **(PF\_HCIV\_004\_IC\_Mat)**

Relational networks also supported the assessment of referred patients and referral notes to identify inherent skills gaps with referring entities which they helped unveil and worked towards addressing to prevent future occurrence. While supporting network members, it emerged that such support was not a one-off engagement but, rather, was embedded in long-term relationships, which was not the case when cases from health facilities far away from/outside the district were being managed. For facilities directly under their oversight, network members engaged in support supervision and review of MCH activities in general that lower-level facility health workers provided for compliance with policy guidelines and technical backstopping. In underserved areas that lacked such closely-knit networks, especially in the hard-to-reach areas such as islands, these benefits were reported to be missing.

### ***Private to public health facilities***

Health worker social networks extending into the lower-level private-for-profit maternity care service providers were used to provide advice to members through a caution on service provision capacity according to the level of operation. This enabled members to



identify mothers who could not be managed at their level and initiate referral early or provide advice on where the required services could be received. Among lower-level private maternity centres where monitoring was not very strictly adhered to, they were reported to offer advice and mentorship on the appropriate use of drugs to prevent the misuse of oxytocin during labour. The same networks were used to support data capture from private providers. In addition, the adoption of proven evidence-based practices such as the use of partograph for labour monitoring, was encouraged among private providers. Such capacity-building efforts through mentorships reflected initiatives for establishing and maintaining long-term relationships aimed at improving the quality of MCH services at the subnational level.

So they usually come with the nurse and we usually first work with her. Like you show her what the problem is which she should have worked on before the referral and when all that is done that is when the nurse leaves. For all the private clinics that have initiated referrals that is how it is done. Initially, they would come and brought a patient for you and would go. But we have devised a means to try and mentor them. So we wouldn't allow them to go without knowing what has been done and what the outcome is. **(PNFP\_Hosp\_002\_MO)**

Other efforts included looping lower-level private maternity service providers into the subnational referral systems through issuing them with referral forms and phone contacts to call while initiating the referral. The same relationships were used to receive feedback about patient management, as echoed by a respondent in the quotation below:

What we have been emphasising is these private practitioners who are referring to us are getting referral forms from the sites where they are referring these mothers. Good enough sometimes they even escort them to the hospital. For me when I get any patient without a documented referral, I make sure if they don't have those forms in their health facilities, I make sure they pick those forms and I encourage the referring health worker to write to us what was given to this mother. **(PNFP\_Hosp\_001\_IC\_Mat)**

Instances detrimental to the network aspirations were also registered. A case in point was when private providers preferred to refer cases outside the district rather than local health facilities. This was particularly true when similar services were offered for free at public health facilities or cost a relatively small fee at PNFP but were instead referred to public facilities located particularly in the city. Other instances included private-for-profit actors holding onto mothers for too long over cases they could not manage but were aware of their availability in other health facilities within the districts.

### ***Health facility to district health management***

District health managers formed the apex of the subnational health system decision-making body. They oversaw all actors contributing to the improvement of the quality of maternal health. In that role, they emerged as key actors within these social networks, where they received surveillance notification for all perinatal deaths from health facilities, which information they would use to seek an explanation of the cause and then tailor CME to address the causes and request that a perinatal death review (PDR) be conducted. In case of high rates, they would make providers aware that the district

was concerned about the high rates from their health facility. District quarterly support supervisions were conducted through which contextual bottlenecks would be identified. The medical superintendents also performed HSD in-charge roles which placed them directly in charge of ensuring that quality MCH services are maintained within their jurisdiction in addition to their health facility in-charge roles. Regular meetings convened by the DHO were organised with participants that included maternal health service providers. These acted as platforms from which network actors engaged and exchanged views regarding implementation aspects. This was the main platform where stakeholders met and dialogued. The quotation below puts this in perspective:

But we always talk during meetings and they will talk about the quick referral here. When we go for the district meetings, we encourage them to refer quickly and monitor mothers well. **PNFP\_Hosp\_002\_MW**

### ***Referral systems***

Network members played varying roles in ensuring the functionality of the referral system. At the individual level, health workers provided their telephone contacts to parturient mothers which they could call in case they wanted quick maternal health advice instead of coming to the health facility to seek the same. These efforts were boosted by an NGO to all facilities providing CEmONIC with a toll-free line from where the mothers would call the health facilities free of charge. Private ambulances were provided by area politicians like Members of Parliament with fuel provided by the users. These supplemented PNFP referral vehicles with toll-free hotlines and networked lower-level health facilities that were encouraged to call in cases where they required pick-ups from their health facilities. Additionally, the public facilities were linked to the national ambulatory system which their officers-in-charge could contact and request transportation from in case they wanted to refer a mother to a tertiary-level facility outside the district for further management of complicated cases.

We would call the in-charge to come and then if the patient requires a referral, he will be the one to provide transport and we refer the patient to the hospital. It's not that we have a facility ambulance but some referrals may be because a mother may present with a previous scar while she was doing ANC and you told her to deliver from where they can do a C-section. We tell them to either go to a hospital or HCIV but sometimes you realise that such cases may again present here when they are in labour and there is no way you chase her away so you counsel and refer her to the hospital again. **(PF\_HCIII\_006\_IC\_Mat)**

A bottleneck in this arrangement was observed where referred mothers would decline and instead opt to go to nearby health facilities and sometimes end up being delivered by TBAs for fear that the referral process would make them incur a lot of costs that they could not afford.

### ***From community to health facilities***

Within the community, with support from partners, the VHT got engaged in the distribution of mama kits to pregnant mothers in efforts to promote facility deliveries.

Cases were also observed where community-level actors within these networks supported improvements in the documentation of shared patients. Specifically, a case was reported of a private midwife offering maternity services having a strict documentation routine that public health facility nurses had to comply with. This is reflected in the quote below:

There is a private midwife and has a maternity home. For her she is strict with her maternity centre... when they are referring to us there is a book and a referral note where they write and you document as you receive this patient and when you receive, they even put your comments. Like you can say I received your patient B but maybe the foetal heart was not there so the midwife takes back that very book and she is also a senior midwife. So she doesn't refer any patient out without that book because she wants us to write in that book the condition under which we received that patient. **(PNFP\_Hosp\_001\_IC\_Mat)**

The networks also consisted of unlikely community-level maternal health service provision actors with whom the health system had to engage, such as TBAs. Health workers embedded in these networks and familiar with this context would fast-track referrals from TBAs and homes because they would have experienced multiple delays along the way to the facility. Although patients continued to be shared with one TBA, engaging her on how to improve timely referral has not been successful, hence the persistence of delays leading to the occurrence of stillbirths, as reflected in the quotation below:

It is hard to engage her because one time we wanted to have a dialogue with her but they told me it's a very hard thing she will not listen and a lot of people have been there so her specifically we have not gone. **(PNFP\_Hosp\_001\_MO)**

### ***With non-state actors***

Non-state actors were reported to be part of the local social network of providers that supported the implementation of interventions to address stillbirth. Specifically, these would identify skills gaps among health workers and the health systems in general, from which they would intervene by providing the necessary support to address those bottlenecks. On the one hand, some supported addressing demand-side barriers. This is reflected in a remark by one respondent: "And we have a partner that is helped us a lot and is from the US. We have now designed an intervention of giving out incentives to the mothers when they come for the first ANC" **(PNFP\_Hosp\_001\_MO)**. Others, however, were involved in supply-side bottlenecks such as health worker training, management strengthening through support supervision and infrastructural support, among others.

### **Discussion**

This study set out to explore the influence of health workers' social networks on the adoption of strategies to address stillbirth risk at the subnational level. We found evidence that health workers implementing maternal and child health policies at the subnational level worked within a social system that constituted an interwoven network. As such, through their interactions, professional and friendship relations emerged

among peers. These to a great extent influenced how they translated policies to address the stillbirth burden. Workplace networks had the greatest influence, which is perhaps reflective of the importance of the implementation context in influencing outcomes. From the different tiers of service delivery, the influence was more of a linkage to other services not available at the point of care, which may be reflective of limited resource contexts. Among the private providers, the influence was in the form of caution and advice to stick to strict policy implementation expectations, which may be reflective of the levels of trust in the ability of these actors to comply with policy prescriptions. Several studies in this area have established that these relationships exert varying amounts of influence on health workers' practices and the eventual translation of policies into service delivery (6, 13, 14).

### **Workplace social networks**

Health workers spend more time with workplace-related social network members compared to any other networks. Our study revealed that members from the health workers' places of work were the most dominant in influencing their practices, which were done through both formal and informal mechanisms, which included coaching which embraced "learning by doing", expert consultations from senior colleagues, occasional reminders about guidelines enforcement and peer learning through organised sessions. Other mechanisms of influence involved the implementation of quality assurance measures, skills-building to address identified gaps, support supervision, and the different interfaces through which staff obtain feedback. Our results compare well with findings from elsewhere which established that contagion, the underlying social influence through personal interactions, affected the adoption of new practices the more (10, 11, 20). Within the workplace setting, networks will inevitably emerge and these take on a professional outlook. It has long been established that professional social networks built on professional consultation about patient care-related issues tend to influence practice in the direction of the mentor's behaviours (13, 21, 22). Direct persuasion as a form of social influence that is transmitted through direct communication among peers towards similar practices through cohesion (5) will tend to emerge in such settings. It is, therefore, key that while planning for the adoption of new practices regarding maternal health services, the influence of workplace setting is not overlooked.

### **Lower-level to high-level service provision**

The implementation context with performance expectations tends to influence the way actors behave. From this study, it emerged that in a health systems hierarchical setting at the subnational level, expectations from secondary-level health facility workers tended to influence the way network members from primary-level facilities supported interventions to address stillbirth risks. This was done through identification and recommendations for appropriate service providers, initiation of advance contact before effecting referrals, re-assessment of referred patients, and provision of referral notes to identify inherent skills gaps. Networks emerging through a requirement for referral have



been reported elsewhere (23, 24). As reported elsewhere (11), this is expected since individuals are driven by the normative desire to conform to socially similar peers through adaptation of behaviours to meet the peer expectations. In particular, the ego will adopt practices similar to those of peers (alters). It is triggered by self-reflection and evaluation of an individual's standing in connection with the subjective norm within a social context (1, 25).

### **Private and public health provider's relationships**

Our study also found that peer comparison between the private and public health service providers influences health workers' adoption of strategies to address stillbirth. The expectation that private providers should try to emulate the implementation practices of public health facilities elicited influence mechanisms which included caution about service provision capacity according to the level of operation, advice and mentorship in the appropriate use of drugs to prevent misuse of oxytocin during labour, support to data capture, adoption of proven evidence-based practices like the use of a partograph for labour monitoring, as well as looping lower-level private maternity service providers into the subnational referral system. Peer comparison is reported to trigger judgement based on structural equivalence as reference points to emulate those they regard as their peers even when they do not often interact directly (11, 26). Within the study setting, this led to efforts to ensure equal expectations from private providers as they implemented interventions to address stillbirth risks. The overall effects of peer comparisons are reported to be determined by how the socially equivalent individuals relate to one another. From our study setting, although the private and public health facilities operate on different business models, they view themselves as providing complementary health services when it comes to interventions to address the stillbirth burden and maternal health in general. It is, therefore, key that once such interventions are rolled out, equal attention and support are given to both the public and private maternal health service providers.

### **From health facility to interlinkages among district health managers.**

The relationships among health workers and district health managers were also found to influence the way they adopted strategies to address stillbirth risks at the subnational level. This is expected as policy translation guidance is transmitted through district health managers to the respective health facilities. However, beyond this, some mechanisms can provide an explanatory context to the observed behaviours. Within the subnational health system setting, many of the actors establish relationships with one another in a socially networked arrangement. Network members often fall back on these whenever specific tasks ought to be accomplished. From our results, it emerged that the mechanism to influence implementation included engagement with particular staff to change practice behaviours, reminders to implement specific policy aspects, such as the conduct of perinatal death reviews (PDR), expression of displeasure with high numbers of stillbirth, which triggered action, as well as working collaboratively to address identified implementation bottlenecks. Similar findings were reported elsewhere,



reflecting physicians' adoption of new practices being influenced by how their network members had adopted the same (6, 27). Where such guidance is from a shared source, practices are likely to reflect recommendations from the originator of the same (5), underscoring the influence of the social system on individual health worker practices. This finding also emphasises the important role of the structure of the social networks in influencing the individual health workers' adoption of practices (7, 28). Similarly, results have been reported about the influence of common contacts (1) and mutual friends (13, 29) on other network members who, in the long run, may develop similar or comparable practices (14, 30).

### **Limitations**

Our study has some limitations. First, the study design was cross-sectional, and such studies have a limitation of predominantly considering views on incidents that may have occurred around the time of data collection and hence missing out on the range of experiences that may have happened sometime before the study was conducted. Second, the purposive sampling may have left out the perspectives of other key actors and, therefore, the results reported here may have represented a one-sided story, especially from health workers directly involved in the implementation of MCH. Third, the study relied on information provided by the respondents, and in a context where relational exchanges among network members during the implementation of maternal and child health programmes are not documented, views may be subject to recall bias. A key strength of this study is that the analysis and discussion draw on the perspectives of multiple respondents at different levels of subnational health systems, which enabled triangulation from more than one source, which ensured reliability of the information collected

### **Conclusions**

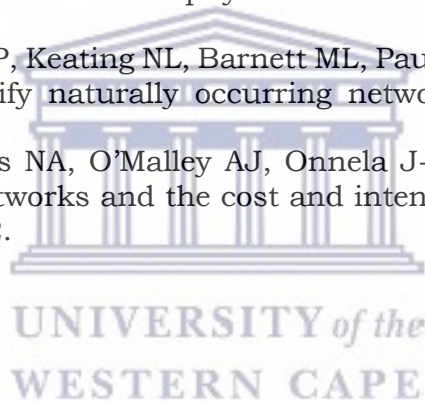
Social network relationships among peers within a local health system supported the implementation of interventions to address the stillbirth burden through different mechanisms. This reflects the potential of social influence over the direction and success of policy implementation at the subnational level. Opportunities to strengthen these exposures through communication exist, hence providing insights into underlying factors for policy adoption which ought to be harnessed for optimal policy outcomes.

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## CHAPTER EIGHT

### **An exploration of health workers' experiences providing care to stillbirth grieving mothers: Results from a qualitative study conducted in Mukono district of Uganda<sup>8</sup>.**

#### **Abstract**

**Background:** Stillbirth is a profound emotion-laden event to the health workers providing care due to its sudden and unexpected occurrence, particularly fresh stillbirths. Health workers providing maternal health services, especially in regions shouldering the highest burden, experience the provision of care to a stillbirth mother in their professional life. However, their experiences seldom get documented as much of the focus is on the mothers. This study aimed to explore the health workers' experiences in the provision of care to mothers following a stillbirth.

**Methods:** A cross-sectional qualitative exploratory study was undertaken on a purposively selected sample of key informants drawn from among frontline health workers and health systems managers directly involved in the provision of maternal health services in a peri-urban district in Uganda. Analysis was guided by a Swanson framework a priori deductively focusing on the five care processes.

**Results:** Disclosure to mothers about the stillbirth loss often took the form of forewarnings, direct and sometimes delayed disclosure. A feeling of unpreparedness to break the news to the mother was common while the whole experience had an emotional effect on the health workers, too, as they tried to establish the cause, particularly in cases without known risk factors. The emotional breakdown was often a reflexive response from the mothers which equally affected the care providers. Health workers engaged in comforting and rebuilding the mothers to transition through the loss. Efforts to identify the skills and health systems gaps to address were a common response targeted at improving the quality of maternal health services to avert similar occurrences in the future.

**Conclusion:** Managing mothers after stillbirth is an emotional and challenging experience for health workers and requires different approaches to disclosure

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<sup>8</sup> A slightly modified version of this manuscript has been submitted to the journal BMC Public Health

and provision of emotional support. Reflection of unpreparedness to handle the tasks shows a lack of required skills, calling for targeted focus to improve health workers' competencies to manage grieving mothers.

**Keywords:** stillbirth, maternal health, bereavement care, health workers

## **Background**

Stillbirth is a profound event for parents but also a crisis for health workers (1). It triggers both grief and emotional turmoil. However, much of the literature speaks to the lived experiences of the mother. To date, there is a dearth of evidence about its effects on health workers who provide care. The provision of support to mothers after a stillbirth is often an emotion-laden experience for health workers (2, 3). The sudden and unexpected occurrence makes it a very traumatic event. Its effects on health workers providing care may include anxiety, emotional distress and mental breakdown (3). It may also create doubt about the efficacy of applied interventions, confidence in health workers' competencies, the accuracy of information responding to risk factors as well as a disrupted provider-patient attachment (4, 5). Besides, caring for grieving mothers can also instil fear, especially where blame is apportioned to the very health worker who provided care. The anxiety and emotional involvement may arise owing to perceptions that at some time in their lives, health workers or their loved ones could experience the same (6).

The health workforce is a crucial currency in exchange for the delivery of quality maternal health care. Most health workers involved in the provision of maternal health services experience the provision of care to a stillbirth mother in their lifetime (7). Those in regions with a high burden of perinatal mortality may, over the years, gain practical experience in providing care to grieving mothers. However, documentation of such experiences has been suboptimal, presenting challenges to the adoption of evidence-based practice. WHO has developed guidelines for the provision of quality maternal health services during pregnancy, around the time of delivery, and postnatal care, including those addressing the mother's emotional wellbeing (8-10). The Reproductive Maternal Newborn and Child Health (RMNCH) quality-of-care guidelines, patient-centred care guidelines, and respectful maternal and child health services are some of them. In the same way, guidelines for the improvement of human resources for health, wellbeing does exist (11, 12). This is in recognition of the fact that health workers who spend a great deal of time caring for mothers may not make adequate efforts to respond to the challenges posed to their emotional wellbeing by the stressful nature of the services they provide.



Interventions to support health workers include welfare schemes to address work-related burnout, psychosocial support as well as health and emotional wellbeing (13, 14). Implementation has been in varying contexts in anticipation of improved health worker productivity (15). However, despite the existence of such interventions, little is known about similar efforts to equip health workers for improved service delivery to mothers after stillbirth. Studies investigating this phenomenon have come predominantly from developed-country contexts and have covered perinatal loss in general and not stillbirth in particular (16, 17). Nonetheless, these studies provide useful insights that reflect health workers' expression of unpreparedness to provide support to grieving mothers after stillbirth (4). A lack of adequate knowledge, mentored experience, communication skills and personal support affected the confidence with which they offered care (18). As a result, some were reported to have considered quitting the profession while others experienced long recovery processes (7).

In the absence of locally documented evidence and a structured support system, health workers' coping strategies are likely to vary by context (18). Whether current practices meet health worker needs to provide adequate care to mothers experiencing a stillbirth remains unclear (7). Learning from their experiences about support to mothers could provide useful insights. This study aimed to explore the health workers' experiences in the provision of care to mothers following a stillbirth.

## **Methods**

### ***Study design***

Details regarding the study methodology have been published elsewhere (19) but, briefly, the study adopted a cross-sectional qualitative design. This manuscript explores the health workers' experiences with the provision of maternal health care to mothers that experienced a stillbirth.

### ***Study setting***

The study was conducted in Mukono district, located in the central region of Uganda. It borders Kampala, the nation's capital city and also main commercial city. The district has both peri-urban and rural characteristics. In terms of health systems, the district is covered by a total of one hospital, three HCIVs, 15 HCIIIs, and 32 HCIIIs. There is strong private sector involvement in health service provision, with both private-for-profit (PFP) and private-not-for-profit (PNFP) providers being present. The private sector is predominantly found in peri-urban areas, with activities mainly located along the great East African Highway that cuts through the district. Under the Public-Private Partnership Policy for Health

(PPPPH) arrangements, the PNFP is supported with primary health care (PHC) funds to deliver services such as MCH, HIV services and immunisation, among others, on behalf of the government. Under this policy, PHC non-conditional grants can be used to cover employee costs, administrative expenses, operation and maintenance, outreach, monitoring supervision and reporting, among others. This is in exchange for supervision, monitoring and sharing of service utilisation data with the Ministry of Health (MoH).

Maternal health services are offered at all levels of clinical service provision, from HCII (outpatient maternal health care) up to hospital level, with referrals recommended outside the district for complicated cases requiring advanced maternal care at regional and national referral hospitals. The VHT structure offers promotive and preventive maternal health services at the community level largely through mobilisation. Within the district, as elsewhere, stewardship of maternal health services is directly under the Assistant District Health Officer (A-DHO) in charge of MCH, a position designated for a senior nurse/midwife. By the time of data collection, the district stood at 90% as per the recommended public service staffing norms (406/449). Recruitment of the health workforce is carried out in line with both national and delegated tasks at the subnational level, where the District Health Service Commission represents the Health Service Commission (HSC) at the national level. The recommended staffing norms in the private sector should ideally follow the public sector structures guided by the level of service provision, although this is not always the case. The private sector largely operates independently with respect to operational issues concerning human resources. Each private facility follows separate managerial and supervision arrangements.

Oversight of the health workforce performance at the district level is both a political and technical affair. Within political prioritisation, maternal health is a sensitive issue and hence tends to attract a lot of political interest, which extends into the supervision arrangements for health workforce activities. These arrangements are complex, with multiple layers and key actors. They include the President's Office, with powers at the district delegated through the office of the Resident District Commissioner (RDC) for monitoring government programmes. Others include the State House Health Monitoring Unit, the political party in government with its manifesto implementation arrangements. Politically elected district representatives also provide oversight of health workforce performance and they include the LC5 Chairperson, the Secretary for Health, and the Social Services Committee. Technically, oversight is multi-layered with a series of interwoven supervision relationships. It involves multiple stakeholders,

including the Ministry of Health (MoH), with delegated powers at the district level through the District Health Officer (DHO) and the District Health Management Team (DHMT), the Ministry of Public Service, for health worker employment arrangements with delegated powers at the district through the Chief Administrative Officer (CAO), and the HSC, which is responsible for identifying health worker requirements and making recommendations for recruitment and deployment. Other delegated tasks from the national level include semi-autonomous bodies such as the professional associations responsible for the professional and ethical conduct of health workers. The health facility heads are directly responsible for the daily performance of the health workforce and they follow guidance from MoH, which provides the overall policy direction. It is within this context that health workers provided care to mothers after stillbirth and where the study was conducted.

### ***Study population***

The study population comprised the health workforce involved in the management and delivery of maternal health services within the subnational health systems. Given the pluralistic nature of the health system at this level, the study purposed to have a blend of representation from both the public and the private sectors represented by the private-not-for-profit maternal health service providers. These included frontline health workers, health facility managers, sub-district health managers, and the District Health Management Team (DHMT).

### ***Sample and sampling procedure***

The study purposively interviewed 16 respondents drawn from medical officers (n=5), nurses (n=2) and midwives (n=9). These were obtained from all levels where maternal health service provision was available within the districts, including the District Health Management Team (n=3), at hospital level (n=6), and at Health Centre IV (n=5) and Health Centre III levels (n=2). As observed above, considerations for recruitment into the study were designed to involve diversity in terms of health cadres and levels of service provision. Priority was given to those health workers that were directly involved in the delivery of maternal health services.

### ***Data collection process***

Data collection was conducted between January and March 2019 by the first author together with graduate-level research assistants. Guidance regarding the potential respondents for the study was obtained from the district health

authorities where a list of health facilities with contacts of key respondents was obtained. All potential respondents were approached at their workplaces. A list of health workers attached to the maternity unit was obtained from each of the health facilities. Potential respondents were approached after the introduction of the study at the facility level with the relevant clearance from the administration. Each key informant was approached for potential participation, and for those who accepted to participate, a consent process was administered before commencement of the interview in a quiet, safe and secure location. Face-to-face interviews with managers and frontline health workers directly involved in clinical and managerial decision-making were conducted at their places of work.

Overall, none of the contacted potential respondents declined to participate. Broadly, the interview guide was developed for this study and informed by the literature, as has been reported elsewhere (19). It contained eight questions that explored the health worker's experiences, and the role of both facility management and individual health workers in ensuring that stillbirth risk factors were responded to appropriately. It further explored the influence of the workplace context and mothers' characteristics in translating guidelines at the frontline. All interviews lasted between 45 minutes and one hour and were audio-recorded with a digital recorder and, at the end of each field day, field notes were expanded and recorded data downloaded onto the computer with a copy saved on the external hard drive

### ***Data analysis***

Data analysis followed thematic content analysis. All audio interviews were transcribed into Microsoft Office Word by the first author and one graduate-level research assistant that had participated in data collection. Thereafter they were entered into Atlas.ti, a qualitative data management software (20). A codebook was developed by the study team following the five themes from Swanson's middle-range theory of care as an a priori framework for analysis (21, 22). The theory stipulates that there are five caring processes and they include: 1) knowing; 2) being with; 3) doing for; 4) enabling; and 5) maintaining belief. This framework was adopted for its ability to cover the diverse experiences related to care for mothers that had experienced a stillbirth. After thorough reading through each of the transcripts, textual data analysis relating to each of the themes in the codebook was highlighted, dragged and dropped into each of the codes. Thereafter query reports were produced for each of the codes, followed by a manual pile sorting process that grouped related texts into piles with similar or related meanings. Each of these texts was once again read through to identify underlying meaning, which resulted in grouping them into sub-themes.

Summarised mini-statement were then used to represent each of the sub-themes. These have been used in the presentation of results, as reflected in the results section to bring out the respondents' voices.

## **Results**

The main results reflect health workers' experience for all the five care processes as described in the Swanson framework. In the first process of knowing, health workers endeavoured to absorb the results from their support to the mother and at the same time communicate the outcome of the pregnancy to the mother. Provision of emotional support was observed in the health worker's response immediately after the mother had been informed of their stillborn babies as the second process. The third phase saw health workers comforting the mother while paying attention to their special needs. This was followed by facilitating the mothers to transition through the loss in the enabling stage. Lastly, our results show that health workers would go on to reassure the mothers that much as the event had happened, they still had hope and faith that they had the potential to conceive again and have a normal baby. The details are presented under each of the specific themes as per the applied framework below:

### **Knowing**

#### ***Helping mothers understand***

While attempting to understand and make meaning of the event, health workers tailored interventions around the mother. Focusing on the mother involved targeting the messages around the cause known to the mother and the appropriate time to disclose to the mother the outcome of the pregnancy. The results revealed that disclosing to the mother took different dimensions, including forewarnings to the mother about the presence of potential risks before the actual stillbirth event. Use of herbal concoctions to induce labour and relieve the pain was specifically mentioned as a common practice that often resulted in abnormal contractions. Once identified, health workers made an effort to caution parturient mothers about the potential risk, including stillbirth.

For those mothers who get fresh stillbirths in most cases, you would have talked to them earlier. Sometimes the mother is uncooperative while pushing or in other instances, you would have caught her already taking some herbal medication, and I warn them that you might lose your baby because of these herbs I have found you taking.  
**(PF\_HCIII\_006\_IC\_Mat)**

The main task revolved around letting the mother know about the outcome of the pregnancy which had resulted in a stillbirth. After confirmation of the stillbirth, a common theme identified while disclosing to the mother centred on



the cause. Under such circumstances, health workers were observed to take on a “tell-it-all” approach when the perceived cause rested less on the health worker. The information delivered would be based on the cause of death, as was revealed in one of the interviews:

I base on the cause of the stillbirth and if it was the baby being distressed some mothers come here when they have used local herbs and when you examine them you find the local herbs so you show them to the mother. Others come here when they have failed from somewhere else and they come when they even have the medical notes. And they come here with cannulas and mother narrates that I was put on a drip. **(PF\_HCIV\_004\_IC\_Mat)**

A feeling of being caught off guard and unprepared for the outcome and to deliver the bad news ran through most of the responses. In some instances, the handling health workers would make the disclosure themselves or call a colleague to handle the disclosure. In one of the interviews, a respondent hinted at a process of passing over the disclosure midway through the process to the other health workers to manage

After doing that you have to counsel this mother or you call the doctor or you go and see the doctor and explain to him that this mother has this and that and I have done this and that. So, you need to take it on from there so when the doctor takes over, he has to do his part by managing this mother. **(PF\_HCIV\_004\_MW)**

This was characterised by delayed disclosure by the health workers. When they felt prepared to confront the emotional burden of disclosing, they would go ahead and pass on the message.

What we do if she is from theatre and we have tried and failed, from the theatre we will tell her the truth. Especially mothers under spinal anesthesia, you tell her you have lost the baby, so she will cry. If the anaesthetist tells you that don't tell her, we will not do it until she stabilises. **(PNFP\_Hosp\_002\_IC\_Mat)**

The process did not go without challenges. The respondents hinted at instances where the first disclosure had gone successfully but was later followed by emotional breakdown when the grieving mother set eyes on her peers holding babies. It took a toll on some health workers, especially in terms of the emotional burden of having to re-do the preparation of the mother once more for emotional support provision, especially those that stayed longer in denial.

When she is still in the delivery room before seeing her friends, she is OK, but when she sees her friends with babies, that is where the problem starts. Sometimes you leave the delivery room when you have agreed on everything and, in most cases, if it's IUFD you tell them immediately but some say that my baby is still alive and I have been feeling the foetal movements and yet it's a macerated stillbirth. **(PF\_HCIII\_006\_IC\_Mat)**

### ***Engaging the self of both***

Health workers also found difficulty in trying to make meaning of the loss for themselves as well as the mothers they were caring for. Connecting with the mother while delivering news of the stillbirth loss for which they equally had no immediate explanation was particularly challenging.

Somebody comes and throughout antenatal the baby is OK and the expected date passes. The mother comes back with an IUFD and you ask what has caused this and the mother can't explain and she is like you told me to come back when contractions start and I have come back when they have started and the baby is dead. **(PNFP\_Hosp\_001\_MW)**

Results revealed that it was a particularly shocking experience, especially when health workers had similar personal stories so that they could relate with the event.

I realised it from my personal friends, then coming here I also realised that women experienced it from our health facility, so I was wondering what is causing it. But since it only happened last month, we were still investigating what could have been the cause of that. **(PF\_HCIII\_006\_IC\_Mat)**

Similarly, a health worker who was pregnant at the time commented on how this experience affected her own pregnancy experience.

I received a very bad experience because I received four mothers on the same day. They all lost their pregnancies and we were all of the same gestation age (26 weeks). And their babies all died, we had the fresh stillbirth, and the same day we got a macerated stillbirth, so it was bad. **(PNFP\_Hosp\_001\_MW)**

### ***Finding answers to piece the puzzle together***

Health workers reported experiencing struggles within themselves to establish the cause of stillbirth in cases where it was not straightforward or where multiple risks existed. The process involved attempting to rule out any possible assumptions and establishing that such efforts went on well after disclosing to and discharging the mother from the facility. This happened at different service provision levels, starting from the maternity unit, facility level, community and subnational levels. In case the problem was due to delayed referrals, some mothers would refuse to reveal the origin of the delay, which prompted the health workers to seek information from the available sources, including other admitted mothers.

Sometimes these mothers don't tell you the truth of where they started from, for example if they started from the TBA. But after delivery, the other mothers with whom she was with on the ward will be the ones to tell you that the mother who has just gone said that they started from the TBA. **(PF\_HCIV\_003\_MW)**

Health workers consulted among themselves, especially those that were present when the mother was admitted. Such processes would sometimes be conducted outside the formal perinatal review proceedings. In a bid to seek clarity about the delayed referrals, health workers reported going a step further to establish which lower-level facilities were responsible for withholding the mother for so long. In one of the interviews, it was reported that officers-in-charge of facilities would initiate contacts with such private facilities or TBAs to establish the triggers.

Some of the facilities around us, we know them and the staff working there know them, so if they see that a mother had obstructed labour they call at the health facility and we use our airtime and find out what happened. Sometimes the midwife can tell you that that mother was referred at such and such a time and we can compare the time of referral and time of arrival at the facility. If I fail on the phone sometimes we meet and discuss, that you know what you sent us a mother with such and such a condition and the outcome was this. **(PF\_HCIV\_004\_IC\_Mat)**

Questions lingered in them on what they suspected could have been the cause and how to communicate it to the mother, especially for fresh stillbirths with initial normal labour progression. Other efforts to piece together the unknowns included waiting for the formal review meetings to establish the cause of the stillbirth. For managers at the subnational level, reliance on surveillance data where stillbirth is a notifiable condition was one way to establish the prevalence and up-to-the-hour performance of health facilities.

### **Being with**

#### ***Emotional presence***

The emotional breakdown as a human and common reflex to news of the loss of a loved one was evident. Ensuring emotional presence was a bigger part of the care provided to women who experienced a stillbirth. After disclosure to the mother, health workers ensured that they were emotionally available to the mother during the difficult time. This involved emotionally relating with the mother to support her to overcome emotions. The care involved sharing mutual emotions of loss with the mother and the health facility in general. Other strategies included remaining available to the mother after discharge, which was reflected in the provision of maternal health advice and messages of assurance of continued working together during the subsequent conception.

We don't have enough space and when you get a mother like this we take that mother to labour ward and we counsel her from there because we don't have space since the one we have here is a bit small. After counselling her and we see that she has accepted it so we start working on her telling her that it is not the end of life and we are trying to save her life now. **PF\_HCIV\_004\_MW**

For quality service delivery in this regard, the respondents expressed a lack of adequate skills to provide the much-needed emotional support at this particular point.

There is a gap when it comes to counselling of these mothers because these days the common counselling is HIV counselling. So when it comes to the counselling of these mothers it is difficult in two ways on the side of the health workers and even the mother. You know after such an experience it is very difficult to sit down with this mother and, in most cases, she might even be blaming you for the death of her child, and yet you are the same person who is counselling her and then telling her to come back is not easy because she might have been attending antenatal from your facility. **(DHMT\_007\_Nur\_02)**

The impact of the loss is what made it a difficult experience for both the health workers and the hospital in general. The respondents observed that the whole experience exacted a toll on the health workers providing such care.

It is a hurting moment for the hospital and actually, as trained medical personnel we would wish to see mothers go back with their babies so it's a bad experience for the hospital. Because as you can see we have big numbers like in six months we have got thirty cases. It is not good for us and as medical personnel, it is not good to see a mother who has carried the pregnancy for nine months go without a baby so it remains not so impressive. **(PNFP\_Hosp\_002\_MW)**

### ***Understanding the loss and attached meaning to the mother***

Health workers provided support to mothers, which reflected empathy. This involved providing support to mothers who expressed reflexive anger due to the inability of the health facility to save their babies. Some of the cases under this category often reported late and despite the availability of interventions to save the baby, it ended up being stillborn owing to the time factor. Such experiences often invoked feelings of self-doubt arising from the health workers' acknowledgment of the health facility's potential to save the pregnancy. Meaningful emotional support included the provision of assurance that once the risk factors are averted, there was a possibility for a mother to manage well subsequent pregnancies.

We normally do counsel any other who has lost a baby and we stress important areas that you should observe during their next pregnancy as a way of trying to curb a re-occurrence of this event. **(PF\_HCIV\_004\_MO)**

The sight of other women holding babies would elicit rage and anger among some mothers who had a stillbirth. In some instances, they would express the desire to leave the facility and go home. This meant adjusting the counselling session to suit the minimum available time given by the mother. The rush to provide emotional support compromised the quality of care, as was reflected in one of the interviews:

Yes, and since we have a high number of women, when one sees that hers didn't survive and the others are having their babies, she becomes desperate and by the time you think of sitting and completing this form, she will just tell you that musawo I will come back to complete this form; they want to take the dead body and we are going very far. (PF\_HCIII\_006\_IC\_Mat)

## **Doing for**

### ***Comforting***

Health workers reported delicate relationships while engaging with the mother in the provision of support. Anxiety was among the stressors they had to deal with while providing meaningful care to the mother. It emerged that identifying a private and quiet space in which to counsel the mother was a recommended practice in settings where such a resource was available on-site. It was aimed at supporting the mother to go through the process with minimal emotional breakdown. Since this was not an ordinary counselling session, the respondents indicated that they paid extra care while providing counselling.

When counselling this mother, you have to handle her very carefully because she has lost a child and she can change there and then and at last she will end up crying, so you have to counsel this mother. (PF\_HCIV\_004\_MW)

### ***Protective of the other's needs***

In navigating ways to support the mother, health workers also took care of their medical needs. A case was cited where mothers who delivered through C-section and ended up with a stillbirth would be retained at the health facility until they had fully recovered both emotionally and medically. The opportunity provided health workers with ample time to manage these mothers.

Of course, if it was a C-section they will keep around for the healing to take place then we usually try to put them in an isolation side which doesn't have mothers with babies because sometimes they go into a bit of depression here and there when they hear the babies cry. (PNFP\_Hosp\_002\_MO)

Paying attention to cultural sensitivity surrounding the mourning of such a loss was also reported. It came out that in some cultures stillborns are buried immediately and that mothers would not have much time to spend at the facility and, therefore, they would rush the health workers through any possible intervention to be in time for the burial. Staying relevant meant paying attention to and respecting such requests. This was revealed in one of the interviews:

These women who lose their babies sometimes don't want to reveal much of their information. They are in most cases desperate after knowing that the baby has died. So when you divert them to completing the forms they will be rushing you that we want to



take our baby since it didn't cry the people supposed to bury it are old and they want to go. (PF\_HCIII\_006\_IC\_Mat)

Instances of supporting the mother to continue with care after discharge to help address their health concerns were also observed. These involved scheduling follow-up visits to ensure close monitoring of such mothers. Where the need for advanced skills in handling the mothers was identified, a more senior health worker would be called in to provide such support.

There is a follow-up if you have had your delivery from here and had a stillbirth. After sometime the administrators call you back to find out how you are doing. We give them strong antibiotics first of all to see that they have recovered and they give them a review date to come back and see how they are managing their lives because to some of those people are not managed well they can go into psychosis. So this follow-up is to see how they are managing, what happened and what is the way forward that we can help them to have another live baby. (PNFP\_Hosp\_001\_MW)

## **Enabling**

### ***Supporting mothers to transition through the loss***

Health workers reported facilitating a process for the mothers' transition from the loss to a meaningful life after. The common theme cutting across transitional empowerment was discussions about subsequent conception and requirements to manage it in a healthy way. For mothers who were initially in denial, the first step involved supporting them to accept and negotiate around the loss. It emerged that while initiating talk on how to keep the next pregnancy healthy, health workers would also discuss the need for the mother to first take time off before the next conception:

I usually tell them to at least take some amount of time before conception again and if they do get pregnant again things may actually be worse than this and they may not be lucky again. We always tell them to take at least two to three years before they conceive again. (PNFP\_Hosp\_002\_MO)

Reflecting the desire to support women to transition, health workers reported covering emotional needs within the transitional talk. Sometimes the strategy would work and other times it would hit a deadlock. A case was shared during one of the interviews where completion of the required documentation before discharge was affected by the restless nature of some of the mothers following the loss.

Sometimes we fail to sit with them and complete the forms when they see that other women are having their babies, they become uncomfortable and will pretend that they are in a rush and want to leave. And if you insist, you will find when she has moved out and you don't get what you want. (PF\_HCIII\_006\_IC\_Mat)

## ***Capacity to grow***

Transitioning out of the loss did not stop at only the mother but also extended to the health workers that handled such a case. Empowering the health workers who handled the mother to grow out of the loss was one way to support them. The respondents indicated that they were followed up with mentorship from their seniors to gain skills in addressing similar cases in the future. A step-by-step process reviewing the documentation about a particular case would be followed to identify skills gaps and address them.

And if you get an FSB we read through and get to know what happened. If we get an MSB the midwife has to know that she has to check for the BS, check for the other conditions. So every day we learn, so I follow them up. If you had an MSB on your duty, I don't want you to get an MSB on another duty. If it happens then you have a problem, not you but there is a problem. So that is how I do my things. **(PNFP\_Hosp\_002\_IC\_Mat)**

Upon establishing that the cause of stillbirth was external to the health facility, such as the referring facility, efforts would be made to follow up the health workers in such facilities in order to also mentor them and address the skills gap. This would sometimes involve providing detailed explanations on the procedures undertaken on the referred mother. Exchanging phone contacts for further engagement regarding the management of the referred mothers was another intervention, as explained in one of the interviews:

But we have devised a means to try and mentor them. So we wouldn't allow them to go without knowing what has been done and what the outcome is. Sometimes we tell them to put a number on the referral form and we call them and tell them the outcome of the referred patient and what the problem was. Maybe if we did a C-section and got an FSB we tell them we did this and that you should have seen that from the foetal heart which was monitored like this. **(PNFP\_Hosp\_002\_MO)**

Provision of feedback was another way of facilitating health workers to grow. It also emerged that health workers would often make efforts to find out what the findings of the inquiry were. A respondent thus noted:

Whenever we finish the reports we give the feedback to our staff. Every Wednesday we have a meeting so if we finish the report on Monday on Wednesday we have to give them a report. ...Someone can ask what happened then you tell them that we got a referral with the ruptured uterus. So all in all you can understand that it wasn't us but it was external. **(PNFP\_Hosp\_002\_IC\_Mat)**

## ***Maintaining belief***

### ***Sustaining faith to get through the loss***

Health workers displayed support while providing care to mothers after a stillbirth by instilling and sustaining faith in them about their capacity to get over the loss. Different strategies were employed to achieve this and it focused on both the mother and the health workers that supported the mother. Such occasions would be used to pass on technical information to help address similar cases in the future.

Of course, we check ourselves and if it was the health worker who was reluctant, next time we have to change. And if it was the mothers, we give health education talks during antenatal such that these mothers attend antenatal early. **(PF\_HCIV\_004\_MO)**

Experiences of getting ahead of the situation by managing without compromising the quality of health services were observed. Health workers were reported to engage in self-assessment upon the occurrence of a stillbirth to identify the possible causes and work around addressing them to avoid similar cases in the future.

We meet and discuss and see what we can improve. Sometimes you find when the midwives have already corrected and sorted out something and they will tell you that when we sat we realised that things needed to be this way, and we affected the change. So you say find and sometimes it may even be better than what you had proposed we work together. **(PF\_HCIII\_006\_IC\_Mat)**

In some instances, it was reported that such occasions would lead to the unveiling of skills gaps prevalent among health workers that health facility management was least knowledgeable about. This extended to the referring health facilities. Upon recognising these gaps, efforts were made to ensure that they were addressed. In one of the interviews, a respondent noted that lack of knowledge about when to refer coupled with the management behaviour of holding onto mothers caused delays in one of the lower-level health facilities.

It was a skills gap. It's a close-by facility; someone can even walk and get here but the mothers delay there. But it was more of a knowledge gap they wouldn't know when to refer. When to look at the danger signs that the mothers would have. Sometimes the mothers would even just escape and come without the official referral when the other person has refused to refer them. **(PNFP\_Hosp\_002\_MO)**

Although health workers managed to maintain the hope and faith that they would get through the loss, they observed that no amount of preparation would empower them to handle the situation in varying contexts. Fear of having to shoulder the blame for having contributed to the loss of the baby' was one of the underlying factors. In one of the instances, a respondent noted that being blamed by the mothers was common.

Even if you get one stillbirth, no one would like to lose their babies. That is why I said that the other incident of two stillbirths on the same day same shift affected me. When you get a stillbirth as a health worker the mother in most cases will cast the blame on

you where she has been especially having her ANC from here. So even our health workers don't want to get stillbirth, be it macerated or fresh. There is that loss and the mother will lose confidence in our services/facility as the people that handled her. So we also try very much to ensure that we go deep to know what the cause was.  
(PF\_HCIII\_006\_IC\_Mat)

### **Discussion**

This research aimed to understand the experiences of health workers in the provision of support to mothers who had experienced a stillbirth. The research broadly embraced the care extended to mothers as a process that involves different stages, as reflected by the Swanson framework. The research adds to the understanding that caring for mothers after stillbirth is an emotional issue that puts to the test the skills and capabilities of the handling health worker. In addition, the research shows that health workers made efforts to provide care to mothers experiencing a stillbirth while going through all the five processes as proposed by the applied framework by Swanson.

### **Knowing**

Delivering sad news of the pregnancy loss is often a tense period that neither the mother nor the health worker can ever adequately prepare for. It is always approached with anxiety and uncertainty, thereby requiring health workers to have adequate skills to deliver the message in ways that do not instead break or stigmatise the mothers the more. Our results revealed that among the strategies employed to let the mother know about the pregnancy outcome was forewarning, which was occasioned in instances where health workers identified potential risks due to the mother's maternal health behaviours which were detrimental to the pregnancy. We can see this as an applied strategy by the health workers to detach themselves from any negative eventualities that could happen as a result of the mothers' practices, thereby exonerating themselves from the stillbirth outcome in case it happened. It can also be seen as a way of sounding an alarm bell to the mother in order to alert her to the reality and possible dangers that may arise from her practices with the baby. According to our understanding, this was done with the motivation that it should trigger efforts to change the way mothers were managing their pregnancies and labour. It could also have been a signal to the mother that it was not how labour should be approached, a message that they could pass on to their friends in the same situation or, better still, themselves during the subsequent pregnancies. This act in itself can be heartbreaking to the mother but, also, was reflective of the lack of adequate skills to manage the mother at that stage of her pregnancy. It is, therefore, important that health workers are equipped with skills of passing on similar messages to the mother in ways that are not heart-wrenching.

Our results also revealed that health workers would sometimes employ the “tell-it-all” strategy while delivering the message of a stillbirth to the mother. We observed that this was the more preferred approach in instances where the cause of the stillbirth was known and it was not attributed to the health worker. Whereas this strategy can be viewed as a sign and an opportunity for the health worker to come clean before the mother, it could also be interpreted as a result of having assessed the emotional burden of disclosure and upon realising that the disclosure process would not be difficult, the health workers opted for a much easier strategy. We observe that whereas this may lighten the health worker’s burden in going through this process, it has the potential of leaving the mother even more devastated owing to the approach used to deliver the bad news. It is, therefore, important to assess the health worker’s competencies in this aspect, identify gaps, and design interventions to respond to these gaps to improve the post-stillbirth experiences of the mothers.

Managing emotions is an important aspect of the psychosocial support extended to mothers following a stillbirth. Unfortunately, this presumed support is not always available when the mothers most need it. A key finding of this study was the feeling of being caught off guard and unprepared on the part of the health workers to deliver stillbirth loss messages to the mothers. Within the study context, this is understandable because some respondents hinted at a lack of counselling skills, and it was found that those who had a certain amount of the skills had learnt them during their pre-service training. Acknowledging a gap is not a sign of weakness but rather a strength and an expression of willingness to address it. For many of the respondents, a number of years had passed since their pre-service training and they had not received refresher training in that area. The only counselling training they indicated to be available was in HIV counselling. We observe that there is a gap and an inability to “configure” aspects of HIV counselling training into the counselling required for maternal health service provision. It is even surprising to us that PMTCT as a maternal health service programme is anchored within the HIV services and it is laden with counselling aspects, such as the counselling given to the mothers. How, then, is it that such skills cannot be extended to mothers when they experience a stillbirth? We, therefore, recommend that other than designing a whole new programme to equip health workers to provide emotional support to stillbirth grieving mothers, the existing counselling capacities from HIV services should be harnessed to improve care for women experiencing stillbirth. This can be approached by first assessing the training content and then tailoring it to suit maternal health services. Better still, many of the beneficiaries of HIV counselling



training are still employed within the health systems, so they can be harnessed to share these skills with their peers through peer-to-peer learning.

### **Being with**

The findings of our study also revealed that while delivering news of the stillbirth loss, health workers would often feel the mutual emotions of loss. This particular finding is important and relatable to the study context. As it is in many settings, the death of a person is a loss to all those that feel relationally attached to that individual, including health workers. What is least prioritised while planning for health interventions is that sometimes health workers are as seriously affected by the loss as the relatives to the persons that they extend care to. Consequently, there are not many interventions designed to cater to the emotional wellbeing of health workers arising from their experience with the loss of a person that they were caring for. Therefore, while planning for interventions to address stillbirth and improve the mother's wellbeing, it is important to think about the health workers and include them in such interventions. Research should also prioritise investigating the impact of the stillbirth experience on the health workers and the health system as a whole.

Our study also found that there was a lack of adequate counselling skills among health workers providing care to stillbirth grieving mothers. This is also understandable within the study context. Preference for further training is oftentimes extended to those individuals that are seeking further education to specialise in their core areas/disciplines. This has both positive and negative effects as promotions are usually tagged on meeting such criteria. Many health workers would, therefore, shun additional training that may not directly contribute to their growth at the workplace. Where exceptions have been registered, it is among health service managers who may include a requirement for a management training programme to enhance their professional and administrative growth within the workplace. Against that background, further training in soft skills programmes like counselling skills may not be appealing to health workers and yet it is essential in their dispensing of clinical health services. It is, therefore, important to review the core competencies required for the dispensing of comprehensive RMNCH services so that such gaps can be identified and addressed within the training curriculum, especially for continuous professional development (CPD) since something similar is already catered for under the pre-service training curriculum. The WHO and MoH aspirations for respectful maternal health care can only be achieved by doing things differently and equipping health workers with such soft skills is one way to achieve that end.

## **Doing for**

Providing support to mothers after stillbirth includes being sensitive to their feelings but also preparing to handle their expectations for future maternal health needs. Our results revealed that to succeed in this, mothers had to feel the utmost comfort with the service provider. It emerged that provision of maternal health-friendly services, including spaces that ensured comfort to the mothers, balancing the medical needs amidst the provision of comfort, addressing the culturally sensitive aspects related to stillbirth were very important in rebuilding the mother's life after the stillbirth event. Similarly, improving a mother's wellbeing after a stillbirth was as important as improving the quality of skills of the service provider as well as the health systems in which they worked. It emerged that the provision of care was a process that would benefit tremendously through the provision of complementary linked services to the mother. Empowering the mother to access these complementary services was also an important empowerment act for the health system to provide all-round care. Improving the social environment in which the mothers lived as well as the maternal health services ecosystem is key if care following a stillbirth is to be improved. Within the UHC framework, thriving is the ultimate goal of the health system and this can only be realised when the environment surrounding this mother is also improved since some services rest outside the health sector.

## **Maintaining belief**

The period following a stillbirth is characterised by doubts about the mother's ability to give birth to normal babies. It is equally a challenging time for the health workers that managed the mother during the pregnancy which ended in a stillbirth. The results show that health workers held on to hope both for the mother and themselves in terms of anticipating better service delivery in subsequent times. To the mothers, this included passing on messages of assurance that subsequent pregnancies will be fine while to themselves it involved making an assessment to establish the cause of death, especially if it was a facility-based fresh stillbirth. It is from this assessment that skills gaps would be identified, which prompted actions to ensure that they are addressed. We infer from both these experiences that the period following a stillbirth is not only the time for grief but also an opportunity to pass on key information that is helpful to the mother in managing her maternal health. It is also a time for reflection on the part of the health workers and the health system as a whole in terms of which direction to take if maternal health services are to be improved. However, for maximum benefit, skills need to be acquired to deliver such information, otherwise retention of such information will depend on managing

the emotional needs of the mother at the time. It is also possible that an attempt to deliver such information may, instead, worsen the mother's wellbeing if not handled well. Having the requisite skills is very key.

### **Limitations**

This study is not without some limitations. First, the social desirability bias is one limitation associated with interviewer-provided information. Stillbirth is a traumatising event not only to mothers but also to the health workers. Where the experience was awful and partly attributable to the health worker, bits of information and the experiences shared may intentionally omit aspects that are not socially desirable. Second, this was a cross-sectional study and such designs usually encounter recall bias in instances where the time between the event and the interview is long. Sometimes the respondent may be unable to recall the event as it happened and, therefore, may be unable to provide the exact experiences as it happened. Third, a fundamental shortcoming was not including the voices of mothers who received these services. Perhaps their experiences would have helped in triangulating the information provided by the health workers. Had the study included them, perhaps we would have reported on their perspectives. Therefore, all that is reported here stems from the perspectives of the service providers. Lastly, context is an important aspect of health services research. It should be recalled that this study was conducted in a resource-limited setting where some of the factors influencing support provision have a great bearing on resource availability. It is our conviction that the experiences would have played out differently had the health workers been exposed to ample resources to support these mothers. Therefore, caution should be exercised while interpreting these results. Nonetheless, all efforts were made to ensure that these limitations were minimised in such a way that they did not affect the integrity of the results in a substantial manner.

### **Conclusion**

Our findings show that managing mothers after stillbirth is an emotional and challenging experience for health workers. Given the political sensitivity of maternal health, such a loss may instead attract blame and backlash against health workers, which may leave them demoralised and demotivated. On top of working to equip them with adequate skills to manage grieving mothers, it may be ideal that compassion is expressed while providing feedback to health workers on how to improve care in subsequent cases. Also, it is key that once causes are identified, some of which may be attributed to health workers, caution is exercised while providing this feedback and in the long term when working collaboratively to address the identified gaps.

**Policy implications:** The integration of grief training in the medical curricula, setting up guidelines for handling such mothers, and institutional support for health worker welfare following perinatal bereavement handling are critical. It is also important to note that the absence of guidelines and documented experiences limits the application of evidence-based practice and consistent delivery of optimal care to women after stillbirth.

**The implication to practice:** Improving soft skills such as counselling, communication skills of health workers, and meeting their psychological needs after providing support to grieving mothers is important.

**Recommendation for future studies:** An investigation into what happens to health workers who provide care to stillbirth grieving mothers is recommended. Such a study could look into the effects of grief pain associated with supporting stillbirth bereaving parents later due to this emotional pain, the interventions available to support those health workers, as well as the mechanisms for coping with stillbirth loss among health workers, among others.

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## CHAPTER NINE

### Conclusions and Recommendation

#### **Scope of the chapter**

This chapter presents the conclusions from the individual studies, starting with the recall to the main findings from each. It proceeds to highlight the contribution of each of the studies to the existing body of knowledge while highlighting the implications of such findings for practice. The limitations to each of the studies are then presented and are preceded by the identified recommendations for further research on the different topics with a general conclusion at the end. Details of each of the areas presented are discussed in the main papers which were either published or submitted for publication and currently under review in the different scientific journals.

#### **Recommendation for policy and programmes**

##### **Paper One: National-level prioritisation of stillbirth reduction**

#### ***Recall to the study***

The study investigated factors that led to the prioritisation of stillbirth prevention at the national level in Uganda. It employed an exploratory qualitative design that adopted the Shiffman (2007) framework for analysing political prioritisation of health initiatives. By using both key informant interviews and a document review process, each of the nine factors advanced by the framework were explored. Our results show that the norm promotion which was triggered by the global stillbirth campaigns gave rise to a global advocacy group. At the time, the team was working on the Lancet Neonatal Survival Series. It played a key role in leading to the prioritisation of stillbirth prevention in Uganda. The financial and technical resources which were available from the donors at the time facilitated the inclusion of stillbirth prevention in maternal and child health programmes. Locally a cohesive policy community that had already converged around MCH right from the MDG era also played a role in fast-tracking the policy learning and transfers through which stillbirth prevention interventions would be implemented. Other factors, from the domestic advocacy angle, included the emergence of champions/policy entrepreneurs willing to push for the prioritisation of stillbirth reduction. Credible indicators, focusing events and clear policy alternatives were the other factors which favoured domestic advocacy. Lastly, within the national political environment was the political transition which was moving towards universal health coverage and integrated service delivery along the continuum of adolescent reproductive maternal and child healthcare which, at the time, was being championed by the Ministry of Health.

#### ***Contribution to the new knowledge***

The main contribution of this study to the existing body of knowledge is that stillbirth prioritisation at the national level appears to have been triggered by the newborn survival movements that had already taken root in the Millennium Development Goals (MDG) era. A cohesive policy network converging around the maternal and child health cluster was key to vetting evidence from research and technical advice from the global campaigns to ensure that recommendations align well with the health systems capacity to implement. Other strategies pursued by the Ministry of Health, such as health service delivery integration at the final point of care as well as delivering reproductive maternal and child health services along the continuum of care, were key to smoothing the adaptation of recommendations into the health systems. Evidence of path dependence was clear. Efforts to address the stillbirth burden had a great bearing on ongoing initiatives to address maternal and child health service delivery, which received inspiration from global efforts, specifically MDGs 4 and 5. Using this framework, our results show minimal influence of the political transition since most efforts to improve MCH in Uganda had already taken off during the MDG era.

### ***Implications of the study***

Results from this objective provide insights reflecting aspects of the adopted framework that are primary in ensuring the prioritisation of stillbirths in national-level programmes. This, however, is mainly exclusive at the national level where variations are expected to exist when it comes to the subnational level. It is important for policymakers to direct efforts towards establishing which factors favour prioritisation at subnational level. Having received momentous support from the global campaigns, this presents implications for sustainability after the momentum from the global campaigns reduces. Ensuring strategies for sustainability are established and strengthened is key to avoiding relapses when global technical support ends.

### ***Limitations to the study***

This study is not without limitations. First, some of the factors within the proposed framework are contextually not applicable. A case in point is the political transition which, in our case, referred to the decentralisation of health services that had happened earlier. The established structures only worked to anchor the recommended interventions from the global campaign but not because they were intended for that purpose in the first instance. Policy implementation processes were still evolving and, therefore, many observations may have changed in the course of data collection.

### ***Recommendations for further research***

The aspect of the framework used which did not come out clearly was the political transition. Further research is recommended to establish how this factor plays out with the prioritisation of global health campaigns in national-level strategies.

### **Recommendations for subnational-level health systems strengthening Paper Two: Subnational-level translation of policy to address stillbirth**

### ***Recall to the study***

The study examined the subnational implementation of strategies responding to stillbirth risks. Adopting an exploratory approach, it traced frontline health workers' implementation of interventions emanating from the global stillbirth campaign recommendations for national governments. We conducted cross-sectional qualitative research where a purposively selected sample of 16 key informants involved in the management and implementation of service delivery in one of the districts perceived to have a high stillbirth burden were interviewed. Our results show that interventions to address stillbirth risks responded to the identified gaps within the health systems. Streamlining of the referral system was prioritised by focusing on the referring entity as well as intensifying efforts to increase family planning services at the health facility level. Other efforts included fast-tracking of perinatal death reviews to establish the causes of stillbirths, improving data systems to capture all cases, and offering differentiated care informed by the magnitude of risks due to the limited resources at the exposure of frontline health workers to attend to all mothers.

### ***Contribution to the new knowledge***

At a subnational level, resource availability other than norm promotion was a major factor in determining how the recommendations finally translate into service delivery. This study highlights the importance of aligning recommendations to health systems' capacity to maximise results. In the event that the health systems lack the capacity to deliver the intended results, it is important that efforts are made to address the gaps. Information from this study also sheds light on the importance of the implementation context at the subnational level. The results also revealed that the package did not translate as highlighted from the global campaign but rather devolved into subnational-level maternal and child health standard service delivery packages. Therefore, ensuring that all aspects are implemented is key, as they will be compartmentalised with other packages of services.

### ***Implications of the study***

Since the package implemented depended on resource availability, it is imperative that all aspects of reproductive maternal and child health services are improved as opposed to exclusive pursuit of stillbirth reduction in isolation of the other indicators. Integration as well as implementation of interventions along the continuum of care is, therefore, the way to proceed. This calls for strengthening of the health systems and making resources available to enable them to deliver recommendations as expected.

### ***Limitations to the study***

This study was conducted in a single district where variations may exist in other locations due to differing implementation contexts which, according to our results, may be key to determining the final package delivered. Also, the varying levels of implementing maternal and child health policies across the public, private not-for-profit

and private-for-profit sectors may present different scenarios. However, the private-for-profit was not represented in this study. The inability to collect service users' perspectives with regard to the implementation of strategies was another limitation of this study. Finally, the adoption process was still evolving by the time this research was being conducted. Therefore, the context may have changed along the way, so may have been different from the time data was collected.

### ***Recommendations for further research***

From the findings, it was evident that improving maternal health services still had a higher priority at subnational level compared to addressing the stillbirth burden. Further research is needed on factors that influenced this trend. Proposals for implementation research to establish how similar strategies for maternal mortality norm promotion can be adopted for stillbirth reduction will go a long way in prioritising stillbirth at subnational level.

### **Recommendations for community-level action**

#### **Paper Three: Social network support to women after stillbirth**

##### ***Recall to the study***

This study set out to investigate the role of women's social networks in the provision of social support during pregnancy and after experiencing a stillbirth. It was exploratory in nature, adopting a social network analysis approach on a purposively selected sample of women who had recently experienced a stillbirth. These participants were recruited from the health facilities where they received delivery services through the health workers. Data from 17 mothers was included in the final analysis and the results revealed that there were no major differences in social support received during pregnancy and after experiencing a stillbirth. The most common support received was intangible support, where emotional support was registered, followed by information support. The least form of social support received was material support. Women who were married and alters from naturally occurring networks were reported to offer more support. Support also followed relationship characteristics such as trust, frequency of contact and from alters who were counted on for support. In terms of network structure, the mean degree centrality was highest among networks that reported spousal support, meaning that spouses played a critical role in galvanising support within one's social network.

##### ***Contribution to the new knowledge***

To our knowledge, this is the first study to investigate social support among women experiencing a stillbirth. It brings to the fore ways to design interventions to prevent stillbirths and those tailored towards helping mothers that experienced a stillbirth while considering the role that communities can play. Current interventions are focusing on health systems, with research looking at communities that are majorly tackling stigma and the negative aspects stemming from communities towards women who experienced

a stillbirth. This study demonstrated that communities can play a bigger role in addressing stillbirths, such as through offering support to women by teaching them how to cope after experiencing a stillbirth

### ***Implications of the study***

Results from this study show that intangible support is mainly prevalent within the women's social network. Future interventions may use this information to design community-based strategies to address the stillbirth burden by mapping these networks. By characterising intangible support that is critical to the mothers before and after experiencing a stillbirth, it may help them not only to cope after but also to respond to the risk factors.

### ***Limitations to the study***

Some of the limitations to this study are the likelihood of overreporting or underreporting social support, given the direction it took. Women that received more support and are comfortable, tend to overestimate their ability to cope; while those that perceive themselves as having received less support tend to underreport even the little that was accorded to them. Participants were only recruited from public and private not-for-profit sectors, and these tend to have some peculiar characteristics that may significantly differ from those mothers who receive services from private-for-profit facilities. Lastly, data was collected from a single district which is peri-urban in nature with peculiar challenges to health care services access and utilisation. This may differ from participants recruited from rural districts, so the results may not be generalised outside this context.

### ***Recommendations for further research***

Further research is recommended on how social support evolves over the long term and how it influences women's subsequent maternal health care-seeking behaviours.

### **Recommendations for individual-level action (perception of stillbirth risk)**

#### **Paper Four: Stillbirth risk perception among women**

### ***Recall to the study***

This study investigated the stillbirth risk perceptions among women of reproductive age in Mukono district. It was a cross-sectional study that adopted a quantitative approach at community level where a survey was administered among 431 women. Data was collected on respondents' demographics, stillbirth knowledge with scores obtained from stillbirth risk scenarios which included maternal medical conditions, foetal medical conditions, women social demographics, lifestyle factors and health systems-related risk factors. Overall, the results revealed that women tended to score highly risk factors that were out of their control, such as foetal medical conditions and health systems-related factors. Pregnancy-related medical conditions such as eclampsia were scored highest



while maternal medical conditions and multiple gestations were scored highly among women's demographics. These perceptions varied by age of respondent, marital status, history of pregnancy complications, current use of family planning and intention to have more children.

### ***Contribution to the new knowledge***

To our knowledge, this was the first study to look at women's perceptions of stillbirth risk which is critical in motivating maternal health care-seeking to address stillbirth risks. Information from this study shows that there were varying levels of risk perception depending on the hypothetical scenarios that were used in this study. This calls for a critical review of the current antenatal care package and devising of innovative ways of delivering it to respond to women's anxieties and risk perception so as to secure their cooperation to maximise service uptake.

### ***Implications of the study***

Women tend to score risk factors highly when they are outside their control, implying that they may overlook risk factors which they have a greater role to play in addressing. It is important to emphasise all risk factors, especially those which women have a greater role in identifying and addressing or reporting. Programme implementers can, therefore, use this information to emphasise the role women can play on their own in addressing stillbirth risks when they are attending antenatal care. This calls for tailoring antenatal care packages that empower women to be in control and for the need to report the factors they cannot address to health workers early so that they can be identified and addressed.

### ***Limitations to the study***

The results reported are from hypothetical scenarios, and the women interviewed were drawn from a community sample. This has implications for their responses, where the results would have been different had they been drawn from a health facility setting or during pregnancy. The research was conducted in a single district that is peri-urban and relatively serviced by multiple health service providers. The perceptions would have been different had the sample been drawn from an underserved district.

### ***Recommendations for further research***

Further research is recommended on the same topic but among women drawn from a health facility-based sample; say, those that have come to attend their antenatal visits. Also, a community-based sample would benefit a lot if the sample is drawn from more districts with diverse backgrounds such as socio-economic status and health service coverage, among others.

### **Conclusion**

To address the stillbirth burden in Uganda, translating a strong norm around its prevention coupled with adequate funding for subnational-level implementation will be key since resource availability guides subnational-level intervention prioritisation. Tailoring information support from network peers towards women's maternal health needs promises to be a viable option to augment the available maternal health services. This will call for sensitisation of the mothers to all potential stillbirth risk factors, including those they perceive to be within their control. Finally, such efforts call for adequate resourcing if strategies are to be turned into quality maternal health services.



## CHAPTER TEN

### **AFTERWORD: Addressing stillbirth in Uganda**

#### **Reflections from the study**

This chapter serves as an afterword for this thesis, which is devoted to understanding the processes that saw the movement of global stillbirth campaigns from the international level, through the national policymaking processes, right down to subnational-level implementation experiences. It also covers the views of the community responses and individuals' perceptions of the burden. I reflect on the thesis' nine chapters and draw the conclusion that whereas the global campaigns had a significant effect in nudging national-level strategies towards addressing stillbirths, a lot more needs to be done at subnational-level to maintain the momentum and sustain the progress so far achieved. I draw on this to propose a couple of recommendations that ought to be followed up by current health systems managers and policymakers as well as those to follow in order to move closer towards the targets of addressing stillbirths.

This thesis has attempted to give a detailed account of the processes that led to the prioritisation and institutionalisation of interventions to address the stillbirth burden. It is built on the understanding of the functionality of the local health system. As presented in earlier chapters, attention to stillbirth reduction emerged on the scene as a realisation of its omission in policy and vital statistics, which rendered it invisible and yet crucial. These efforts need to be sustained to avoid a relapse of what has so far been gained. This will call for equipping the health system with the requisite capacities to respond to the burden. The different papers in this thesis explored these contextual factors at different levels of intervention implementation.

At the proposal stage, our plan was to use individual perceptions of stillbirth risks as the entry point to understanding the national response and end with the policy arena surrounding national strategies. However, along the way it became apparent that such a strategy would not comprehensively lead us to the origin of the national response. The study approach was altered to start from the national-level perspective while drawing a link from the global campaigns (1). Following that, we were able to direct our next efforts at the policy translation from national to subnational level and later at the details of policy translation into service delivery (2). Thereafter, the stillbirth interface with social support

from community networks to affected women in terms of social support was investigated (3). We concluded the study with an inquiry into the women's perceptions of stillbirth risks and whether they can trigger the motivation to take up the available maternal health services.

After data collection and midway through the analysis process, we realised that we had more than enough data than what we had anticipated. This pointed to new insights, although they were initially not part of the study, which were worth sharing ("orphaned results"). Within this thesis, they have been presented as additional papers. First, while the data was being analysed, it emerged that there were variations between national- and subnational-level implementation of interventions to address stillbirths. The initial objectives of the study were never to investigate these differences. It became apparent that, although not part of the objectives of the study, sharing these variations with the scientific community was a worthwhile effort, and this culminated in the production of a manuscript that was submitted for publication and is currently under review.

Further, in analysing subnational implementation dynamics, it emerged that the health workers' social networks played a role in how they translated some of these policies through sharing of information and professional advice on how to handle these related cases. This, too, was never part of the initial objectives of the study, although it turned out to be worth sharing. These particular findings were compiled into a manuscript that, too, has been submitted for publication in a scientific journal. Lastly, while narrating their individual experiences during the translation of policies to address the stillbirth burden, health workers would do so while extending care to stillbirth grieving mothers. We subsequently took a decision to compile this into a manuscript that is worth sharing with the scientific community. Because most studies in this area were conducted in developed countries, the inadequate evidence from low-resource settings led us to conduct a further analysis of this phenomenon, which has also been submitted for publication for wider sharing.

Accomplishing a task of this magnitude comes with a sense of gratitude that majorly manifests in two ways; first, that it has been executed as planned and, second, by receiving feedback that the work that was published is being read and communicates a message. In the period following the submission of the draft thesis for examination, I embarked on writing and converting some of the chapters into draft manuscripts for submission to different journals as a dissemination strategy for wider impact. I have been lucky to learn that my work is being read upon publication and communicates a message. The highlight of this was the feedback from a distinguished scholar whose framework I applied

while navigating the national-level prioritisation of stillbirth reduction (4). In his personal communication to me, he concurred with my observation on this framework that some aspects needed to be modified further to account for contexts that were not comprehensively covered in its current form.

As I come to the end of this journey, I particularly reminisce about the concern raised by Prof. Mbonye (RIP) and co-authors with respect to the future of newborn survival interventions in Uganda (5). They observed that tremendous progress had been realised in the areas of newborn survival policy and implementation through the work of the Newborn Steering Committee, a national-level multi-disciplinary advisory committee to the Maternal and Child Health (MCH) cluster of the Ministry of Health (MoH). Although it remained influential at national level, its sustainability and level of influence at both regional and district levels were a critical area of concern and a test as to whether sustainability of gains was to be ensured in the long term. Nine years into our work, we encountered similar observations when it comes to stillbirth reduction interventions at subnational level. Details have been highlighted in two of our papers in this thesis (1,2). We have specifically highlighted that most of the stillbirth reduction efforts are more visible at the national level and get fused into the routine standard of care while being moved to subnational level. Their visibility at this stage needs to be emphasised for actors to appreciate them.

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5. Mbonye AK, Sentongo M, Mukasa GK, Byaruhanga R, Sentumbwe-Mugisa O, Waiswa P, Naamala Sengendo H, Aliganyira P, Nakakeeto M, Lawn JE, Kerber K; Uganda Decade of Change and Future Implications Analysis Group. Newborn survival in Uganda: a decade of change and future implications. *Health Policy Plan*. 2012 Jul;27 Suppl 3: iii104-117. doi: 10.1093/heapol/czs045. PMID: 22692413.



## APPENDICES

### Appendix 1: Ethics clearances and permission letters

#### UWC Ethics Letter



**OFFICE OF THE DIRECTOR: RESEARCH  
RESEARCH AND INNOVATION DIVISION**

Private Bag X17, Bellville 7535  
South Africa  
T: +27 21 959 2988/2948  
F: +27 21 959 3170  
E: [research-ethics@uwc.ac.za](mailto:research-ethics@uwc.ac.za)  
[www.riid.uwc.ac.za](http://www.riid.uwc.ac.za)

13 November 2017

Mr E Ssegujja  
School of Public Health  
Faculty of Community and Health Sciences

**Ethics Reference Number:** BM17/9/1

**Project Title:** Risk perception of stillbirths among women of reproductive age and current policy response in Uganda. A mixed methods case study of Mukono district.

**Approval Period:** 13 November 2017 - 15 November 2018

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

**Please remember to submit a progress report in good time for annual renewal.**

*The permission from the Health Department must be submitted for record keeping purposes.*

The Committee must be informed of any serious adverse event and/or termination of the study.



Ms Patricia Justus  
Research Ethics Committee Officer  
University of the Western Cape

**PROVISIONAL REC NUMBER -130416-050**

FROM HOPE TO ACTION THROUGH KNOWLEDGE

## Makerere University Ethics Letter

**MAKERERE**

P. O. Box 7062,  
Kampala, Uganda  
Cables: MAKUNIKA



**UNIVERSITY**

Tel: 256-41-545040/0712 207926  
Fax: 256-41-530185  
E-mail: maksrec@gmail.com

**COLLEGE OF HUMANITIES AND SOCIAL SCIENCES  
SCHOOL OF SOCIAL SCIENCES  
RESEARCH ETHICS COMMITTEE**

Your Ref:

Our Ref: MAKSS REC 12.17.110

22<sup>nd</sup> March 2018

**Erick Segujja**

Principal Investigator (MAKSS REC 12.17.110)  
Makerere University School of Public Health, HPPM Department  
P.O.Box 7072 Kampala Uganda,  
Tel: 256-0712-95 04 52/ 256-0704-946259/ 256-0778-610088  
E-Mail: [ssega2001@yahoo.com](mailto:ssega2001@yahoo.com)  
Skype: ssega2001

**Initial Review – Full Board**

**Re: Approval of Protocol titled: "Risk Perception of still births among women of reproductive age and current policy response in Uganda. A Mixed methods case study of Mukono District"**

This is to inform you that, the Makerere University School of Social Sciences Research Ethics Committee (MAKSS REC) granted approval to the above referenced study. The MAKSS REC reviewed the proposal using the full board review on 14<sup>th</sup> December 2017. This has been done in line with the investigator's subsequent letter addressing comments and suggestions.

Your study protocol number with MAKSS REC is **MAKSS REC 12.17.110**. Please be sure to reference this number in any correspondence with MAKSS REC. Note that, the initial approval date for your proposal by MAKSS REC was 14<sup>th</sup> December 2017. This is an annual approval and therefore, approval expires on 13<sup>th</sup> December 2018. You should use stamped consent forms and study tools/instruments while executing your field activities at all times. However, continued approval is conditional upon your compliance with the following requirements.

**Continued Review**

In order to continue on this study (including data analysis) beyond the expiration date, Makerere University School of Social Sciences (MAKSS REC) must re-approve the protocol after conducting a substantive meaningful, continuing review. This means that you must submit a continuing report Form as a request for continuing review. To avoid a lapse, you should submit the request six (6) to eight (8) weeks before the lapse date. Please use the forms supplied by our office.



**Please also note the following:**

- No other consent form(s), questionnaires and or advertisement documents should be used. The Consent form(s) must be signed by each subject prior to initiation of my protocol procedures. In addition, each research participant should be given a copy of the signed consent form.

**Amendments**

During the approval period, if you propose any changes to the protocol such as its funding source, recruiting materials or consent documents, you must seek Makerere University School of Social Sciences Research and Ethics Committee (MAKSS REC) for approval before implementing it.

Please summarise the proposed change and the rationale for it in a letter to the Makerere University School of Social Sciences Research and Ethics Committee. In addition, submit three (3) copies of an updated version of your original protocol application- one showing all proposed changes in bold or "track changes" and the other without bold or track changes.

**Reporting**

Among other events which must be reported in writing to the Makerere University School of Social Sciences Research and Ethics Committee include:

- i. Suspension or termination of the protocol by you or the grantor
- ii. Unexpected problems involving risk to participants or others
- iii. Adverse events, including unanticipated or uninterpreted but severe physical harm to participants.

Do not hesitate to contact us if you have any questions. Thank you for your cooperation and commitment to the protection of human subjects in research.

The legal requirement in Uganda is that, all research activities must be registered with the National Council for Science and Technology. The forms for this registration can be obtained from their website [www.nscst.go.ug](http://www.nscst.go.ug)

Please contact the Administrator of Makerere University School of Social Sciences Research and Ethics Committee at [makssrec@gmail.com](mailto:makssrec@gmail.com) OR [bjindim@westerncape.ac.za](mailto:bjindim@westerncape.ac.za) or telephone number +256 712 207926 if you counter any problem.

Yours sincerely,



Dr. Stella Noema  
Chairperson

Makerere University School of Social Sciences Research and Ethics Committee



c.c.: The Executive Secretary, Uganda National Council for Science and Technology



## Uganda National Council for Science and Technology Letter



### Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS 4575

3<sup>rd</sup> August 2018

Mr. Erick Seeguja  
Makerere University School of Public Health  
Kampala

Dear Mr. Seeguja,

**Re: Research Approval: Risk Perceptions of Stillbirths among Women of Reproductive Age and Current Policy Response in Uganda; A Mixed Methods Case Study of Mukono District**

I am pleased to inform you that on ~~19/07/2018~~, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of ~~19/07/2018 to 19/07/2019~~.

Your research registration number with the UNCST is SS 4575. Please, cite this number in all your future correspondences with UNCST in respect of the above research project.

As Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the research protocol or the consent form (where applicable) must be submitted to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval prior to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local IRC for review with copies to the National Drug Authority.
4. Unanticipated problems involving risks to research subjects/participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST review.
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project.

---

#### LOCATION/CORRESPONDENCE

Plot 6 Kibira Road, Ntinda  
P. O. Box 6884  
KAMPALA, UGANDA

#### COMMUNICATION

TEL: (256) 414 705500  
FAX: (256) 414-234579  
EMAIL: info@uncst.go.ug  
WEBSITE: <http://www.uncst.go.ug>





## Uganda National Council for Science and Technology

*(Established by Act of Parliament of the Republic of Uganda)*

Below is a list of documents approved with this application:

	Document Title	Language	Version	Version Date
1.	Research proposal	English	1.0	December 2017
2.	Consent forms	English and Luganda	1.0	December 2017
3.	Document screening and extraction form	English	1.0	December 2017
4.	Confidentiality form for research team members	English	1.0	December 2017
5.	Questionnaires	English and Luganda	1.0	December 2017
6.	KII guides	English	1.0	December 2017

Yours sincerely,

Isaac Makuwa  
For: Executive Secretary  
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY



Copied to: Chair, Makerere University School of Social Sciences, Research Ethics Committee

UNIVERSITY of the  
WESTERN CAPE

---

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FAX: (256) 414-234579  
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WEBSITE: <http://www.uncst.go.ug>

**District administrative clearance**



## Appendix 2: Participant information sheet



### UNIVERSITY OF THE WESTERN CAPE School of Public Health

Private Bag X17 • BELLVILLE • 7535 • South Africa  
Tel: 021- 959 2809, Fax: 021- 959 2872  
E-mail: [ssega2001@yahoo.com](mailto:ssega2001@yahoo.com), [mandipatin@uwc.ac.za](mailto:mandipatin@uwc.ac.za)



#### Participant information sheet

**Title: Stillbirths in Uganda: Women's Perception of Risk, Role of Social Network, Current Policy Response and Frontline Health Workers' Application of Discretion to Translate Policy into Practice**

#### **Background to the study**

Despite the high burden of still birth especially in sub-Saharan Africa posed by the numerous challenges of care seeking along the continuum of care, little remains done to address the high rates. This study is being conducted to understand the mothers' perception of stillbirth risk as well as the role of social networks in addressing the coping mechanism and the current policy response.

#### **Aims of the study**

This study is being carried out as partial fulfillment for the requirements for the award of a PhD in Public Health of the school of Public Health University of Western Cape. The information obtained may be used by program planners and implementers on the best way to devise strategies to address the problem of still birth. This study involves multiple types of data collection covering up to 490 quantitative interviews including individual respondent survey and a social network analysis survey and sixty key informant interviews.

#### **Voluntary participation**

Participation in this study is absolutely voluntary and the choice to take part in the study is entirely yours. You can opt to pull out from the study midway without anything happening to them.

#### **Informed consent**

You are being asked to participate in this study because you are

a mother of reproductive age. It is however your decision whether or not to be in this study. You can stop the survey and refuse to answer any question anytime. And whether you choose not to participate in the study, it will not affect you in any way of the MCH services that you receive from the facility. Your role during this exercise is to provide honest opinions and answers to the questions being asked. In case anything is not clear, feel free to ask for clarification. After you are satisfaction with the explanations, feel free to provide your consent by appending your signature at the end of this form.

### **Benefits**

There is no direct benefit to you for completing the survey.

### **Potential risks from participating in the study**

This is a behavioral study where almost all the interactions will be during data collection process, minimal risks arising from taking part in this study are anticipated. These may involve emotional breakdown and discomfort arising from encroaching on the privacy of respondents. A number of safeguards have been put in place to ensure that the conduct of research is in consonance with the provisions of the Helsinki declaration.

### **Protection of data confidentiality**

We affirm that privacy, anonymity, and confidentiality of data/information identifying you as participant will strictly be maintained. We will not let anyone outside the study see or hear your answers. We will do our best to keep your information safe by not linking your name and personal information with the information you provide us. The data will be stored for future research purpose, but the confidentiality of individual responses will be protected. We will combine all of our results before reporting them in order to protect every respondent's confidentiality. Dissemination of the results will not identify any of the participants in this study.

### **Contact details of the researcher**

Any questions regarding this study can be directed to the researcher, Eric Ssegujja on Email: [ssega2001@yahoo.com](mailto:ssega2001@yahoo.com); Telephone: +265712950452 or the supervisor, Assoc Prof. Michelle Andipatin on email; [mandipatin@uwc.ac.za](mailto:mandipatin@uwc.ac.za) and telephone; 0219592453. Questions related to violation of your rights should be directed in confidence to: The chairperson of the Makerere University School of Social Sciences Research and Ethics Committee; P.O Box 7062, Kampala. Tel: +256 41-545040, or Uganda National Council for Science and Technology, Plot 6, Kimera Road, Ntinda Kimera Rd, Kampala P.O. Box 6884, Kampala, Uganda Phone:

+256 41 4705500.

**What appending your signature on the consent form mean**

Your signature (or thumbprint/mark) on this form means:

- You have been informed about this study's purpose, procedures, possible benefits and risks.
- You have been given the chance to ask questions before you sign.
- You have voluntarily agreed to be in this study.

---

Print name of Participant	Signature of Participant	Date
---------------------------	--------------------------	------

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Name of Person Obtaining consent	Signature	Date
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## Appendix 3: Published papers

### Paper one

Ssegujja and Andipatin *Globalization and Health* (2021) 17:66  
<https://doi.org/10.1186/s12992-021-00724-1>

Globalization and Health

#### RESEARCH

#### Open Access

# Building on momentum from the global campaigns: an exploration of factors that influenced prioritization of stillbirth prevention at the national level in Uganda



Eric Ssegujja<sup>1,2\*</sup>  and Michelle Andipatin<sup>3</sup>

#### Abstract

**Background:** Of the close to 2.6 million stillbirths that happen annually, most are from low-income countries where until recently policies rarely paid special attention to addressing them. The global campaigns that followed called on countries to implement strategies addressing stillbirths and the adoption of recommendations varied according to contexts. This study explored factors that influenced the prioritization of stillbirth reduction in Uganda.

**Methods:** The study employed an exploratory qualitative design adopting Shiffman's framework for political prioritization. Data collection methods included a document review and key informants' interviews with a purposively selected sample of 20 participants from the policy community. Atlas. Ti software was used for data management while thematic analysis was conducted to analyze the findings.

**Findings:** Political prioritization of stillbirth interventions gained momentum following norm promotion from the global campaigns which peaked during the 2011 Lancet stillbirth series. This was followed by funding and technical support of various projects in Uganda. A combination of domestic advocacy factors such as a cohesive policy community converging around the Maternal and Child Health cluster accelerated the process by vetting the evidence and refining recommendations to support the adoption of the policy. The government's health systems strengthening aspirations and integration of interventions to address stillbirths within the overall Maternal and Child Health programming resonated well.

**Conclusions:** The transnational influence played a key role during the initial stages of raising attention to the problem and provision of technical and financial support. The success and subsequent processes, however, relied heavily on domestic advocacy and the national political environment, and the cohesive policy community.


**Keywords:** Stillbirth, Global campaigns, National prioritization, Norm promotion, Policy Community, Maternal and Child Health

## RESEARCH ARTICLE

## Open Access

# Prioritization of interventions in pursuit of maternal health policy objectives to mitigate stillbirth risks. An exploratory qualitative study at subnational level in Uganda



Eric Ssegujja<sup>1,2\*</sup> , Isaac Ddumba<sup>3</sup> and Michelle Andipartin<sup>4</sup>

## Abstract

**Background:** Global calls for renewed efforts to address stillbirth burden highlighted areas for policy and implementation resulting in national level translations. Information regarding adapted strategies to effect policy objectives into service delivery by frontline health workers remains scanty especially at subnational level. The study explored strategies prioritized to mitigate stillbirth risk in the context of operationalizing recommendations from the global campaigns at a subnational level in Uganda.

**Methods:** A cross-sectional qualitative exploratory study was conducted among a purposively selected sample of sixteen key informants involved in delivery of maternal and child health services in Mukono district. Analysis followed thematic content analysis deductively focusing on those policy priorities highlighted in the global stillbirth campaigns and reflected at the national level in the different guidelines. *Results.*

Interventions to address stillbirth followed prioritization of service delivery aspects to respond to identified gaps. Efforts to increase uptake of family planning services for example included offering it at all entry points into care with counseling forming part of the package following stillbirth. Referrals were streamlined by focusing on addressing delays from the referring entity while antenatal care attendance was boosted through provision of incentives to encourage mothers to comply. Other prioritized aspects included perinatal death audits and improvements in data systems while differentiated care focused on aligning resources to support high risk mothers. This was in part influenced by the limited resources and skills which made health workers to adapt routine to fit implementation context.

(Continued on next page)

## RESEARCH

## Open Access



# The role and attributes of social networks in the provision of support to women after stillbirth: experiences from Uganda

Eric Ssegujja<sup>1,2\*</sup>, Yusuf Mulumba<sup>3</sup>, Sally Guttmacher<sup>4</sup> and Michelle Andipatin<sup>5</sup>

## Abstract

**Introduction:** Communities exert stigma on mothers after stillbirth despite their potential to offer social support to the grieving family. Maternal healthcare-seeking behaviors are socially reinforced rendering a social network approach vital in understanding support dynamics which when utilized can improve community response to mothers experiencing stillbirth. However, the form and direction of social support for women when in need is not clear. The study explored the role and attributes of women's social networks in the provision of support to mothers who have experienced a stillbirth in Uganda.

**Methods:** An exploratory cross-sectional study design adopting a social network approach was conducted. Data collection following established procedures was conducted on a convenient sample of 17 mothers who had experienced a stillbirth six months before the study. Frequencies and bivariate analysis were conducted to determine the factors influencing the provision of social support from 293 network members elicited during the alter generation. We then performed a Poisson regression on each of the social support forms and the explanatory variables. Network structure variables were calculated using UCINET version 6 while Netdraw facilitated the visualization of networks.

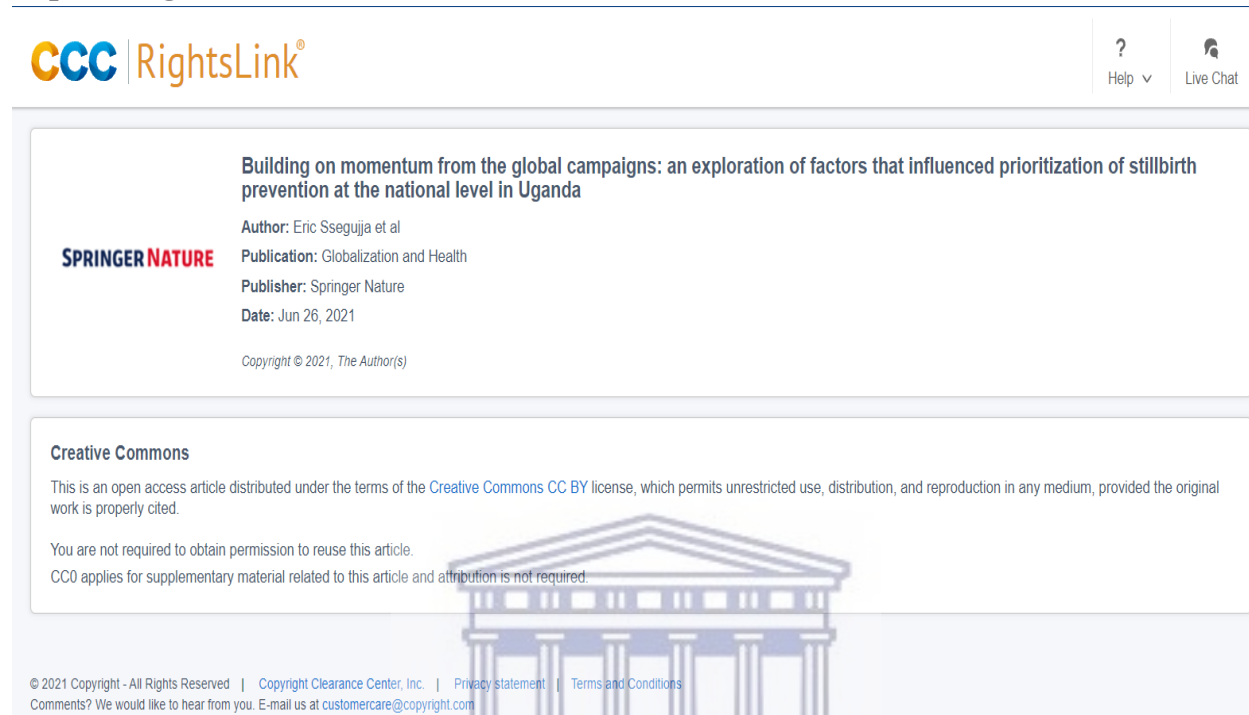
**Results:** Overall, social support was available from all network relations mentioned by the respondents. No major variations were observed between the two time periods during pregnancy and following a stillbirth. The most common support received was in form of intangible support such as emotional and information support, mainly from females who were married and from the naturally occurring networks such as family and friends. We also observed that social support followed patterns of network relational characteristics including trust, frequency of contact and alters counted on for support more likely to provide the same.

**Conclusions:** A great potential for social support exists within women's social networks to help address stillbirth risk factors during pregnancy and cope after experiencing the same. Alter characteristics like being female, married, and from naturally occurring networks together with relational characteristics such as trust, frequency of contact, and count on alter for support were predictors of eventual social support. Interventions aiming at addressing stillbirth risks at the community level ought to harness these network characteristics for benefits to the mothers.

**Keywords:** Stillbirth, Social support, Social network

## Appendix 4: Copyrights and permissions of published papers

### Paper 1 rights:



The screenshot shows the top of a Springer Nature article page. At the top left is the CCC RightsLink logo. At the top right are links for Help and Live Chat. The main content area displays the article title: "Building on momentum from the global campaigns: an exploration of factors that influenced prioritization of stillbirth prevention at the national level in Uganda". Below the title, it lists the author as Eric Sseguija et al, the publication as Globalization and Health, the publisher as Springer Nature, and the date as Jun 26, 2021. A copyright notice states "Copyright © 2021, The Author(s)". Below this is a Creative Commons section stating the article is distributed under a CC BY license, allowing unrestricted use with proper citation. It also notes that CC0 applies for supplementary material. At the bottom of the screenshot, there is a footer with copyright information and links to privacy and terms pages.

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## Paper 2 rights:

### Prioritization of interventions in pursuit of maternal health policy objectives to mitigate stillbirth risks. An exploratory qualitative study at subnational level in Uganda

**SPRINGER NATURE**

**Author:** Eric Ssegujja et al

**Publication:** BMC Health Services Research

**Publisher:** Springer Nature

**Date:** Jan 11, 2021

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## Paper 3 rights:



### The role and attributes of social networks in the provision of support to women after stillbirth: experiences from Uganda

**Author:** Eric Sseguija et al

**Publication:** BMC Women's Health

**Publisher:** Springer Nature

**Date:** Oct 6, 2021

**SPRINGER NATURE**

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