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Rachel A. Leavitt   Date

She Failed, We Failed, They Failed: Using Qualitative Social Autopsy to Understand Why Women Die During Pregnancy in Iganga District, Uganda.

By

Rachel A. Leavitt
MPH

Hubert Department of Global Health

_____
Roger Rochat, MD
Committee Chair

_____
Dawn Comeau, PhD
Committee Member

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By

Rachel A. Leavitt

B.S.
Northern Arizona University
2011

Thesis Committee Chair: Roger Rochat, MD

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Abstract

She Failed, We Failed, They Failed: Using Qualitative Social Autopsy to Understand Why Women Die During Pregnancy in Iganga District, Uganda.

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Maternal mortality is a complex issue that is disproportionately found in developing countries, like Uganda. Previous research in Uganda has mostly focused on barriers to maternal health and maternal cause of death studies conducted in hospital settings. This omits information on important barriers in the community and at lower level health facilities that contribute to maternal deaths, as well as, social and behavioral contributors to deaths. This study aimed to identify the individual and community level factors that contributed to maternal death in Iganga district, Uganda to assist in the expansion of services for a local NGO, SAFE Mothers SAFE Babies. Qualitative social autopsies, using the Three Delays framework, were used to gain insights into the social, behavioral, and health systems contributors to maternal deaths in Iganga district, Uganda. Qualitative in-depth interviews were conducted with twelve family members of recent maternal deaths. Information was collected on the woman's care seeking behavior and the barriers to care during pregnancy and the obstetric emergency that led to her death. The study found that the initial decision to seek care was not a barrier in these cases. Lack of knowledge about danger signs, cost of treatment and transportation, community perceptions of health facilities, the availability of transportation, and women's status emerged as common social and behavioral contributors to death. Health system contributors such as poor provider training, low availability of emergency obstetric care and essential medicines, and a poorly functioning referral system all proved to be insurmountable obstacles for women. Interventions should focus on improving the referral system, achieving quality emergency obstetric care at lower level health facilities, increasing quality of care at all health facilities, expanding access to transportation, and increasing community knowledge of obstetric danger signs. Adjustments to the Three Delays framework to better account for changes in care seeking behavior and the referral system is necessary. Resolving issues of transportation and disorganization of the health care system could reduce maternal death in this setting.

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List of Abbreviations

Acronym	Full Title
ANC	Antenatal Care
CoD	Cause of Death
CPR	Contraceptive Prevalence Rate
DHS	Demographic and Health Survey
EmOC	Emergency Obstetric Care
HCW	Health Care Worker
HRH	Human Resources for Health
HSSP	Health Sector Strategic Plan
ICD-10	International Classification of Disease – 10
INDEPTH	International Network for the Demographic Evaluation of Populations and Their Health
LMIC	Lower and middle income countries
MCH	Maternal and Child Health
MDG	Millennium Development Goals
MMR	Maternal Mortality Ratio
PMM	Prevention of Maternal Mortality Network
PNFP	Private-Not-for-Profit Organizations
PVLC	Private Village Level Clinic
SA	Social Autopsy
SAFE	SAFE Mothers, SAFE Babies Organization
SDG	Sustainable Development Goals
TBA	Traditional Birth Attendant
TCMP	Traditional medicine practitioners
TFR	Total Fertility Rate
UNMHCP	Uganda National Minimum Health Care Package
VA	Verbal Autopsy
WHO	The World Health Organization

Chapter 1
Introduction

<u>Introduction and Rationale</u>

Maternal mortality is an issue of human rights and the right for women to have access to health and equality in society. These rights include the right to health, the right to life, and the right to equality and non-discrimination (Office of the United Nations High Commissioner for Human Rights, 2010). The systematic discrimination against women which leads to maternal mortality is a violation of human rights for women because it prevents women from accessing services, education, and resources. To advance the human rights of women it is imperative then to understand and reduce maternal mortality.

Not only is maternal mortality an issue of human rights for women but it also extends to health, economic, and social ramifications in all aspects of society. Miller and Belizan (2015) state that women are the "center of home, production, reproduction, social relations, socialization of children, guardians of morality, education and health" (Miller & Belizán, 2015). This is seen in increased risks of death of neonates, decreases in educational attainment and decreases in access to health care for children who have a mother who suffered a maternal death (Bazile et al., 2015; Moucheraud et al., 2015). Additional effects of maternal mortality include losses in economic activity, economic crisis in families, emotional costs, and the burden of disease (Miller & Belizán, 2015) (The World Health Organization, 2014a). Maternal mortality has implications that reach to gender inequalities, health system functioning, and economic and social development (Miller & Belizán, 2015).

Despite increased attention on maternal deaths world-wide and the ability to prevent a majority of maternal deaths we have been unable to reach global maternal mortality targets (The World Health Organization, 2015). Since the inception of the Millennium Development Goals (MDG's) in 1990 the global maternal mortality ratio has declined about 44% (The World Health Organization, 2014a). This is great progress but far from the 2015 deadline of reaching a 75% reduction in maternal mortality set out by MDG-5 (The World Health Organization, 2015). The introduction of the Sustainable Development Goals (SDG's) in 2016 has renewed investment by the global community to continue to reduce maternal mortality. The Target of SDG 3, "Good Health and Wellbeing", asserts to "reduce the global maternal mortality ratio to less than 70 deaths per 100,000 live births" by 2030 (The World Health Organization, 2015). This is a huge reduction from the current global maternal mortality ratio (MMR) which is estimated at 216 maternal deaths per 100,000 live births (The World Health Organization, 2014a). The World Health Organization (WHO) estimates that about 66% of all maternal deaths occur in Sub-Saharan Africa which has a MMR of 546 per 100,000 live births (The World Health Organization, 2014a). Making achieving this difficult global goal, even more challenging in this high maternal mortality region.

The ability to prevent a majority of the maternal deaths that occur globally makes the issue of maternal mortality that much more distressing. Challenges of accessing maternal health services are more prevalent among poor and rural women and these are the women most likely to die from complications due to pregnancy (The World Health Organization, 2015). Issues that these women face in receiving health care services include: lack of or inadequate maternal health services, lack of skilled health workers, poverty, distance to health facilities, and cultural

practices (The World Health Organization, 2015). The development of the Three Delays model

by Thaddeus and Maine (1994) attempted to assess the barriers women faced in receiving health

care before maternal deaths (Thaddeus & Maine, 1994). These delays are delay in deciding to

seek care, delay in reaching a medical facility, and delays in receiving appropriate treatment at

health care facilities (Thaddeus & Maine, 1994). This framework has seen widespread

popularity in assessing contributors to maternal death. In order for reductions in maternal

mortality to occur contributors to maternal death must be understood and addressed at all levels.

Uganda is a country located in Sub-Saharan Africa and has high maternal mortality. The

MMR was 325 maternal deaths per 100,000 live births in 2013 with an average annual reduction

of 2.8% (The World Health Organization, 2014a). Uganda was unable to attain the three fourths

reduction target set by MDG-5. Importantly maternal mortality estimates are notoriously difficult

to measure and calculate and are subject to large sampling errors due to the large sample sizes

necessary for accurate detection (Uganda Bureau of Statistics & Macro International, 2011).

Other indicators should be used in addition to the MMR to assess the status of women's health in

a country. In Uganda the total fertility rate (TFR) is 6.2 with rural women having almost twice as

many children as urban women (Uganda Bureau of Statistics & Macro International, 2011).

Contraceptive prevalence rates (CPR) are low in Uganda with 21% of all women aged 15 to 49

using modern methods (Uganda Bureau of Statistics & Macro International, 2011). The WHO

indicators recommend skilled attendance at birth and the provision of four Antenatal care (ANC)

visits beginning before the fourth month of pregnancy (The World Health Organization). In

Uganda 95% of mothers receive at least one ANC visit, while only 48% receive all four

recommended visits (Uganda Bureau of Statistics & Macro International, 2011). Skilled birth

attendance has increased to 58% (Uganda Bureau of Statistics & Macro International, 2011). These indicators do not however measure quality of the care received nor do they attempt to understand behavioral and social factors regarding maternal health and death. Although indicators for maternal health are improving in Uganda there are still gaps that need to be filled to ensure women have equitable access to quality women's health provisions and to better understand maternal mortality in the country

The Problem

Despite some decreases in maternal mortality in Uganda, high rates of preventable maternal deaths are still occurring. Women are facing many barriers in accessing appropriate, quality maternal health services that could save their lives. Previous research has been associated with understanding the causes of maternal death and maternal health service utilization among women who are recently pregnant. In order for appropriate interventions to be implemented we need research to understand the social, behavioral, and health systems contributors to maternal deaths that are occurring. With this knowledge new interventions can be implemented to help women to overcome these barriers and to reduce maternal mortality in this region.

Purpose

The purpose of this study was to devise a qualitative social autopsy methodology to assess the social, behavioral, and health system contributors to maternal deaths as they relate to the Three Delays model. The purpose is to assess the contributors among women who have recently suffered a death during pregnancy to serve as points of intervention for the reduction of

maternal mortality in Iganga District, Uganda. This study aimed to answer the following research questions:

1) What are the social, behavioral, and health systems contributors to maternal deaths in Iganga, Uganda?

Significance

This study will assist in the advancement of understanding maternal deaths in this region. Knowledge of perceptions and barriers that hinder care seeking, traveling to health facilities, and receiving appropriate care among women who have died will help to inform future interventions in the region. By proxy it will also help to improve women's status, economic, and social outcomes for women and their families. Additionally, this study can provide understanding to the community on maternal deaths to assist in community level understanding.

Definitions of Terms

Maternal Mortality: The death of a woman whilst pregnant or within 42 days of delivery or termination of pregnancy, from any cause related to, or aggravated by pregnancy or its management, but excluding deaths from incidental or accidental causes. This investigation used ICD-10 definition of maternal mortality (The World Health Organization, 1994).

Social: Social contributors to maternal death included interaction of community and cultural influences.

Behavioral: Behavioral contributors to maternal death included individual and household factors that contributed to deaths.

Health Systems: Contributors to maternal death relating to any factor within the health system, this includes government or private health care. This also included formal or informal care such as traditional birth attendants.

Malfeasance: when a provider purposely affected the ability for a women to receive appropriate treatment

Chapter 2
Background and Literature Review

Background

Uganda and East Central Region

Uganda is a land locked country located in East Africa with an area of 241,038 square kilometers (Uganda Bureau of Statistics & Macro International, 2011). In 2006 Uganda had a population of 24,227,300 people with a population density of 124 people per square kilometer (Uganda Bureau of Statistics, 2006). The country has an annual growth rate of 3.2% and the population is expected to reach 44 million by 2020 (Government of Uganda, 2010). The life expectancy is low at 50.4 years. The country is mostly rural with only 12.3% of people living in urban areas (Uganda Bureau of Statistics, 2006). The economy is largely based in agriculture with 57.3% and 55% of women and men respectively employed in the agriculture sector, with a majority of the population surviving on subsistence farming (Uganda Bureau of Statistics & Macro International, 2011). In the East Central region 59.2% of the population says the agriculture sector is their main source of work and this region is largely rural. According to the 2011 Demographic and Health Survey (DHS) only 10% of rural households had access to piped water and 5.3% had access to electricity (Uganda Bureau of Statistics & Macro International, 2011). Indicating low standards of living for a majority of the population that lives in rural settings.

Uganda passed universal primary education in 1996 to increase school enrollment for both girls and boys, which has seen increases in enrollment (Ssengooba). However 17.6% of people in the East Central region have no formal education with a median of 5.4 years completed

for women and 5.7 years for men which is comparable to the national average (Uganda Bureau of Statistics & Macro International, 2011). Education is still low but there is a fairly equal distribution among men and women. Literacy rates among younger women are higher than among older women which indicates more chances for younger women to engage in learning and education. Uganda is a religious country with diversity in religious beliefs. Catholics make up the largest religious group with 43%, 31% of people are Protestant and Muslims make up 13% of the population. The rest of population identifies as Pentecostal or Seventh-day Adventist. Uganda is a high fertility country with children under 15 making up 52% of the population and an average household size of 4.9 people. The median age of marriage among women is 17.9 years and recent years have seen a decline in child marriage (girls under the age of 15). Polygamous unions are common in Uganda, especially among the Muslim population. Nationally 25% of women are in polygamous unions, the East Central region has the second highest rate of polygamy at 39% of women.

Recent History

In the past 55 years, Uganda has faced political and economic turmoil. Uganda was colonized by Britain and achieved emancipation in 1962 after its first democratic election (Uganda Bureau of Statistics & Macro International, 2011). In 1971 Prime Minister Obote was overthrown in a military coup led by Idi Amin. Amin abolished the constitution that Obote put into place and gave himself absolute power. Idi Amin's rule was landmarked with "economic decline, social disintegration, and open human rights and ethnic violations" (Uganda Bureau of Statistics & Macro International, 2011). Amin began a war with Tanzania, which saw further declines in the economy and infrastructure of the country. In 1979, Amin's rule came to end

when he was forced to flee to Libya by Tanzanian military forces. Obote returned to power soon after in 1980, and this time his reign saw immense human rights violations until 1985 when he was exiled.

Before Idia Amin's rule Uganda's health system was one of the best in the region characterized by well-staffed and well-stocked health units and hospitals and a focus on growth and equity of health (Mukasa, 2012). The political and economic turbulence during the 1970's and 1980's caused the degradation of the health system and its infrastructure, forcing the health system to become reliant on donor funding. The vertical programs enacted by donor funding has led to fragmentation and inequity in the health system (Unknown, 2005).

In 1986, the National Resistance Movement came to power led by Yoweri Musevni, which focused on re-establishing a political and economic environment for growth by instituting broad economic reforms and freedom of the press, and ended the human rights abuses of previous regimes (Uganda Bureau of Statistics & Macro International, 2011; USAID & Ministry of Health Uganda, 2011). In 1986, the health system of Uganda was on the verge of collapsing with healthcare worker shortages and low morale; and poorly equipped and dilapidated health facilities. During this time Uganda saw the reemergence of diseases like TB and measles, and the emergence of HIV/AIDS (Unknown, 2005). These diseases out even more strain on an already strained health system. The health reforms in 1986 shifted focus to primary health care and on restoring and rehabilitating the current health infrastructure. Since this time, economic growth has slowly returned to Uganda which has varied between 5.6% and 7.1% annually (Uganda Bureau of Statistics & Macro International, 2011). In 1996 Museveni was elected the president of Uganda in its first election and has held elections every five years and Museveni has been

reelected each time since, and continues to hold the presidential power in Uganda. In the presidential elections of 2016 Museveni was re-elected but faced accusations of fraud, intimidation, and a lack of transparency (The BBC, 2016).

Health Care System

The health care system in Uganda is largely decentralized and functions under a national health system model similar to that established by England (Ministry of Health Uganda, 2010). Uganda began to decentralize their health system in 1995 with a new constitution and in 1997 with the implementation of the local government act which created District Health Systems and gave them the freedom to manage health sector plans and budgets. Uganda spends $33 per capita on health which is lower than the East Africa regional average (USAID & Ministry of Health Uganda, 2011). The country is currently under the second health policy plan and the Health Sector Strategic Plan III (HSSP III), which provides goals, guidance, and functionality for health system activities from 2010 to 2020. The focus of HSSP III is on health promotion, disease prevention, and early diagnosis and treatment of diseases, with the implementation country wide of the Uganda National Minimum Health Care Package (Ministry of Health Uganda, 2010). The UNMHCP continues a commitment to providing primary health care to all citizens in Uganda. A key proponent to the UNMHCP is the provision of maternal and child health care services to decrease maternal and child mortality rates to meet the recently ended MDG's. However, this package of care is not likely to provide the intended outcomes of decreasing mortality and providing health care for all as it currently only receives 30% of the funding necessary to provide all of its provisions (USAID & Ministry of Health Uganda, 2011). Uganda still relies heavily on donor financing for health services, estimated at greater than 50% of funding (USAID &

Ministry of Health Uganda, 2011). One of the major challenges facing the health system is a

human resources crisis. In 2011, it was estimated that there is 1 doctor and 3 nurses per 10,000

people in Uganda (Mukasa, 2012) with 37% of public sector health posts remaining vacant and

large disparities between urban and rural human resources (USAID & Ministry of Health

Uganda, 2011). Other challenges include drug stock outs, inconsistent quality of care, and a

nonfunctional referral system (USAID & Ministry of Health Uganda, 2011).

Service Delivery

Uganda's health care system functions with a public and a private sector. The Ministry of

Health of Uganda is responsible for operating the eleven Regional Referral Hospitals and the two

National Referral hospitals. The public healthcare system functions under district health systems

which are managed at a district level (Government of Uganda, 2010). See Table 1 for

descriptions of health facility levels and services offered at each level. The national health

system structure should allow anyone to use public facilities at no cost (Ministry of Health

Uganda, 2010). Uganda has a significant problem with shortages of clinical staff throughout the

country with the shortages often concentrated in rural areas (Government of Uganda, 2010). The

private healthcare system consists of Private-Not-for-Profit Organizations (PNFP), private health

practitioners, and traditional medicine practitioners (TCMP) (Ministry of Health Uganda, 2010).

Private healthcare facilities may charge user fees for their services. Three Fourths of the PNFP

sector is made up of four organizations: The Uganda Catholic Medical Bureau, The Uganda

Protestant Medical Bureau, The Uganda Orthodox Medical Bureau, and the Uganda Muslim

Medical Bureau. These organizations also operate 70% of the practitioner training institutions

Table 1: Types and services of public health facilities in Uganda (Ssengooba).

Health Facility Type	Level	Services
Village Health Team (VHT)	village	No health facility, community based services, health promotion
Health Center Level II (HC II)	parish	Preventative, promotive, curative outpatient services, sometimes ANC
Health Center Level III (HC III)	Sub-county	HCII services, plus maternity and in-patient services
Health Center Level IV (HC IV)	Sub-district	HCIII services, plus emergency surgery, blood transfusions, EmOC (C-sections and post-abortion care)
General Hospital (GH or DH)	District (serves population 500,000)	HCIV service, plus x-rays and laboratory services
Regional Referral Hospital (RRH)	Population serves 2,000,000	GH services, plus specialist clinical services, higher level surgical and medical services
National Referral Hospital (NRH)	Population serves 30,000,000	RRH services, plus comprehensive specialist services, health research and teaching

located in Uganda. Oversight and regulation of these institutions is largely lacking due a lack of

policy and personnel (USAID & Ministry of Health Uganda, 2011). TCMPs are comprised of

TBA's, herbalists, and the recent additions of Chinese and Ayuvedic medicines (Ministry of

Health Uganda, 2010). These providers are largely not integrated into the rest of the health sector

and are unregulated. This has the effect of poor management of medical and obstetric

conditions, high morbidity and mortality, and late referrals into the formalized health system.

Sixty percent of the population obtains care at these providers. These providers are important to

the health outcomes of the population of Uganda.

Literature Review

Understanding maternal mortality is a challenging endeavor complicated by inefficient

and costly measurement tactics, unreliable data sources, and complexity of etiology. The

following literature review will explore the strengths and weaknesses surrounding various methods for measuring maternal mortality, its causes, and contributors.

Estimating Maternal Mortality

Understanding the rates and numbers of maternal deaths across the global is an important step towards working to make child birth safe for all women. There are various statistics and methods for measuring maternal mortality most of which are resource intensive, imprecise, and complex (Mbonye, Asimwe, Kabarangira, Nanda, & Orinda, 2006). The common source of vital registration systems to record cause of death data are absent in most low and middle income countries, and when present is often limited to only deaths that occur in a health facility (Kalter, Salgado, Babille, Koffi, & Black, 2011; Leitao et al., 2013; Waiswa, Kallander, Peterson, Tomson, & Pariyo, 2010). This leads to many challenges to collecting accurate reliable maternal mortality data, especially in places where it is needed most. The most common measure to assess maternal mortality is the Maternal Mortality Ratio (MMR) which can be calculated using various data sources.

The MMR is used to assess the likelihood that a pregnant women will die from complications of pregnancy. This indicator is useful in measuring the progress of maternity services and is a key indicator of the health status of a population (Uganda Bureau of Statistics & Macro International, 2011). The global MMR has fallen 44% from 1990 to 2015, according to the world Health Organization (WHO), and rests at 216 maternal deaths per 100,000 live births (The World Health Organization, 2014a). This ratio varies significantly by region. The WHO estimates Sub-Saharan Africa to have a MMR of 546 per 100,000 live births, which is over two

times the global MMR. The country specific MMR, for Uganda, was estimated by WHO to be

343 maternal deaths per 100,000 live births in 2015, slightly lower than the regional average

(The World Health Organization, 2014a). These estimates differ slightly when comparing

different sources. According to the 2011, Uganda Demographic and Health Survey (DHS) the

MMR was estimated at 524 per 100,000 live births in 2000 and 438 per 100,000 live births in

2011 (Uganda Bureau of Statistics & Macro International, 2011). The WHO estimated Uganda

to have a MMR of 620 per 100,000 live births in 2000 and 420 per 100,000 live births in 2010

(The World Health Organization, 2014a). The trend between sources shows a decrease in

maternal mortality over time, but the differences in estimates are important to understand.

Each of the above data sources uses slightly different methods to calculate the MMR,

which can account for the difference in estimates. The Uganda DHS is a population-based survey

that uses the Sibling Survival Method which assess whether the sisters of women participants are

deceased and if they were pregnant at the time in which they died (Uganda Bureau of Statistics

& Macro International, 2011). This is assessed for the seven years preceding the survey. The

WHO paper used country specific data from vital registration systems, population-based surveys,

specialized studies, surveillance studies, and censuses and applied a Bayesian maternal mortality

estimation model (The World Health Organization, 2014a). There are many challenges with

developing maternal mortality estimates which include sampling error due to survey recall, large

non-sampling error, synthesizing data from various sources and misclassification of maternal

deaths (Kassebaum et al.). Non-sampling error is important in the case of countries that lack

robust vital registration systems, like in Uganda, in which the deaths that are most likely to go

unreported are those of the poor [2-4]. The importance of understanding these deaths lies in the

fact that much of the public health and policy agendas are based on these estimates (Leitao et al., 2013).

Misclassification is especially important due to the information needed in order to determine that a maternal death has occurred. According to the ICD-10 a maternal death is defined as "the death of a woman whilst pregnant or within 42 days of delivery or termination of pregnancy, from any cause related to, or aggravated by pregnancy or its management, but excluding deaths from incidental or accidental causes" (The World Health Organization, 1994). Using this definition it is imperative to know the cause of death of the women and the timing of death in relation to her pregnancy (AbouZahr, 2003), which in many lower and middle income countries (LMIC) can be difficult to ascertain when vital registration records are not available and many deaths occur at home (Kalter et al., 2011; Leitao et al., 2013). Less than one third of the maternal deaths that occur globally are medically certified as such (Waiswa, Kalter, Jakob, & Black, 2012). In Uganda, a civil registration system is in place but coverage in incomplete and the data is not adequate for population health information (Uganda Bureau of Statistics & Macro International, 2011; USAID & Ministry of Health Uganda, 2011). This can cause misclassification and underreporting of maternal deaths. Studies have shown that misreporting of maternal deaths can range from 25% to 70% of maternal deaths (AbouZahr, 2003). This has serious implications for public health decisions that are made on these high level indicators.

Global, regional and country specific measures of overall maternal mortality are important for understanding the overall problem and estimating progress towards achieving reductions in maternal mortality. However, these measures are subject to many biases and underestimations of the problem. This is especially prevalent in countries, like Uganda, that lack

robust civil registration and vital statistic systems. Additionally, these measures do not give context to the problem of maternal mortality and leave out much of the story that is necessary in order to lead to improvements in maternal health at a community level.

Biomedical Cause of Death Studies

Many investigations into maternal death focus on understanding the biomedical cause of death (CoD). This is because death registries and CoD information is often not collected in LMIC's which impedes the ability to plan, monitor, and improve public health (Leitao et al., 2013). Maternal CoD investigations use quantitative methods in order to gauge the prevalence of various causes of death. Maternal death is classified into two types; direct and indirect causes. Direct maternal death is the result of a complication from a women being in a pregnant state (AbouZahr, 2003). According to a systematic analysis of maternal death conducted by the WHO (Say et al., 2014), globally 73% of maternal deaths are due to direct causes. The top three direct causes of maternal deaths are hemorrhage at 27.1%, hypertensive disorders at 14%, and sepsis at 10.7% of maternal deaths. Other direct causes of death include abortion and embolism. Post-partum hemorrhage is the most common form of hemorrhage and is defined as a blood loss of 500mL or more from the genital tract within 24 hours of birth (AbouZahr, 2003). Hypertensive disorders are a group of disorders involving high blood pressure during pregnancy including eclampsia and pre-eclampsia (AbouZahr, 2003; The World Health Organization, 2016). Symptoms of which are edema, severe headache, upper abdominal pain, blurred vision, protein in the urine, and in severe cases convulsions (The World Health Organization, 2016). Sepsis in this case refers to infection of the genital tract with fever being the most common symptom

(AbouZahr, 2003). Other less common causes of maternal death include obstructed labor which is when the baby is trapped in the birth canal.

The WHO systematic analysis looked at the distribution of cause of death by region. In Sub-Saharan Africa they found that 70.0% of maternal deaths were direct causes with 24.5% caused by hemorrhage, 16.0% caused by hypertensive disorders, and 10.3% caused by sepsis (Say et al., 2014). Although this investigation used estimates from 23 studies and 417 country databases it is prone to similar weaknesses as many quantitative investigations of maternal death. These weaknesses include high likelihood of misclassification of cause of death, missing deaths of women who did not seek care, and missing or incomplete data from countries with inadequate surveillance mechanisms (Kassebaum et al.). This last weakness is important to maternal mortality because many of the countries with the highest incidence of maternal death have very weak surveillance. This means that it is possible that CoD estimates are incorrect or understated, leading to priority setting that is ineffective.

The second type of classification of maternal death is indirect cause. Indirect maternal death is defined as "death resulting from previous existing disease or disease that developed during pregnancy and which was aggravated by the physiologic effects of pregnancy" (AbouZahr, 2003). This includes women who die of HIV/AIDs, Malaria, Anemia, Tuberculosis, or Diabetes while pregnant. According to the WHO analysis indirect causes accounted for 27.5% of maternal deaths globally, and 28.6% of maternal deaths in Sub-Saharan Africa from 2003 to 2009 (Say et al., 2014). HIV/AIDS related deaths were the highest in Sub-Saharan Africa at 6.4% of maternal deaths. Indirect maternal deaths are often not reported as maternal deaths and face under reporting and misclassification.

Causes of maternal death can vary widely by region. A maternal death review conducted in 2006 which investigated cause of death at health facilities in 54 districts in Uganda found that the leading causes of maternal death were hemorrhage at 42% and prolonged/obstructed labor at 22% of deaths that occurred in health facilities (Mbonye et al., 2006). They also found that 65% of indirect maternal deaths were caused by Malaria and 19% by Anemia. These statistics are appreciably different from the global and regional estimates of cause of death and illustrate the variation that can occur. Additionally, this illustrates the importance of national and regional level estimates for understanding maternal mortality.

Understanding Cause of Death Using Verbal Autopsy

The verbal autopsy (VA) technique was developed to assist in collecting high quality CoD data, overcoming shortcomings and using less resources than other data collection methods. VA is a quantitative survey technique that ascertains CoD through post-mortem interviews with caretakers or witnesses of the death about signs, symptoms, and circumstances surrounding the death (Leitao et al., 2013). These investigations often achieve a higher level of understanding about maternal deaths by gaining an understanding of events surrounding each death (Somigliana et al., 2010). Surveys are physician-certified or computer validated to ascertain the CoD. VA is often used in settings in which vital registration systems are not fully functional and in deaths that occur outside of health facilities (D'Ambruoso, Byass, Qomariyah, & Ouédraogo, 2010). One of the many challenges to maternal death review studies including VA, regardless of methods used, is the reliance on retrospective 3rd party accounts to collect the data.

In a small maternal death review using VA methodology at a single hospital in northern

Uganda investigators looked at 17 cases of maternal death that occurred in a one year period and

found 13 (76%) of the deaths were direct maternal deaths, with post-partum hemorrhage (5

cases, 29%), unsafe abortion (5 cases, 29%), and eclampsia (2 cases, 11%) as the leading causes

(Somigliana et al., 2010). Although the sample size of this investigation was small and the data

are not generalizable to the population, the investigation was much more detailed that larger

studies. These detailed findings include evidence of staff negligence in 18% (3 cases) of the

maternal deaths and a lack of emergency room services was estimated to cause 35% (6 cases) of

the deaths. This shows areas of intervention that could help reduce maternal death in this

hospital. The depth of the investigation lends to less misclassification bias and can show where

community level interventions could best be implemented. This investigation still does not

access maternal deaths that occur in the catchment area of the hospital but outside of the health

facility. Lastly, validated VA methodologies are unable to show non-biological contributions to

maternal death (Waiswa et al., 2012).

Sometimes quantitative VA methodologies have been expanded to attempt to understand

social factors that contribute to maternal deaths. This was attempted in study by Webber, et al. in

Tanzania (Webber & Chirangi, 2014) that used quantitative surveys with some qualitative

responses to interview family members of deceased women in the 5 years preceding the survey.

They found 36 deaths and found that a majority of women died of bleeding or retained placenta

(32 out of 36), according to the family members. The important aspect of this investigation is

that it also collected information on factors that surrounding the death other than CoD

information. For example they found that most of the women had births attended by family

members only and many women died en route to a health facility. The most common barriers to receiving care were finding transportation and the distance to the health facility. Again this shows areas of intervention to help prevent these deaths. Although this study had weaknesses of a long recall period and reporting bias, it still provides important information surrounding maternal deaths and includes deaths occurring outside of health facilities. Another study conducted in Burkina Faso and Indonesia used VA mixed methods to collect CoD information, care pathways, and opinions on how to prevent maternal deaths (D'Ambruoso et al., 2010). In this investigation they found delays in seeking care, reaching and receiving care in two thirds of the 174 maternal death interviews. Important aspects of this study are the ability to understand maternal deaths outside of health facilities. Overtime the collection of social contributors has become more common in VA, which has prompted the development of a social autopsy methodology for collecting this information.

Problems that can be faced when using the VA methodology are plenty. VA is a relatively new methodology to be used for death registries and CoD on larger scales and there is a need to identify the optimal sample sizes for investigations, streamlining and simplifying methodologies, and optimizing VA platforms for both computerized and physician-certified instruments (Setel, 2011). Most of these quantitative investigations focus on correlations between CoD and sociodemographic characteristics (Parkhurst, 2006) which can overlook important cultural perspectives. Often even when an attempt is made to understand deeper relationships on decision making and barriers they are in a dichotomized format. This still impedes understanding of how and why key decisions are made and barriers that women

overcome in the pathway to death. What are the series of complex events and decisions that happened before a maternal death? To understand this more qualitative methods are needed.

Contributors to Maternal Mortality

Although measuring the MMR and CoD data are important to understanding the magnitude of the problem these measures leave out important information. Research that identifies the contributors to maternal death are important to overall understanding of the problem and identifying points of intervention. Many studies attempt to identify these contributors. In the following section the discussion of measuring contributors to maternal mortality will continue to be expanded.

Assessing contributors by using an ecological approach

An ecological study conducted from 1997 to 2006, attempted to identify the health system, education, and economic factors that are associated with high maternal mortality in Sub-Saharan Africa (Luis Alvarez, Gil, Hernández, & Gil, 2009). An inverse relationship was found between MMR and higher female enrollment in education, government expenditure on health per capita, ANC, and births attendance by skilled providers. This shows that high rates of female education are associated with lower maternal mortality. Additionally, increased spending on health and a robust health system that is utilized by women are all factors that are associated with lower MMR countries. This study sheds light on the population level associations between a countries MMR and demographic factors but doesn't show individual level determinations of maternal mortality.

Assessing contributors by measuring health systems performance

Due to the difficulty in measuring maternal death and its contributor's researchers often focus on maternal health and maternal health services to understand maternal mortality and where to implement interventions. Such studies may focus on assessing the quality of service provisions for maternal services, such as ANC. A study in Eastern Uganda, did just this using observational and interview surveys and found that capacity to deliver ANC services including infrastructure and diagnostic testing ability were good throughout the regions, but that 53% of women did not receive the diagnostic tests they were supposed to at their ANC appointments (Tetui et al., 2012). This shows disconnection between the availability of services and patients receiving them. This disconnect could be explained by the 40% shortage of health care workers found in this study. Other studies also describe a shortage of skilled staff as a contributor to maternal mortality (Luis Alvarez et al., 2009; Mbonye et al., 2006). Additional findings that could contribute to maternal mortality include finding poor counseling on risk factors (58%) and birth preparedness (50%) at ANC visits (Tetui et al., 2012). This could be due to the shortage of staff or poor training, and has large implications for women's care seeking behavior later in pregnancy. This study also found that twelve out of the fifteen health facilities in the study had poor drug availability (Tetui et al., 2012) which is echoed in other studies (Mbonye et al., 2006; Namazzi et al., 2015). The implications of this are high since many of the life saving measures for obstetric emergencies require the use of drugs. Although this study highlights many areas of deficits in ANC in Eastern Uganda, it does not connect any of these deficits with maternal mortality directly.

Other studies have tried to assess the availability of services in health facilities to gain a better understanding of health care quality and the contributors to maternal death. Health facilities were assessed in 54 districts in Uganda on the availability of emergency obstetric care (EmOC) signal functions (Mbonye et al., 2006). The signal functions for EmOC are broken down into comprehensive and basic functions. Basic signal functions include the ability to administer antibiotics, oxytocin, and anticonvulsants through IV or injection, the manual removal of the placenta, removal of retained products, perform assisted vaginal delivery, and perform neonatal resuscitation (WHO, UNFPA, UNICEF, & AMDD, 2009). Comprehensive EmOC includes all the basic functions with the additional ability to perform Caesarean section and blood transfusions (WHO et al., 2009). The study assessed whether the facilities were able to offer the services that they were supposed to according to the Ugandan health policy. The results of the study were dire. They found that 97% of health facilities that were supposed to offer basic EmOC were unable to provide all of the functions and 93% of health facilities that were supposed to offer comprehensive EmOC could not even provide basic EmOC. These findings were especially apparent in HC IVs with very few having the ability to offer blood transfusions or Cesarean sections (Mbonye et al., 2006; Namazzi et al., 2015). This study concluded that many of these maternal deaths that occur in health facilities are due to inadequate care. With this study we still do not understand the contributors to maternal death that occur outside of health facilities.

Assessing contributors by measuring maternal health seeking behavior

Other mixed-methods research using quantitative and qualitative methods have been conducted to attempt to assess the socio-cultural contributors to maternal health seeking

behavior. This is important because cultural differences could significantly affect maternal outcomes. One study used quantitative surveys, key informant interviews, and focus group discussions to understand how women's status, traditional beliefs, and household resources affected care seeking behaviors in a western district of Uganda (Kyomuhendo, 2003). They found that during pregnancy 46% of women used both traditional and biomedical services during delivery and 31% sought both types of care. This dual care seeking behaviors could have implications such as delaying seeking EmOC or using traditional methods that exacerbate conditions. Traditional beliefs were important in this study, as women who delivered without assistance were designated as more powerful and strong. This was the manner with which women derived most of their power in the culture and could be a large factor in delaying seeking care.

Qualitative investigations are especially useful for gaining more nuanced understanding of barriers to care-seeking and receiving. One investigation interviewed 30 women in a western district of Uganda who used professional delivery services to attempt to understand how decisions around care seeking were made and barriers overcome (Parkhurst, 2006). This study found that often husbands were the main decision makers, but women also felt decisions were made jointly. Additionally, decisions to deliver in a health care facility were made in advance and husbands were responsible for planning to overcome barriers such as saving money and transportation.

Assessing the knowledge of obstetric danger signs and birth preparedness are used to understand maternal health care utilization. A study conducted in rural south-western Uganda interviewed 764 recently delivered women who were surveyed on key danger signs and birth

preparedness (Kabakyenga, Ostergren, Turyakira, & Pettersson, 2011). Key danger signs are different in each phase of pregnancy. During pregnancy they include severe genital bleeding, blurred vision, and swelling of the hands and face. During childbirth they include labor lasting more than 12 hours, severe vaginal bleeding, retained placenta, and convulsions. After childbirth (postpartum) danger signs again include severe vaginal bleeding, fever, and foul-smelling vaginal discharge. Key findings for the study were that 52% of women knew at least one danger sign with severe vaginal bleeding being the most frequently discussed. This seems to correlate with hemorrhage being the most common CoD. Only 19% of women knew three or more danger signs in each of the phases. This is important because knowledge of danger signs is a motivator for women to seek care in cases of obstetric emergency. An obvious problem with these types of investigations in understanding maternal mortality is that they are not measuring the population of interest. Women who died during pregnancy could be fundamentally different than the women who sought services and did not die. Therefore these studies gain insight into maternal health services utilization but not necessarily maternal mortality.

Social Autopsy

Social Autopsy (SA) is a methodology to investigate maternal mortality through maternal death reviews including interviews with family members, caretakers, and/or healthcare personnel that were witness to a maternal death (Kalter et al., 2011). In this way SA is similar to the VA methodology with one key difference. The aim of SA investigations are to identify the "social, behavioral, and health systems contributors" to maternal death and not to determine CoD as in a VA (Kalter et al., 2011). These types of investigations can utilize either quantitative or qualitative methods. Qualitative methods allow participants to describe rich narratives with their

own beliefs and can assist in illuminating the care seeking process (D'Ambruoso et al., 2010; Kalter et al., 2011). These investigations provide a deep understanding of maternal deaths, as they are seen by those in the communities of interest and illustrate opportunity for community level improvements (Kalter et al., 2011).

There is no standardized methodology for conducting SA investigations. SA was chosen for this investigation for two reasons; the level at which SA investigations are conducted and the ability to identify social, behavioral, and health system contributors to maternal deaths. First, SA are most often conducted at the sub-district, district, or regional level (Castro, Campero, Hernández, & Langer, 2000; Cham, Sundby, & Vangen, 2005; Kalter et al., 2011). Second, SA investigations are able to identify contributors to death. In this respect they expand on the abilities of VA and the two are often combined to establish CoD and contributors (D'Ambruoso et al., 2010; Moshabela et al., 2015). Similarly to VA there is no standard methodology or standard validated instrument to conduct a SA, therefore some investigations use quantitative surveys (D'Ambruoso et al., 2010; Kallander et al., 2011; Moshabela et al., 2015) and others use qualitative interviews (Castro et al., 2000; Cham et al., 2005).

Each method has strengths and weaknesses. Quantitative methods are more standardized and can be streamlined to decrease the amount of resources and cost needed to conduct these investigations. Weaknesses in quantitative investigations, especially when combined with VA, are the number of questions and variables can be overwhelming to gain understanding of all contributors to maternal death. Additionally, quantitative surveys have trouble identifying the key aspects of some contributors such as, gender dynamics of decision making, local perceptions of illness and providers, and poverty (Kallander et al., 2011). Many of these deficiencies can be

overcome with qualitative methodologies, however the increase in resources needed may outweigh the benefits. Understanding the purpose of the investigation is required to implement the appropriate SA methodolgy. SA methods have limitations similar to VA including third party perspectives through family members and caretakers and the possibility of missing valuable information by not interviewing the women themselves (Castro et al., 2000). Small sample sizes or long recall periods could lead to under reporting or distortion in the recalling of events (Kalter et al., 2011).

The Three Delays

The Three Delays framework was developed by Thaddeus and Maine (Thaddeus & Maine, 1994) as a framework for assessing and classifying the delays that a women encounters from the onset of obstetric complications to death. The three delays include: Delay 1: delay in the decision to seek care, Delay 2: delay in reaching an appropriate health facility, and Delay 3: delay in receiving care at the facility. Thaddeus and Maine developed the Three Delays framework from conducting a literature review of maternal health and mortality studies (Thaddeus & Maine, 1994). They describe the unique set of factors that lead to each delay and that can be points of intervention. See Figure 1 for information on each of the unique factors that lead to the three delays. This model has seen wide spread popularity in maternal mortality, and has expanded to include contributors to neonatal and early childhood mortality. This is because the framework looks at maternal mortality as caused by many complex and diverse factors, not a single isolated factor (Castro et al., 2000). It is important to look at each of the delays separately as they each contribute to maternal mortality.

The barriers that are proposed to affect the decision to seek care are distance to a health facility, cost, perceptions of quality of care, and sociocultural factors (Thaddeus & Maine, 1994). An important sociocultural factor is the ability to recognize illness. This is often measured by the ability of caretakers to identify symptoms of complications and illness and can be affected by the prevalence of the illness within the population. For example, a severe illness that occurs often in a society may be regarded as normal and be ignored. Therefore in a high fertility, high maternal mortality society, like Uganda, pregnancy and pregnancy complications may not be recognized by women or caretakers as needing medical care (Thaddeus & Maine, 1994). Education, economic, and women's status are all social determinants of the first delay. Qualitative and quantitative investigations in Gambia, Mexico and other countries used the three delays framework to conduct a maternal death review (Castro et al., 2000; Cham et al., 2005; D'Ambruoso et al., 2010). They found that the first delay was caused by underestimating the severity of the illness, cultural hierarchy, past poor experience with the health system or not understanding provider instructions (Castro et al., 2000; Cham et al., 2005; D'Ambruoso et al., 2010). The cultural hierarchy took the form of a women needing the permission of her husband or of an older woman counterpart. Poor economic status or a lack of money was determined to be a delay in two of the studies (Castro et al., 2000; D'Ambruoso et al., 2010). Additionally, the interpretation of symptoms of illness as traditional diseases and seeking traditional remedies was associated with the first delay (Castro et al., 2000). A quantitative investigation in Burkina Faso and Indonesia found between 45% and 57% of women faced delay 1 in the process to seek care (D'Ambruoso et al., 2010). After the barriers to delay one are overcome the next step is the process of obtaining transportation to a health facility.

Figure 1: Factors that lead to each of the three delays according to Thadeeus & Maine (Thaddeus & Maine, 1994).
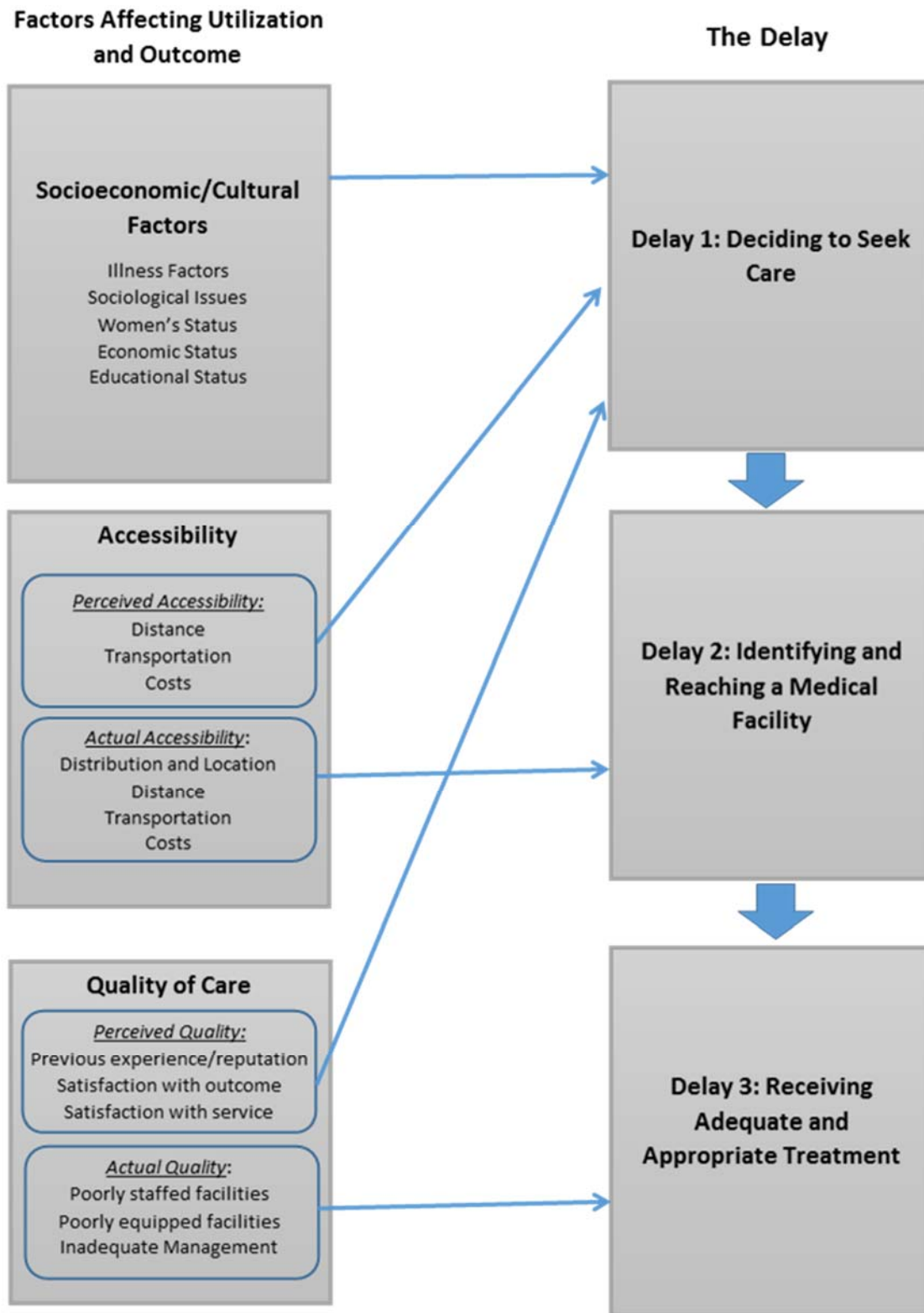
The barriers that are proposed to affect the delay in reaching an appropriate health facility after the decision to seek care has been made are the distribution of health facilities, the time it takes to travel, and the availability of transportation (Thaddeus & Maine, 1994). In the Gambia study, a majority of women faced the second delay (Cham et al., 2005). These delays were caused by a lack of transportation, including poor road condition, no fuel, no transportation, prolonged transportation, and seeking care at multiple health facilities (Castro et al., 2000; Cham et al., 2005). Other factors that contributed to the second delay were referral systems that required women to seek care at multiple facilities (Castro et al., 2000). Other studies found between 63% and 66% of women faced the second delay due to distance to health facility and the type of transportation, often bicycles and motorbikes in Burkina Faso (D'Ambruoso et al., 2010). Often women that faced these types of delays came from communities faced with poverty and isolation (Castro et al., 2000). Once they arrive at the facility women must be able to access appropriate health care services.

The ability to receive appropriate quality medical care once at the facility is hindered by ill staffed, ill equipped, and ill managed medical facilities (Thaddeus & Maine, 1994). These factors can lead to delays in receiving care, unavailable treatments, and incorrect diagnosis and actions. Multiple studies have found that many women face inadequate care once they reached a health facility caused by a lack of basic medical supplies and blood transfusions (Cham et al., 2005; D'Ambruoso et al., 2010). An inability by medical personnel to manage or treat complications, insufficient human resources, and excessive workloads all contributed to delays in receiving quality health care (Castro et al., 2000). Other factors found include bribery, long lines, and referrals (D'Ambruoso et al., 2010).

Common critiques of the three delays frame work are that the sequential nature of the delays are not as straightforward as described (D'Ambruoso et al., 2010). This is often the case in places where there is a referral system in place, in which case the delays may repeat or not in each of the health facilities.

Social Autopsy and the Three Delays in Iganga, Uganda

This investigation used a qualitative SA methodology developed using the Three Delays framework to understand maternal deaths in Iganga district, Uganda. Much of the research that has been conducted in Uganda using SA under the Three Delays framework has focused on child deaths (death of children under 5) (Waiswa et al., 2010). There have been minimal attempts to investigate maternal deaths using these methods. As, part of the Uganda Newborn Study, which occurred in Iganga/Mayuge, an attempt was made to implement maternal death review committee's in 20 health facilities from 2009 to 2011 as part of a capacity building initiative (Namazzi et al., 2015). However, the committees failed to be taken up by the health facilities citing fear of retribution and excessive workload. To the investigators knowledge there have been no other attempts at a maternal death review using SA and the three delays framework for maternal deaths in Iganga district, Uganda.

Chapter 3
Methods

Introduction

This study was conducted in Iganga District, Uganda with the support of a local NGO, SAFE Mothers SAFE Babies (SAFE). This study developed a qualitative SA methodology to understand the contributors to maternal death using the Three Delays framework. In-depth interviews with caretakers of deceased women were conducted and transcribed from local language. Data analysis used case-based and cross-case qualitative analysis using MaxQDA software. A second social autopsy study was conducted simultaneously investigating the contributors to child deaths (in the first 1,000 days of life). Study methods and results for the child death study are not discussed here.

Iganga District

Iganga District is a 393 sq. mile district located in the east central region of the country with a population of 466,200 in 2010 (Ministry of Health Uganda, 2013). According to the Ministry of Health in Uganda 45% of women deliver in a government or Not-For-Profit health facility and the region had only 73% of its health posts for providers filled in 2013 (Ministry of Health Uganda, 2013). This indicates a need for more health care workers in the region. The district has one functional operating theater and three facilities that offer EmOC. See Table 2 for information on the types of health facilities located in the district.

Table 2: The type and number of health facilities that are located in Iganga District, Uganda by ownership according the MoH Uganda (Ministry of Health Uganda, 2012).

Ownership	General Hospital	HC IV	HC III	HC II	**Total**	Operating Theaters
Government	1 (100 beds)	2	12	25	40	1[a]
NGO/Private	0	0	2	15	17	0
Total	1	2	14	40	57	1

[a]The MoH reports three operating theaters in the district, but only one is operational. Therefore only the theatre that is able to provide services was counted.

Study Population

Family members and caretakers, over the age of 15 years, who cared for a pregnant women or child, aged two years or younger, during an illness that led to death were interviewed. The deaths occurred in Iganga district, Uganda in the Nawandala or Nabitende sub counties. Pregnancy status was defined using the ICD-10 classification by the WHO as "the death of a woman whilst pregnant or within 42 days of delivery or termination of pregnancy, from any cause related to, or aggravated by pregnancy or its management, but excluding deaths from incidental or accidental causes" (The World Health Organization, 1994). The death had to have occurred in the 24 months prior to being interviewed to reduce recall bias (Campbell & Ronsmans, 1994; Webber & Chirangi, 2014).

Health care workers were not interviewed in this investigation for many methodological reasons. These reasons included anecdotal knowledge that women seek care at multiple health facilities, a lack of reliable health records, and inability to provide information on the first two delays. Lastly, study staff felt health care workers would be unwilling to discuss these deaths due to fear of retribution.

Data Collection

Recruitment

Multiple methods of recruitment were used for this study due to difficulty in finding these deaths. Difficulty finding deaths stemmed from stigma from health providers and the community regarding these deaths. The study team visited local health facilities at each level in specified sub-counties to ask facility staff if they had heard of, witnessed, or attended the burial of any women of reproductive age in the past 24 months. Study staff then attempted to determine the pregnancy status of identified deaths. Study staff, including interviewer and principal investigator, then visited the households of identified deaths. The purpose of the SA was explained in local language and the most ideal respondent was identified. Informed consent was obtained orally in local language due to high rates of illiteracy in the region. When possible a community leader or Village Health Team (VHT) member escorted the interviewer to the family's location to introduce the study. Community escorts that had established relationships with the SAFE organization were compensated for their time. Participants received no incentives for participation. Snowball sampling was also used. After an interview, the participant was asked if they knew any other families who may have suffered this type of death and their location.

Training

All interviewers in this study were from the local community. These interviewers were trained on qualitative techniques including interviewing and transcription, as well as, obtaining informed consent and preventing coercion. The initial training lasted three days before any interviews were conducted. The training was developed by the study team based in Atlanta, GA.

During the training interviewers reviewed the interview guides for cultural appropriateness and relevance. Changes to interview guides were made based on this feedback. An additional one day re-training occurred after pilot testing to strengthen interviewer skills and improve data quality.

In-depth Interviews

In-depth interviews were chosen due to the sensitive nature of these deaths to family members (Hennink, Hutter, & Bailey, 2010). Two interview guides were developed, one for the family member of a maternal death, and one for the family member of a child death. The interviews followed the following format screening questions, introduction and informed consent, appropriate term to use, interview guide, and demographic questions. The appropriate term to use section was included to ensure sensitivity to the participant on how they preferred the interviewer to refer the "The Deceased". The interview guide included questions about the deceased's pathway to death from recognition of illness to death, focusing on the three delays. Guides were adapted from some of the most widely used tools in the field of SA including the WHO Verbal Autopsy Standards (2014)(The World Health Organization, 2014b) and the International Network for the Demographic Evaluation of Populations and Their Health (INDEPTH) SA Tool (2009) (INDEPTH Network, 2009; Leitao et al., 2013).

After interviews, the interviewer debriefed with the principal investigator on challenges faced, themes that emerged during the interview, questions about the interview process, or suggestions for improvements to the guides. The interview guides were developed and changed in response to suggestions from study staff using the iterative process of qualitative research

(Hennink et al., 2010). Interviewers recorded observations and field notes, which were used as supplemental information during analysis.

Staff attempted to collect fifteen total maternal death interviews with five interviews at each of the three delays. For example, five interviews in which women died at home, five in which they died en route to a facility, and five in which they died at a health facility. At the end of the study twelve interviews had been conducted, no women died in their home, two women died en route to the health facility and ten died at a health facility.

All interviews were conducted in the language that the respondent was most comfortable using, Lusoga or Lugandan. Interviewers attempted to have the interviews in a private location whenever possible by requesting to have the interview away from other family members, often outside of the home. The interviews were recorded using Samsung Galaxy tablets or handheld recording devices. The study team planned to use a tablet based version of the entire interview guide using Open Data Kit software. This method was not viable due to issues with the suitability of the chosen software for the research. The study switched to paper based versions of the interview guides after pilot testing.

Pilot testing occurred during the first two interviews. These interviews were transcribed, reviewed and changes to the interview guides were made accordingly. A third party spot checked the transcriptions for accuracy. Pilot interviews were included in the analysis.

Data Analysis

Sample

Interviews with family members on 12 suspected maternal deaths that occurred in Iganga District, Uganda from July 2013 to May 2015 were collected. Of the 12 interviews, nine were included in this analysis. Two interviews were excluded because pregnancy status could not be verified (case 3 and 4), and the third due to poor data quality (case 5).

Data Analysis

Verbatim translation and transcription was completed by interviewers simultaneously in a single step (Hennink et al., 2010). This was chosen due to limited time and resources. To help reduce bias, no interviewer transcribed their own interview.

The purpose of data analysis for this study was to identify the contributors to maternal deaths in the region. As such, a case-based analysis was chosen for the initial analysis. This type of analysis allowed the principal investigator to understand the delays that occurred within each case and to develop causal pathways on how the delays affected each case (Bazeley, 2013). Visual representations for each case were created detailing in chronological order the key aspects and events of the death. These key events included places care was sought, when care was sought, key illness characteristics, place of delivery, place of death, and aspects of healthcare quality. Additionally, how each of the events related to the three delays was documented. These visual representations were termed the woman's "Pathway to Death" that occurred from recognition of pregnancy status until death.

In the second phase of analysis, key themes and barriers that occurred across cases were identified from the visual representations. Cases were split into three groups due to differences in care seeking behaviors for a cross-case analysis (Bazeley, 2013). The three groups were determined by the types of care women sought and included, 1) TBA/Private Village Level Clinics (PVLC) only, 2) PVLC and higher level health facilities, and 3) higher level government facilities only. For the cross-case analysis one interview from each group was coded in MaxQDA, using inductive and deductive codes identified in the first part of data analysis. Code definitions were then refined and all interviews were coded using the refined codes. The three main codes that corresponded to the three delays included knowledge, transportation, and health care quality.

After coding, the attributes and dimensions for each code were described in code summaries for each case. For example, the code transportation included type, access, and cost of transportation. These summaries were then compared across cases to determine similarities and differences. Additionally, matrices were used to compare overlapping codes. For example, when the code for decision makers overlapped with transportation the codes were examined across the matrix to understand how codes interacted with each other.

Initial Data Analysis Plan

Initial data analysis attempted to segment the interviews by each of the three delays and conduct analysis of each of the delays across cases. This proved to be impossible due to significant overlap between the delays. For example, healthcare quality affected the care seeking process for women, an overlap of delay 3 and delay 1. Additionally, the three delays did not

progress in the linear fashion as typically exemplified in the Three Delays model. For these

reasons, the initial data analysis plan was not used and the principal investigator used the

aforementioned procedure. Results are presented by key themes within the data, not in the Three

Delays framework.

Ethical Considerations

The Emory University IRB determined that no IRB review was required for this study,

due to its classification as a quality improvement effort within the Safe Mothers, Safe Babies

organization and was considered not human subject research. Meetings were held with

community leaders, chiefs, and chairpersons of sub districts and villages that the study worked

in, to gain permission and local support for the project.

Chapter 4
Results

__Demographic Characteristics__

The age range for the nine maternal death cases was 16 to 43 years old (Table 3). The majority of women were married (7/9) with 5/7 married women participating in polygamous unions. Death for all of the included cases occurred during or soon after (within 24 hours) of delivery. All but one death (8/9) occurred in some type of health facility, either government, private, or TBA clinic. The other death occurred on the way to a second health facility, and no deaths occurred at home. The most popular place for first point of care was a TBA clinic or private village level clinic (PVLC). TBA clinics were defined as points of care confirmed to be a TBA by the participant. All other small village clinics described by participants that were not government facilities are included in PVLC. Neither of these types of facilities provide emergency obstetric care (EmOC). The lack of deaths occurring at home, and fact that all women decided to seek health care, shows a shift in the three delays models. Only one case reported owning motorized transportation in their home. Additional demographic characteristics of the cases can be found in Table 3. Participants placed the month of death for all women in November (4), July (3), or August (3). The researchers could not hypothesizes on the clustering of the months of deaths for cases in this study.

Types of Pathways to Deaths

Cases were categorized into three groups corresponding to the cases first point of care and pathways that led to deaths. The groups include: Group 1: women who sought TBA or private village level clinic care ONLY (3 cases); Group 2: women who sought TBA or private

village level care and then attempted to access at least one other healthcare center (3 cases);

Group 3: women who sought care at government healthcare centers as first point of care (3

cases). See Figure 2 for more information on the locations of deaths for each of these groups.

Group 1 consisted of older women (36 to 43 years old) who were currently on their ninth or tenth

pregnancy, all of whom were in polygamous unions. The women in Group 2 are more varied

demographically than the women in group 1. All of these women used a PVLC as their first point

of care. Group 3 consists of the youngest average age (23 years old) and two of the three cases

were in there first or second pregnancy. See table 4 for a review of the health facility levels in

Uganda.

Table 3: Demographic characteristics of the cases included in this study.

	Case 1	Case 2	Case 6	Case 7	Case 8	Case 9	Case 10	Case 11	Case 12
Age of Mother (years)	25[e]	42	22	43	16	30	36	40	22
Religion	Catholic	Protestant	Protestant	Born Again	Muslim	Muslim	Born Again	Catholic	Protestant
Tribe	Musoga	Musoga	Musoga	Musoga	Musoga	Musoga	Mulamoji	Mulamoji	Musoga
Level of Education	Some Primary	Some Primary	Secondary	Some Secondary	Some Primary	Secondary	Secondary	None	Some Secondary
Owned mobile phone	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Marital Status	Married	Married	Never Married	Married	Married	Married	Married	Married	Never Married
Order of Wife[a]	1	1	-	Unknown	-	2	1	-	-
Total Number of wives	3	2	-	2	1	3	4	1	-
Parity	3	9	2	10	1	5	10	Unknown	1

Table 3 Continued: Demographic characteristics of the cases included in this study.

	Case 1	Case 2	Case 6	Case 7	Case 8	Case 9	Case 10	Case 11	Case 12
Functional Transport Owned in Household	Car	None	Bicycle	Bicycle	None	None	Bicycle	Bicycle	None
Place of Birth[b]	PVLC	TBA clinic	DH	PVLC	HC III	HC III	TBA clinic	PVLC/lg Private facility	DH
Place of Death	DH	TBA clinic	DH	PVLC	en route	DH	TBA clinic	large private facility	DH
First Point of Care	PVLC	TBA clinic	DH	PVLC	HC III	HC III	TBA clinic	PVLC	PVLC
Number of Facilities Visited	3	1	1	1	1	2	2	2	2
Group[c]	2	1	3	1	3	3	1	2	2
Time between death and interview (months)	7	11	7	7	12	24	8	23	23
Relationship to the Deceased[d]	Daughter[e]	Husband	Sister	Mother	Sister-in-Law	Sister	Husband	Husband	Mother-in-Law

[a]In polygamous unions the order in which the deceased was in the household. 1 indicates she was the first wife to the husband.
[b]The location in which the deceased gave birth to the child in which they suffered this death.
[c]These groups are determined by where the woman sought care during this delivery, group 1: TBA/PVLC only, group 2: PVLC + higher level facilities, group 3: higher level facilities only.
[d]The relationship of the participant to the deceased.
[e]These data may be incorrect.

Case Descriptions

The following are three case descriptions of maternal deaths that occurred in this study. They serve to illustrate the various delays and barriers that women encountered during this time, that led to death. Additionally, Figure 3 shows a general conceptual framework for the barriers and delays that women faced before their death.

Evelyn – Group 1 (Case 10)

Evelyn, who died at 36 years old, was in a polygamous marriage and was the first of four

wives. She died after giving birth to her tenth child. She received ANC care for this pregnancy at

the government health facility level II in her village and made the decisions to seek this care on

her own. Evelyn also used traditional methods of prenatal care such as showering in local herbs

and sitting in a mixture of snail shell ash which she learned from her parents. Evelyn was

traveling to a nearby village to attend a funeral with her mother when she began to have labor

pains. She expressed wanting to return to her village to give birth but her mother told her to go to

her sister-in-law's house, who was a TBA, nearby the funeral. Evelyn proceeded to her sister-in-

Figure 2: The types of pathways that resulted in women's death. The deaths are categorized into three types, informal care only, informal and formal care, and formal care only.
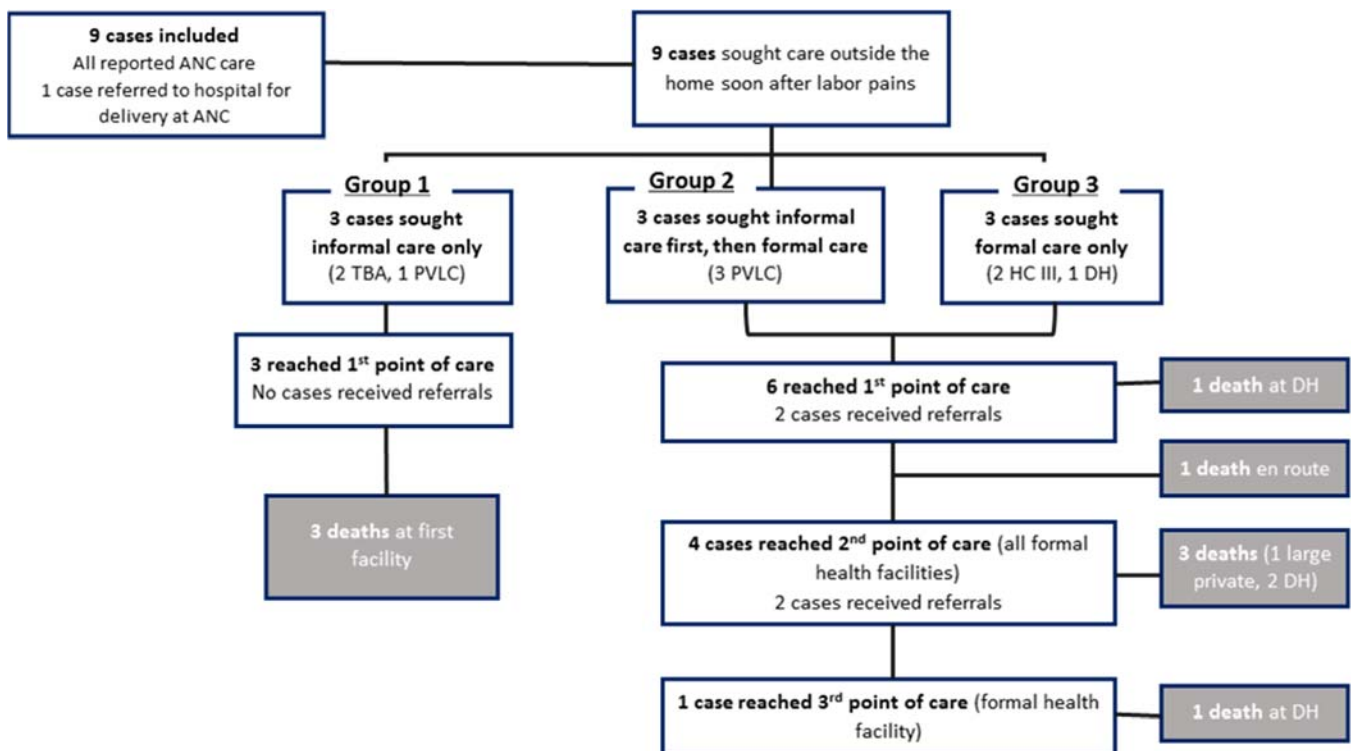
law's on foot at 5:00 pm. When she arrived at the TBA, Evelyn was examined and told she was

in labor, but the sister-in-law could not give her care because she was going to a seminar. Evelyn

was sent to another nearby TBA clinic. She walked alone to this TBA clinic and arrived around

7:30pm. She gave birth well at 8:00pm, at which time her caretakers, including her mother and

sisters left the TBA clinic and returned to the funeral. Around 10:00pm Evelyn noticed she was

sweating heavily and called the TBA for help. The TBA thought the illness was *Amakairo* and

began to treat her by smearing her skin with local herbs. Soon after Evelyn began bleeding and

the TBA gave her tabs and an injection. Realizing the treatment was not working the TBA called

out for help. The TBA could not travel to find Evelyn's caretaker because she feared to travel

alone at night as a woman. The TBA stayed at her clinic and continued to yell for help. Evelyn

passed on at 1:00am before anyone heard or arrived to help.

Florence – Group 2 (Case 1)

Florence was 25 years old when she died after the delivery of her third child. She visited

the government facility for ANC several times and received traditional care of smearing oils with

egg shells on the skin during pregnancy. After the onset of labor pains, Florence walked to a

nearby PVLC at 10:00 am. She was in labor for 26 hours and gave birth at noon the next day.

After delivery, the provider at the PVLC gave her two injections and then left the facility to

attend a funeral, leaving Florence and her caretakers without care. Soon after, Florence began to

complain of dizziness and her caretakers noticed "she changed" in her health status. They treated

her with traditional treatments of rubbing herbs and kerosene on her head and skin. This

condition was attributed to a traditional illness known as *Amakairo.* When this failed to improve

her condition Florence was transported by motorcycle taxi with her mother and brother-in-law to

Table 4: Types and services of public health facilities in Uganda (Ssengooba) with the number of each type of facility in Iganga District and Nawandala sub-county where the majority of cases lived (Ministry of Health Uganda, 2012).

Health Facility Type	Level	Services	Number of Facilities in Iganga District (Nawandala Sub-county)
Village Health Team (VHT)	Village	No health facility, community based services, health promotion	No data available
Health Center Level II (HC II)	Parish	Preventative, promotive, curative outpatient services, sometimes ANC	40 (2)
Health Center Level III (HC III)	Sub-county	HCII services, plus maternity and in-patient services	14 (1)
Health Center Level IV (HC IV)	Sub-district	HCIII services, plus emergency surgery, blood transfusions, EmOC (C-sections and post-abortion care)	2 (0, 1 in neighboring sub-county)
General Hospital (GH/DH)	District (serves population 500,000)	HCIV service, plus x-rays and laboratory services	1 (0, estimated 30 km from Nawandala HC III)
Regional Referral Hospital (RRH)	Population serves 2,000,000	GH services, plus specialist clinical services, higher level surgical and medical services	0 (0)
National Referral Hospital (NRH)	Population serves 30,000,000	RRH services, plus comprehensive specialist services, health research and teaching	0 (0)

a HC III. At the HC III she was given two IV drips and the providers realized they could not treat the patient and told her caretakers to rush her to the district hospital. Again the brother-in-law found transportation, a motorcycle taxi, and they travelled 40 minutes to the hospital. When they arrived at the hospital the line was long and Florence died before she received any care.

Irene – Group 3 (Case 8)

Irene, who died at age 16 years old, was married and this was her first pregnancy. During her pregnancy she suffered from fevers, pale/yellow skin, and severe vomiting. For these symptoms she attended ANC for three visits beginning during her six month of pregnancy and also received traditional treatment. This consisted of drinking an herbal mixture that was taught to her sister-in-law by her mother. During labor Irene was brought to the HC III at 11:00pm on a motorcycle by her husband, who abandoned her at the facility with no food or money. Her sister-in-law, the participant in this study, was called by healthcare workers to come help. Irene delivered her baby at 12:00am, but her placenta was retained. Over the next 9 hours the providers at the health center tried to pull it out without success, eventually tearing the placenta and moving away from the patient after realizing they were unable to help. Her sister-in-law noticed her worsening situation and waited for a referral. At 9:00 am, she decided to take Irene to the district hospital without receiving a referral. She leaves the health center to locate a motorcycle taxi to transport them, which cost 10,000 UGX (~ $3 USD), money that was provided by the brother-in-law. As Irene and her sister-in-law are traveling to the hospital she passes away, never reaching the district hospital.

Key Themes and Barriers

Community Knowledge

The community beliefs surrounding pregnancy were diverse. Participants described multiple reasons for seeking ANC such as: "because we are told to", wanting the provider to have an understanding of the pregnancy, women recognizing abnormal symptoms during pregnancy, and fear of not receiving treatment during delivery from providers if they did not

seek ANC (fear of retribution). While some of these reasons paired with good quality ANC care could help reduce the delays encountered during delivery the fear of retribution could have the opposite. One participant whose sister died from hemorrhage at the district hospital after not receiving a blood transfusion, explains her reason for seeking ANC was for fear of retribution and wanting the provider to understand the pregnancy:

Figure 3: A generalized pathway with key points that lead to the maternal deaths highlighting the three delays. Illustrates the effect of key time points on barriers that women face.
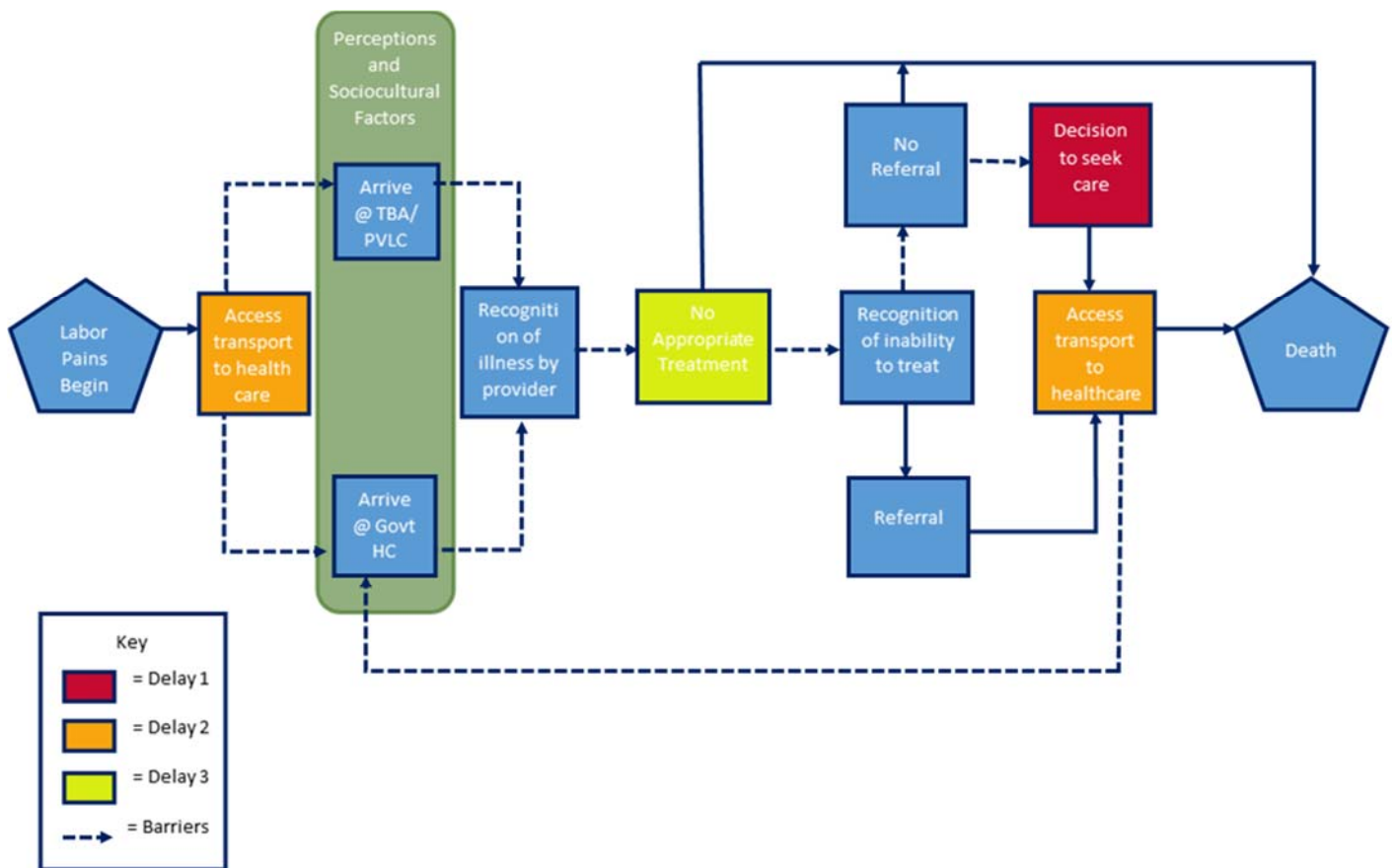
"I know very well if I don't go for ANC and time comes that I have to deliver the

providers will take long to attend to me because I delayed to do that. They don't know

my problems, they don't know my weaknesses, and for the provider to start helping me,

she doesn't know where to start from…So I think there she decided to go for ANC

basing on what she was feeling and the effect if you don't go." – Group 3, Case 9

ANC was often paired with traditional methods of prenatal care which included drinking

herbal teas, smearing herbal mixtures on the skin, or sitting in a mixture of ashes to help widen

the pelvis and guard against a traditional illness known as *Amakairo[1]*. *Amakairo* occurs after

delivery and is described with a mix of biomedical and folk symptoms including pain in the legs,

fever, shivering, "struggling", "something pulling the woman", and sometimes the mother eating

the child. This is often described as the final illness that the woman has before death. One

participant describes *Amakairo* as follows:

"It just come abruptly…you start shivering as if your feeling cold and you are

unconscious. And they say that if they harden [the illness progresses, becomes more

severe] on you, you can even eat the child in the absence of the people." – Group 2, Case

1

Beliefs regarding providers and health facilities were often negative and could cause a

delay in seeking care among community members. Participants perceived that providers yell at

women, beat women, and believe women are unhygienic if they fail to follow birth preparedness

guidelines, such as buying the necessary delivery supplies of covera (plastic sheet that goes over

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[1] This is the phonetic spelling of this word in the Lusoga language. Lusoga is a spoken language, there is no agreed upon spelling of this word that the author could find.

the birthing bed), a razor, and a cotton pad. When asked about the care that her daughter received

from a PVLC during delivery before she arrived, one participant replied:

"She didn't have any indications that maybe she was beaten because there are some

providers who always beat women in that time. She wasn't beaten". – Group 1, Case 7

Another participant discussed how his wife selected a facility for her delivery. He explained:

"There are some people [healthcare providers] whom they fear because when you go to

them they bark [shout] at you, they abuse you and so people fear them" – Group 2, Case

11

These two examples illustrate the community beliefs about providers and care received in health

facilities. Women were more familiar with TBA's and PVLC's in their communities, which were

said to be staffed with providers who took good care women, this familiarity lead to more

comfort with these places and therefore women choose them as their first point of care over

government health facilities. They often knew other women in the community who delivered at

these facilities leading to perceptions of better care, whether this care was adequate or not. For

example, one husband described perceptions of good quality care at a PVLC his wife delivered

at, even though his sister-in-law died soon after delivering from the same facility. Figure 4 shows

the facilities in which women visited during and after delivery.

Transportation

Once a decision to seek health care was made, poor transportation caused a considerable

delay in obtaining health care. Transportation as a barrier to care relates to delay 2 in the three

delays model. Transportation barriers included a lack of access to suitable means and cost

associated with transportation. These barriers varied by facility type.

Figure 4: The ways in which women travelled through health facilities. The n in the circles indicates how many women used this type of facility as their first point of care. The n in the black pentagons indicates the number of women who died at the corresponding facility. Cases that died en route and at a large private hospital are not included in the total n for the deaths.
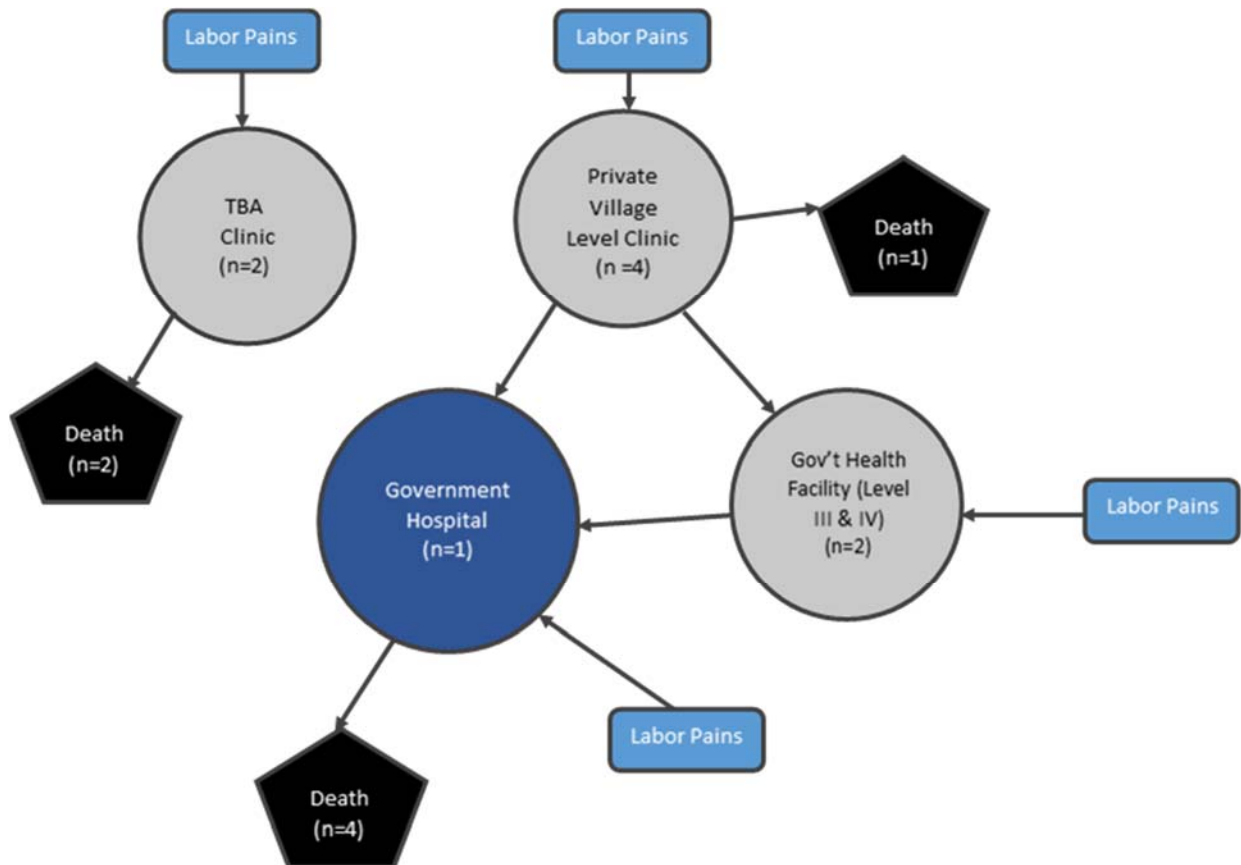
Transportation to TBA/PVLC

Most women walked to the TBA or PVLC due to the facilities nearby proximity in the

villages. The economic incentives of walking (i.e. no financial cost) influenced the decision to

seek care at the TBA or PVLC as the first point of care over higher level government health

centers because the TBA and PVLC facilities were closer. One participant described her decision

to take her daughter to a PVLC as the first point of care during delivery. Her reasons included

not having money to travel to a farther health facility and not having a man to travel outside the

village with:

"First and foremost, I didn't have money to take us far and I was alone, I didn't have

anyone in case of [needing to go to] any other place." – Group 1, Case 7

This quote illustrates the prohibitive effect of cost on a person's decision to seek care at

particular facilities and women's status on the choice of where to seek care. In this case women's

status showed the inability of women to travel outside the village alone and women's often

limited financial resources. In regards to the ability to travel alone outside the village this was

found at night only. It is unclear if this is due to fear of traveling alone for safety reasons or

because women are not permitted to travel alone. This delays future decisions to seek EmOC at

more qualified health centers that are located further distances.

Transportation to Government Health Centers

Government health centers were located farther distances than village level care from

women, this combined with the cost of transportation was a deterrent for seeking care at these

locations. To access more advanced transportation options, such as motorcycles, caretakers had

to search the areas surrounding health facilities on foot, producing another delay. The inability to

quickly secure transportation resulted in the loss of valuable time for these women. Often women

took Boda Boda (motorcycle taxis) with multiple family members to these government health

centers. Boda Boda's are the most readily available transportation in the area but was not

appropriate in all cases. Cases when women are in very critical states and cannot hold on, or they

need to travel with small children the Boda Boda is not feasible. The addition of poor road

quality added to the problems facing women using this form of transportation. The distance from

the HC III in the sub-county to the district hospital is about 19 miles. In one case a women

attempted to travel the 19 miles with her sister-in-law by Boda Boda in a critical condition, she did not finish the journey and died before reaching care.

When other means of transportation were needed, such as a car, the cost and delay of the transportation increased. In addition, participants discussed the problems with a lack of transportation available, the unavailability of fuel, and the decreased options for transportation at night. For example, one women's sister described the situation of transportation in their village:

> "With the transport, on this whole village, we have two motorcycles, when they reached one Boda man's place he had gone to town with the Boda, the other Boda man, the motorcycle didn't have fuel. But on the whole village we have one person who sells fuel, when they reached there, they found the fuel wasn't there, that is where we found the problem… we suffer a lot, indeed that is the problem, transport is not easy." – Group 3, Case 9

Journey by motorized transport to these government health centers lasted between 20 minutes and three hours. The cost of transportation was more prohibitive if the health facility was farther away due to the overall greater expense and because families had already spent funds on transportation and care at other facilities. The money for transportation was often provided by the husband or brother-in-law. This takes autonomy and power of decision making away from the woman and affected the ability of women to seek care if her husband did not support her choice. Other sources of money for transportation included friends and community members. The search for money delayed transportation to the facility and subsequently delayed a woman's care. Costs for transportation ranged from 10,000 UGX to 50,000 UGX (~$3 -$17 USD). One mother describes her journey to obtain money for transport to a higher level health center, after her daughter began having seizures after delivery:

"When I saw that she was so much complaining about it, I hurried to tell my friends who were still attending the funeral to see what we could do, by the time I reached, she had already passed on and that is where I lost my mind" – Group 1, Case 7

Recognition of Danger Signs

During Pregnancy

During pregnancy, women often described danger signs and symptoms experienced for which they sought ANC and traditional care. Some danger signs were not recognized as complications in pregnancy including Malaria and previous pregnancy complications, such as "over-bleeding" or hemorrhage. However, these illnesses or symptoms and the ANC care sought did not affect the care seeking process during delivery. Many women still sought care at PVLC's even though they may have had more complicated pregnancies that required more advanced provider skills to manage. In one case the care sought influenced the woman to go directly to the district hospital during delivery because she received a referral at 8 months gestation. It is believed that this woman had severe pre-eclampsia (she had many symptoms including, high blood pressure, and leg swelling), additionally one of her twins was transverse. Even though she did seek care at a hospital, she waited at least 12 hours from the start of labor pains to initiate the care seeking process. Again, this shows that the ANC care did not improve the care seeking process in cases of complicated pregnancy.

During and after delivery

The initial decision for women to seek care at a health facility did not follow the Three Delays model logic in these cases. These cases did not discusses facing delay 1 (delay in

recognizing the need to seek care during delivery) when seeking care during labor. In most cases, women sought care soon after labor pains began. In all but two cases, women sought care at what they believed to be clinics with skilled providers. These clinics included government facilities and PVLC which participants thought had skilled providers for delivery care. Often the mother, mother-in-law, or older sister was consulted and had some authority to decide where to seek the first point of care. In group 1 cases, the mother or mother-in-law determined that the woman would seek care at a TBA facility. This affected what type of care a woman received during an obstetric emergency.

During and after delivery caretakers of women (non-providers) recognized worsening of the woman's condition but language used indicated vague understanding of the illness. Phrases used to indicate this recognition of a worsening illness were "she changed" or "the situation worsened". A sister describes when they recognized the illness:

> "She was not in a very bad condition that would scare, she was in a normal way as any other person in labor. The situation changed after she bled. But she wasn't ill, that maybe she would not give birth, no. After that, she was so weak, the condition changed, she changed the color. She was pale and she could indicate that she didn't have blood." – Group 3, Case 9

There was a lag in time from the recognition of these changes until a higher level of care was sought, even after realization that the current provider was unable to manage the condition. As illness progressed symptoms recognized by caretakers included dizziness, weakness, confusion, bleeding, retained placenta (in one case), being pulled or having a struggle (possibly convulsions). One participant described her daughter's progression of her illness as follows:

"She gave birth very well, I talked to her, and it was after like 10 minutes that she

complained about the stomach ache. In the same process she said she was feeling hungry,

like someone who has run mad. There, that's when she started struggling, she complained

of the legs, the legs, and severely she complained about the legs." – Group 1, Case 7

During and after delivery women lacked appropriate medical attention and referral to higher

levels of health care by providers.

Health Facility Knowledge

Women sought care at various types of health facilities. Knowledge of locations of health

facilities was not a barrier because participants knew where to seek higher levels of care at in

their communities. Most women sought care initially at a TBA or PVLC and in most cases the

participants did not know the credentials of the provider. Many participants assumed that

providers were midwives or that they were skilled providers. One husband describes the

credentials of his wife's provider at a PVLC she visited as follows: "I can't tell the level at which

she [the provider] is. It's true she's a professional but I don't know the level at which she is" –

Group 2, Case 11. This belief by participants that these PVLC's are staffed by skilled providers

lead to delays in receiving appropriate treatment due to a lack of capacity for EmOC at these

facilities, contributing to delay 3. Additionally, this leads to lengthy referrals by increasing the

number of health facilities visited and time in transportation, delay 2.

Health System

Referral System

The results in this study confirm other research findings that the referral system in

Uganda is highly ineffective and contributes to major delays in the care seeking process.

Participants reported general feelings of distrust and a lack of confidence in the referral system.

Also, participants expressed anger towards providers who did not refer women who they were

unable to treat appropriately. One participant discussed her sister's experience with a provider

who was neither able to provide proper medical treatment nor a referral. She explained:

"If the health workers see that things are worsening in the next hours let them refer us

faster to people who can manage the issue better than them. That our lives may be

saved…Because the health worker may stay with the patient for a long time yet he knows

very well that he will not manage the situation because from midnight [I waited] and I

decided to tell them in the morning to refer us. When there was no one saying that I

should take her to another facility. That one hurt me a lot. That's when I said, 'no let me

get my patient and do what? And I take her. Let them give her to me.'" – Group 3, Case 8

In this quote, the lack of ability to treat or refer by the provider corresponds to delay 3, receiving

appropriate treatment at a health facility, and delay 1, delay in the decision to seek care.

Additionally, this could affect the future care seeking by community members if they lack faith

in the ability of the health care system to appropriately treat patients.

All of the women who sought care at a TBA or PVLC did not receive a referral or

received a delayed referral from the provider to a higher level of care. In many cases women died

at these clinics. Women who sought care at higher level government health centers also faced

issues in not receiving referrals. After noticing "changes" and "worsening" of the deceased's

condition and witnessing the health center staffs inability to manage the patient's condition families decided to seek care elsewhere. The lack of a referral caused a delay in caretakers making the decision to move to another facility. The reasons for these delays included fear of anger from providers, no provider present at the clinic, and caretakers not recognizing symptoms until it was too late for appropriate care to be reached and received.

TBA/PVCL

Women who sought care at TBA's and PVLC's faced unique challenges at these types of facilities. These challenges included not receiving appropriate treatment and malfeasance. These correspond to the third delay, the delay in receiving appropriate treatment once at a health facility.

Not receiving appropriate treatment

Many women who visited TBA and PVLC often received traditional treatments of rubbing herbal mixtures or kerosene on the skin when illness was recognized. In addition they often received tabs and/or injections to treat the complication. Participants were not aware of the names or purposes of these medications and the appropriateness of these treatments could not be determined. Communication between providers and caretakers was not present leading to delays in the ability for the caretaker to seek higher skilled care. In some cases caretakers were required to purchase or bring their own medications for injections.

Malfeasance

Malfeasance was defined as when a provider purposely affected the ability for a women to receive appropriate treatment. At TBA and PVLC's malfeasance manifested as denying patients treatment or patients being left at the facility without care. Both of these factors were associated with delays in receiving appropriate treatment and needing to find care at other facilities, or multiple other facilities. Here a participant describes why they visited various healthcare facilities:

> "We went because of the situation of the deceased and the provider had left us there [at the PVLC] and she change so we had to go to another level, when we reached there [government HC III] they put her on drip but they noticed no change that is when they sent us to …[government hospital]…."' Group 2, Case 1

Government Health Centers

Seeking care at government health centers created its own set of barriers that were different from TBA's and PVLC's. These barriers included not receiving appropriate care, bribery, and malfeasance. While some of these themes overlap with TBA and PVLC's there attributes and dimensions were different.

Not receiving appropriate treatment

Often women that sought care at the only district hospital faced long lines and delays in treatment for emergency situations. Three cases encountered long lines when they arrived for treatment at the district hospital. Two of these women died before receiving any treatment. The district hospital was the final point of care for many women. Staff shortages were also described

in the participants' experiences. A sister describes the situation at the hospital when they arrived

for care:

> "So I was there and I was like eh what shall I do and the nurses were showing me that
>
> they were very busy. Women were all over the place scattered they are crying from there.
>
> They were shouting nurse come and help me and I saw all nurses were busy on their
>
> work." –Group 3, Case 6

Staff shortages or absence of skilled midwives at lower level government facilities (HC III and

HC IV) were discussed as reasons to not seek care at these places. These long lines and staff

shortages led to delays in treatment corresponding to delay 3. Common descriptions of

treatments received included receiving tabs (tablets or pills), injections, and drips though

participants were again not aware of the names or purposes of these medications. Women and

caretakers again faced a lack of communication from providers at these facilities. Additionally,

provider stock-outs of medications and essential supplies, such as blood for transfusions led to

deaths.

Bribery

Almost all of the cases that received treatment at a government hospital had to pay bribes

to hospital staff in order to receive treatment. The knowledge that care at a higher level

government health facility would require these types of informal payments was universal. These

bribes ranged from 10,000UGX to 150,000 UGX (~$3 USD - $50 USD). The economic and

stress burden from having to pay these was apparent and it is possible that this knowledge of the

cost of treatment is why most women sought care at the PVLC first. The following are examples

of bribery described by participants:

"I really feel bad about that doctor…because he never showed responsibility, he just shouted at us, saying we don't have blood here, who told you that we normally have blood here? And we all wondered, we went and told the doctor that if you need money, we are going to give it to you" – Group 3, Case 9

"The man who operated the deceased at that time I didn't have the money he had requested for I told him "sir the money shall come tomorrow because I didn't carry it with me but had kept some money somewhere". I had kept some money somewhere purposely for that person because I'd known that she has to deliver from here [hospital]….he asked me don't you have even 10,000 [UGX] (~ $3 USD) so I told him I only had transport that brought us but by tomorrow the money shall be here. Now the time he arrived... in the [next] morning to come and demand for the money. The time he arrive he found something had struck the deceased and was struggling…But shamelessly he told me to go to the bank and get for him what? The money" – Group 3, Case 6

Malfeasance

Malfeasance by a health care provider was found in a little over half of the cases of this investigation. At government health centers malfeasance ranged from withholding or denying treatment to a patient to providers giving up on treatment without referring the patient to a facility that could handle the complication. Withholding treatment that was available at the facility was the most common form of malfeasance and occurred at the government hospital. This occurred simultaneously with bribery in which the care was withheld until payment was

discussed or received. Participants often expressed highly negative feelings regarding this type of treatment from health providers.

Seeking care at multiple facilities

Seeking care at multiple facilities was an underlying factor in many of the barriers mentioned above. In this study women seeking care at multiple facilities faced significant delays at each point of care. Each instance that a woman needed to seek a higher level of care was hindered by receiving a referral, the decision to seek care, issues of transportation, and receiving appropriate care at the next health facility. See Figure 2 for the interaction of these barriers and delays. These delays correlate with the each of the three delays, but not necessarily in the linear fashion in which the theory is designed.

Chapter 5
Discussion

<u>Introduction</u>

The maternal mortality rate continues to remain high in Uganda at 343 deaths per 100,000 live births despite pushes to improve maternal health in the global community (The World Health Organization, 2014a). Iganga District faces one of the highest maternal mortality rates in Uganda (Uganda Bureau of Statistics, 2009). Past research in Uganda has focused on maternal health and cause of death studies (Anyait, Mukanga, Oundo, & Nuwaha, 2012; Kabakyenga et al., 2011; Kyomuhendo, 2003; Mbonye, Asimwe, Kabarangira, Nanda, & Orinda, 2007; Parkhurst, 2006; Rutaremwa, Wandera, Jhamba, Akiror, & Kiconco, 2015; Somigliana et al., 2010). Thus far there has been little emphasis on the social, behavioral, and health systems contributors to maternal deaths in this region. These factors are important to understand the full continuum of maternal health care, to identify inefficiencies, and to create targeted interventions to reduce maternal mortality (Moshabela et al., 2015). The long and convoluted chain of events that eventually result in a maternal death must be understood to enact meaningful change.

The Three Delays model has previously been used to understand the intersections of this complex series of events. In its current form the model proved to be ineffective in understanding the maternal deaths in this study. Based on this research an update of the Three Delays model is necessary to capture the changing landscape of maternal care seeking. To reduce maternal death in Iganga district there need to be improvements in emergency transportation, EmOC, provider training, and healthcare quality.

<u>Changes in Care-Seeking Behaviors</u>

Much of the previous research that involved maternal death reviews in Uganda has

focused on hospital based methods for the identification of maternal death cases (Somigliana et

al., 2010). A primary purpose of this study was to gain a deeper understanding of maternal death

in the region including women who did not die in a health facility. This aim was achieved by

using both health facility and community based methods to identify maternal deaths. We found

that all of our cases were reported to have sought care soon after labor pains began with a

minority using TBA clinics. No women died at home or before reaching a first point of care

indicating that delay 1 was not an issue in these cases. A study conducted in Senegal found that

the initial decisions to seek care were not a problem but that later delays contributed to deaths

(Moshabela et al., 2015). Past research on maternal care seeking in Uganda found that in a

majority of cases women planned in advance the location in which they would deliver

(Parkhurst, 2006). These results are similar to this study and indicate a shift in the care seeking

behavior of women since the development of the Three Delays model. It is possible that the

initial decision to seek care was a problem in these cases and that women did delay in their care

seeking during delivery. However, this was not mentioned by respondents.

This shift is significant in that it shows that women are in fact attempting to seek skilled

attendants for their births. Skilled birth attendance is one of the WHO's recommended indicators

for measuring improvements in maternal health (The World Health Organization). In this study,

group 1, which consisted of older women who had higher parity, were the only group of women

who sought delivery care at a TBA. Groups 2 and 3, which were younger on average, attempted

to seek skilled birth attendants. It is possible that interventions and messaging targeting women

seeking skilled attendants is encouraging younger women to seek this care.

The shift in care seeking does not mean that delay 1 was not present in this study. The

first delay was present but did not appear until women had an obstetric emergency and needed to

seek a higher level of care at a second health facility. Each of the three delays was present but

not in the sequential fashion in which the model was designed. In these cases the delays present

most often in the following order: issues in receiving appropriate treatment at a facility first

(delay 3), then barriers to making a decision to seek care at a second health facility (delay 1), and

then barriers in accessing transportation (delay 2). This sequence of delays often repeated during

the obstetric emergency that eventually lead to the woman's death. This made data analysis using

the three delays model difficult. A focus on a more cyclical framework for the three delays,

especially in places in which women seek care at multiple facilities may be better suited

(D'Ambruoso et al., 2010). Additionally, expansion of the three delays to include a fourth delay,

delay in receiving an appropriate referral, should be considered in contexts in which a referral

system is in operation. This delay was arguably one of the largest contributors to maternal deaths

in this study. The referral system is discussed in greater detail below.

Understanding Illness in the Community

Although the initial decision to seek care was not a barrier in this study, seeking an

appropriate level of care was a barrier. All women in the study were reported to have attended

ANC care from a government health facility. Often these women sought care due to the

recognition of abnormal symptoms during their pregnancy. In some cases these symptoms were

signs of complicated pregnancies in which women should have changed their care seeking in order to appropriately manage the conditions during delivery but this did not happen. This suggests a lack of appropriate counseling on management of risk factors during ANC visits. A study conducted in Eastern Uganda found that counseling on birth preparedness and risk factors was the poorest aspect of ANC care performed (Tetui et al., 2012) and less than half of women were able to recall warning signs of pregnancy complications at exit interviews (Kaye, 2000). Additionally, 40% of women were not advised on where to deliver (Kaye, 2000). This could be why women did not seek appropriate levels of care during delivery to manage possible complications from risk factors. Other possibilities for women not seeking appropriate levels of care during delivery could be miscommunications between providers and patients (Cham et al., 2005). A study conducted in a neighboring district on the quality of midwifery care found that many midwives themselves were not able to recall the symptoms and causes of pregnancy complications (Kaye, 2000), indicating a significant gap in knowledge among midwives.

The quality of ANC care is very important in that deficiencies in this care can diminish women's faith in the usefulness of ANC and increases the risk of maternal mortality (Sundari, 1992). To affect the care seeking of women improved counseling by providers on birth preparedness and key danger signs and improvements in the overall quality of ANC visits should be a focus of intervention efforts. This should address the gaps in basic knowledge of providers. To be effective the intervention would need to include improved technical supervision on the job and encouragement for providers to share knowledge among each other (Kaye, 2000). This intervention would help to diagnosis and treat conditions early and educate women on their

pregnancy status. Additionally, in order to encourage women to seek referrals in cases of emergency the knowledge of key danger signs is important (Kabakyenga et al., 2011).

Another important aspect of understanding illness in the community, especially during an obstetric emergency, is the knowledge of key danger signs among caregivers. In this study the ability for caretakers to recognize illness often came too late after symptoms had progressed to a critical state. As discussed above, knowledge among women of key dangers signs is low. One study estimated that 19% of women were able to identify key danger signs in all three periods of maternity (pregnancy, childbirth, and postpartum) (Kabakyenga et al., 2011). It is plausible to suggest that among those who are not recently pregnant this knowledge of obstetric danger signs is even lower. Additionally, danger signs during delivery in a high maternal mortality setting may receive less attention because they occur so frequently they are normalized (Thaddeus & Maine, 1994). In these places only severe complications evoke a response from woman or caregivers (Kyomuhendo, 2003). This normalization and inability to recognize danger signs among community members is important during an obstetric emergency because at some point women become unable to care or make decisions for themselves and must rely on a caretaker.

This reliance on the caretaker's ability to recognize illness in an emergency brings to light the need to focus education on danger signs not only among pregnant women but also among caretakers including, sisters, sisters-in-law, mothers, and husbands. These people were most often present during the occurrence of emergencies and could have the greatest impact in reducing delays in seeking care at higher level second points of care. An intervention that could assist in this building of knowledge among caregivers and women would be using a mobile phone based education platform. Mobile phone access was almost universal among cases in this

study with 8/9 women having a functional mobile phone. A study in Rural Uganda used mobile phone platforms to improve adherence to antiretroviral treatment among HIV positive people and found significant improvements among people in the intervention group (Kunutsor et al., 2010). Although the condition is different this type of intervention is a low cost way to disseminate information among women and caretakers without the excess burden of time and travel to women.

Traditional explanations of illness were common in the later stages of obstetric emergency among cases in this study. The traditional condition of *Amakairo*, a fever that occurs after delivery which leads to death, among women was common and was explained with both biomedical and traditional symptoms that varied among respondents. *Amakairo* was often the final explanation of illness and participants spoke about it with a sense of defeat. These traditional explanations of pregnancy complications are common around the world (Castro et al., 2000; D'Ambruoso et al., 2010). This traditional illness was often treated with traditional treatments. The traditional explanations of illness around pregnancy has often affected behavior, care seeking, and treatment (Castro et al., 2000; D'Ambruoso et al., 2010). The normality with which this traditional illness of *Amakairo* was mentioned shows how common maternal death is among these communities and how it is understood. The perception that death is somewhat inevitable from this illness is can lead to perceptions that nothing can be done which is a manifestation of the first delay (Thaddeus & Maine, 1994). By bringing understanding of danger signs during pregnancy it is possible to alter the defeatist perspective with which this illness is viewed and encourage caretakers and providers to continue to seek and give treatment to these women.

The community perceptions of providers at health facilities yelling at and beating women during ANC and delivery could negatively affect care seeking behaviors. Although no accounts of the cases actually receiving this type of treatment were reported in this study the perception that these acts occur was present. These perceptions are determined by people's personal experiences and people they knows experience with the health system and can affect where women chose to seek care at (Thaddeus & Maine, 1994). This perceived quality of care relates to delays in care seeking behaviors and has been shown in research studies in Uganda and elsewhere (Castro et al., 2000; Cham et al., 2005; Kyomuhendo, 2003). In Uganda, women described healthcare workers at government facilities as being rude and discriminatory and sought care at these facilities as a last resort (Kyomuhendo, 2003). Another study conducted in a neighboring district in Uganda found that perceptions of kindness about HCWs at a particular facility correlated with women being more likely to seek care in that facility (Anyait et al., 2012).

Positive perceptions and familiarity were discussed in relation to PVLC's in this study. Perceptions in the community that providers at PVLC's were kind and provided good care, as well as, knowing someone that previously delivered at these facilities created a preference among women to deliver at PVLC's. These clinics were viewed to provide equal or better care than government health facilities. Additionally, in a baseline investigation conducted by SAFE Mothers, SAFE babies on care seeking among mothers 95% of women reported that these clinics were staffed by a midwife or doctor (Cutts et al., 2015). However, investigation into these facilities revealed that the majority were in fact not staffed by skilled providers (Cutts et al., 2015). This misperception could create greater delays for women to receive treatment in an

emergency if the providers at the PVLC's are not trained. Unfamiliarity with government health facilities affects the decision about where to seek care (Kyomuhendo, 2003; Sundari, 1992) and could also delay the decision to seek higher level care at these facilities. In order to encourage women to seek delivery care at facilities that are better equipped to handle these cases increased familiarity and perceptions of kindness are necessary among providers at government health facilities.

Transportation

The delay in the ability to reach a medical facility after the decision to seek care has been made is known as the second delay (Thaddeus & Maine, 1994). Rather than perceptions that affect care seeking this delay encompasses actual physical barriers that women face in getting to treatment. This delay is arguably one of the most important aspects in reducing maternal mortality, especially in rural settings (Macintyre & Hotchkiss, 1999). If women are unable to traverse the distance to a health facility in a timely manner it does not matter what the quality of care is at the health facility. Barriers to transportation effected where women decided to seek care and how long it took to get there. Delays in reaching a health facility occurred every time a woman needed to seek care at another health facility and were exacerbated by late provider referrals. When women needed to seek care at multiple health facilities this added up to very costly delays. Delays in transportation and late referrals account for a disproportionate amount of maternal deaths (Sundari, 1992). The negative and costly effects of these delays are well documented in the literature (Castro et al., 2000; Cham et al., 2005; Fawcus, Mbizvo, Lindmark, & Nystrom, 1996).

The distance's to government health facilities was a deterrent for seeking care there and described as a reason to seek care at TBA or PVLC which were located closer to women. Women did not have access to motorized transportation in their households. When care needed to be sought at farther distances barriers included the need to search areas surrounding health facilities to procure transportation, long periods of time traveling, and costly transportation fee's. The problem of distance to a health facility is further escalated during obstetric emergency in this district due the lack of availability of EmOC. The district hospital is the only facility in the district with the ability to perform Cesarean sections and store blood (Ministry of Health Uganda, 2012).

Women's status negatively affected the ability for women to travel to health facilities. Due to the inability of women to travel alone at night and a lack of access to money for transportation. In cases in which there was not a husband or brother-in-law available women had to wait until daylight to seek care for an obstetric emergency. This extended to female providers not being able to access help due to fear of traveling alone at night. It is unclear from this data whether this inability to travel alone at night was due to concerns of safety or community norms. Whatever the underlying cause this leads to costly delays for women. The unequal distribution of income is common in rural and developing countries and negatively impacts the ability of women to make decisions regarding their care (Evjen-Olsen et al., 2008; Parkhurst, 2006; Rutaremwa et al., 2015). Therefore solutions that reduce the need for women to rely on men for economic and social support are needed. Improvements to women's empowerment are essential to improve economic and social development which also influence rates of maternal mortality (Miller & Belizán, 2015).

The need for improvements in the availability of transportation in emergencies is not new. However, the rural setting of this region makes the problem of accessing health facilities in a timely matter difficult. Previous interventions to address the problem of transportation have been implemented in the region by the organization in which this study was conducted in conjunction with. The e-ranger motorcycle ambulance program which provides subsidized transportation on a motorcycle ambulance that was implemented received support from the community (Safe Mothers Safe Babies, 2014). However the program faced viability issues around unsanctioned use of motorcycle, drivers charging money, and inability to repair the vehicle. Interventions that supply motorized ambulatory services these regions are often met with sustainability concerns. The new iteration of the motorcycle ambulance program by SAFE will attempt to use locally manufactured motorcycle's to overcome the inability to repair, and will use community based collections to sustain the program (Safe Mothers Safe Babies, 2014). The community-based collection schemes are often a solution suggested to overcome issues of transportation.

Other interventions that attempt to address transportation barriers include subsidies to transportation unions, development of ambulance services, and community based emergency loan funds (Macintyre & Hotchkiss, 1999; Shehu, Ikeh, & Kuna, 1997). Often these solutions are met again with sustainability issues. An interesting solution of community based insurance schemes (similar to the SAFE community-based collections) to help community members to meet the cost of emergency care, including obstetric emergency care and transportation, are increasingly being implemented to solve this problem (Macintyre & Hotchkiss, 1999). These risk-sharing schemes help to address the issue of financial barriers leading to delays in

transportation and treatment. These schemes have seen some success but have problems with high overhead and capital costs (of vehicles if transportation is included in the scheme), the need to define accepted medical uses for the insurance, and skepticism and distrust from the community (Macintyre & Hotchkiss, 1999). The issue of sustainability with these programs is often very difficult to overcome.

An alternative to financing schemes and the introduction to ambulatory services (or perhaps in addition to these interventions) would be to bring the services that women need to them instead of bringing women to the far away services (Thaddeus & Maine, 1994). This means expanding the package of EmOC services that are available to women at facilities that are closer to them. This would reduce the number of facilities that women would need to travel to, the time spent travelling, and the cost of transportation for families.

According to the Health Sector Strategic Plan in Uganda, HC IVs and district hospitals should provide comprehensive EmOC, including blood transfusions and Cesarean sections, while HC III's should provide basic EmOC (Mbonye et al., 2006). Currently in Iganga district there are three government health facilities that are supposed to provide comprehensive EmOC (1 DH, and 2 HC IV) but only one is able to do so (Ministry of Health Uganda, 2012). An intervention to make these two additional theaters operational and implementation of blood banks at each would reduce the distance women need to travel for EmOC. This solution was enacted in Prevention of Maternal Mortality (PMM) network interventions and they found declines in case fatality rates and increases in access to EmOC in regions of Sierra Leon and Nigeria at lower costs than creating new infrastructure (Maine, 1997).

By providing a package of basic EmOC at HC IIIs, including parenteral antibiotics, removal of retained products, assisted vaginal delivery, manual removal of placenta, oxytocic's, anti-hypertensive's, and neonatal aspiration most obstetric complications could be handled at lower tiers of care (WHO et al., 2009). Currently in Iganga district there are 14 HC III. A 2003 needs assessment showed that in Uganda only 6% of HC IV were able to provide comprehensive EmOC and only 4% of HC III could provide basic EmOC (Orinda, Kakande, Kabarangira, Nanda, & Mbonye, 2005). In one case in this study the providers at the HC III were unable to assist a woman with the removal of the placenta and negligence by the staff caused her death. Previous interventions to train midwives in EmOC at lower level health facilities increased the number of women who sought care and decreased the number of referrals that were necessary (Maine, 1997). This expansion of services would reduce the distance women need to travel to the district hospital for services (Maine, 1997) and could have very positive effects on maternal mortality in Uganda. However the need to increase spending and resources of MCH at health facilities would need to be enacted for this to take effect (Sundari, 1992). This would include increased access to essential medicines included in basic EmOC.

The Health Care System

First Point of Care

While the expansion of EmOC services at lower level government facilities would decrease delays in traveling to health facilities for women the majority of cases in this study used PVLC and TBA clinics as their first point of care. The use of these facilities as the first point of care had direct effects on the events that occurred during and after delivery.

At the time the study was conducted the study staff was unaware of the presence of private village level clinics or PVLC's. After realizing that many women were delivering at these facilities an assessment of these clinics was conducted by SAFE in the region in which the study occurred (Cutts et al., 2015). This assessment found that in the study region 83% of PVLC's were staffed by unskilled providers with minimal training (Cutts et al., 2015). They also found that the availability of equipment, such as blood pressure cuffs, and essential drugs, such as Oxytocin and Ergometrin, was very low (Cutts et al., 2015). These clinics operate outside of government oversight and do not adhere to Ugandan standards of care or have access to controlled pharmaceuticals that government facilities do. The lack of essential supplies and training in these PVLC's causes an inability by providers to handle obstetric emergency. The illegitimate status of the facility may also act as a deterrent for providers to offer referrals to women. The failure of these providers to refer women was a significant barrier for cases in this study. This led to longer delays in women accessing appropriate levels of care. The phenomena of untrained attendants in Mexico led to these providers giving up on care or providing incorrect care and stating that it was correct (Castro et al., 2000). Although this study is unable to determine the appropriateness of treatment in these cases, we can assume from this other research that failure to treat appropriately was a delay faced by women at PVLC's.

Among women who recently delivered in the region about a fourth have delivered at PVLC's (Cutts et al., 2015). Additionally, these clinics have good perceptions of care in the community and are located close to women in their villages. This could allow for a reduction in delay 2 and possibly delay 3 faced by women if they are able to provide appropriate care. Therefore it is feasible to suggest that an intervention of basic provider training on delivery care

and first aid to be provided to the HCW's at these clinics. This training should be implemented with regular supervision and improved communication with referral facilities (Byrne & Morgan, 2011). Improvements in the ability of these providers to provide basic care, to recognize obstetric complications, and the empowerment of being a trained provider could help to improve care and referrals at these facilities. Multiple studies have shown increases in TBA referrals with the intervention of training and regular supervision (Byrne & Morgan, 2011). Meta-analysis on interventions that provided training to TBA's showed improved knowledge, attitudes, behaviors, and referrals given to women (Sibley & Ann Sipe, 2004). PVLC facilities are different from TBA clinics in that they are currently functioning under the pretext of a health center. Thus this intervention could be more effective among this population of providers because they are already accepting of the ideology of western medicine.

As part of this intervention increased communication among PVLC's and referral clinics would be integral. Previous interventions introduced into Iganga district attempted to improve communication between TBA's and health facility staff with radio communication for the provision of referrals and medical advice (Musoke, 2002). This intervention helped to increase referrals from TBA's because they could communicate with referral facilities and overcome issues of illiteracy for referring (Musoke, 2002). To increase referrals and care at PVLC's that are already present in these villages training, communication, and supervision should be provided to these clinics to promote quality of care and empowerment for referrals. For this intervention to be effective health system improvements at government facilities would also need to be enacted (Byrne & Morgan, 2011). All of this requires increases in funding and support to reducing maternal mortality.

Additionally, it would be ideal if these clinics were also included under the regulations of the Ugandan MoH and required to adhere to the same standards of care as government health facilities. As of 2011, these facilities, as well as TBA's and pharmacies (unregulated) are not accredited by any government body or council, and are technically not operating illegally because there are no laws to regulate these facilities (USAID & Ministry of Health Uganda, 2011). Additionally, the private health sector under which these facilities operate often goes unregulated due to a lack of government capacity and a continued growth of the sector (USAID & Ministry of Health Uganda, 2011). Increased ability for oversight in the Ugandan MoH would need to be a reality for this to be possible. More research should be conducted on the prevalence and use of these types of facilities throughout Uganda to assess if a national level intervention is necessary.

The expansion of EmOC to lower level government health facilities and increasing the ability of PVLC's to recognize obstetric complications would mitigate many of the delays women faced in this study.

Referral System

As discussed throughout this thesis the referral system utilized in this region of Uganda is highly ineffective and leads to immense delays for women seeking care. The author believes that the inability to receive an appropriate referral is its own delay, the fourth delay. This fourth delay is significant in that it affects each decision point afterwards and was faced by all cases. The fourth delay had its own unique set of contributors which included perception of severity of illness by providers and caretakers, type of health care facility, transportation, and quality of

care. Thaddeus and Maine include the ability for a provider to refer into delay three, the ability to receive appropriate treatment (Thaddeus & Maine, 1994). In fact the problem with referral spans not only the health system but also social and behavioral factors of caretakers. Clearly, TBA's, PVLC's, and HC III's were unable to manage obstetric complications and providers at these clinics were unable to provide appropriate referrals to the district hospital. This factor hampers progression of care for patients and "increases rates of mortality, as well as, patient dissatisfaction and distrust" (Moshabela et al., 2015). This distrust and dissatisfaction could lead to decreases in utilization of health care services in the community.

In many cases the referral system was not activated when an obstetric emergency occurred or it was activated too late. In cases when it was activated too late women often did not arrive at the second point of care in time to receive treatment. The providers may have been unable to identify the severity of the illness in these cases. In other cases providers gave up on treating a patient after realizing they were unable to treat and did not refer. The referral process is being hindered at these points of service, which is detrimental to outcomes for these women. Some providers may fear retribution from government agency either because they are operating illegitimately (in PVLC's) or because they fear being fired or punished (in government health facilities). This was apparent during data collection when health facility staff were reluctant to discuss maternal deaths that happened. Often staff stated that no deaths or obstetric emergencies had occurred in the area. It is important to further investigate the causes for the lack of referral by providers to appropriately address the inefficiency.

The lack of referrals by providers is not the only barrier that women face in the referral system. Women who did not receive referrals from providers often sought care at a second

facility anyway. However, in these cases there was a delay in the time it took for caretakers to recognize the illness was progressing and to make the decision to seek care without the referral. The families sometimes pressured providers to give them a referral to another facility after it was apparent that providers were unable to treat the patient. After this decision was made the transportation available was another barrier to getting to the referral facility. The ability to obtain and use affordable transportation in an emergency is thought by some to be one of the largest barriers of the referral system (Macintyre & Hotchkiss, 1999). Therefore to address the inefficiencies of the referral system it is also necessary to address community knowledge about obstetric danger signs and the availability and cost of transportation. Both of these factors are discussed above.

The implementation of ineffective referral systems in many other countries has led to women to seeking care at multiple health facilities, which often leads to delays and fatalities (Castro et al., 2000; Cham et al., 2005; D'Ambruoso et al., 2010). In order to improve maternal mortality this fourth delay, the delay in receiving a referral, needs to be improved.

District Hospitals

While improvements at private care facilities and in transportation to health care centers would help to reduce the barriers that women face the inadequacies of government health facilities proved to be the final barrier that many women faced before their deaths. These barriers were faced by women at all facility levels, but most notably the district hospital, which was the final point of care for many cases. Improvements to lower level government health facilities (HC III and HC IV) were discussed above. This discussion will focus on necessary improvements at

the hospital level as they relate to this data. Throughout the government health system women faced the inability of providers to treat there conditions appropriately. This inability to treat consisted of mismanagement of patient cases including malfeasance, provider shortages, and lack of essential supplies and medicines.

Provider shortages were very apparent in all cases that arrived at the district hospital for care. In many cases women received no care and did not even see a provider before death due to the long lines that they faced waiting for treatment. These women arrived in critical states during their obstetric emergency due to previous delays. When women did receive care they had to wait in long lines and the care often came too late. This shortage of trained personnel is known to affect and contribute to maternal mortality (Castro et al., 2000; D'Ambruoso et al., 2010; Sundari, 1992). In Uganda, the deficit in human resources in health (HRH) is well known and document (Government of Uganda, 2010; Ssengooba; USAID & Ministry of Health Uganda, 2011). Estimates of HRH vacancies range from 37% to 47% of public health sector positions (Tetui et al., 2012; USAID & Ministry of Health Uganda, 2011), with strong rural and urban differentials, and skilled care being focused at higher level regional referral hospitals and national referral hospitals (USAID & Ministry of Health Uganda, 2011). This leaves women in rural areas without access to highly skilled providers, such as Doctors and Medical Officers. The causes of these shortages include unattractive wages and incentives in the public sector leading to attrition to the private sector and immigration to neighboring countries (USAID & Ministry of Health Uganda, 2011). Poor training capacity, poor quality at training institutions, and doctors and nursing moving to non-clinical roles, such as management add to shortages (USAID & Ministry of Health Uganda, 2011). Additionally, high rates of absenteeism are common among

healthcare workers (USAID & Ministry of Health Uganda, 2011). All of these factors create a serious shortage of personnel to treat the large number of cases that seek care at the only district hospital and operational surgical theater in a region with a population of 466,000 (Ministry of Health Uganda, 2013).

The intervention of improving the provision of services at HC IVs and HC IIIs, discussed above, and improvements in the ability to treat at PVLCs would decrease the strain on staff at the District Hospital. However, in order for health facilities (HC III and HC IV) to expand their services more quality trained midwives and doctors would need to be available and willing to work at these facilities. This means that higher incentives and improvements in the capacity and quality of training of health care workers would need to be implemented. One suggestion to reduce the strain on HRH in Uganda has been to ensure that clinical staff are spending the majority of their time in direct patient care and they are not moving to non-clinical management roles (Ssengooba).

In Uganda, newly trained doctors are often not competent to handle obstetric emergency due to the ability to opt-out of obstetrics and gynecology rotations during medical school (Ssengooba). This leads to the inability for these providers to appropriately manage obstetric emergency cases and increases the third delay (Sundari, 1992). This also speaks to the status and priority given to women and maternal health in Uganda. In order for large reductions in maternal mortality to occur the status of women needs to be improved not only through the requirement for doctors to be able to handle women's health needs but in communities as well. This is seen in the ability for women to be autonomous in their decision making abilities.

In this study we were unable to determine which types of treatments women were given due to lack of caretaker knowledge on the types of drugs given to cases. The lack of essential supplies at health facilities has been discussed in previous research (Mbonye et al., 2006; Ssengooba) and presented in this study as the inability for women to receive blood transfusion in cases of hemorrhage. The lack of this essential supply is one of the most important inadequacies in a health facility leading to maternal death (Sundari, 1992). Improvements in the procurement of blood for these cases is integral to preventing these maternal deaths. In a study of the PMM network a community level campaign to increase the number of blood donations was conducted and increased monthly blood donations at a hospital from 41 to 121 donations (Maine, 1997). A simple campaign such as this could ensure that blood is available when a patient needs it. Other factors that are important for these cases is the understanding by providers of the extent of blood loss that is occurring so that lifesaving treatments can be administered in time. The above discussion of implementing two additional blood banks at the HC IV's could also ensure that women receive this treatment in a timely manner.

Treatment received at government health facilities should be free to patients according to Ugandan health policy. However, it was universally known to participants that this was not the case. Informal payments were expected to be given to doctors in order for women to receive lifesaving treatments. This led to delays in care seeking because family members needed to find money for transportation and treatment, leading to economic strain on caretakers. Some caretakers expressed preparation and saving for these types of treatments but not all did. Further interventions to encourage this type of preparation for emergency care should be nurtured at the community level. This type of intervention is currently implemented as part of the SAFE

intervention package (Safe Mothers Safe Babies, 2014). The acceptance of bribery by the community speaks to the larger state of the health system and the economic status of people in Uganda. The low pay of health care workers, lack of supervision, and corruption all lead to this behavior. Bribery proliferates negative feelings by participants about the providers at these facilities, which can affect future care seeking. In order to enact true improvements to maternal health these underlying problems in the public health sector need to be addressed.

Important to the understanding of maternal health conditions, care, and feelings of safety is communication with providers. In most cases this communication with providers was absent. This shows a general lack of respect for the patient from providers which affects care seeking and perceptions about providers. The lack of communication also proliferates misconceptions in the community around maternal deaths and misunderstandings. In order to increase the acceptability of government health facilities there needs to be improvements in communication between providers, patients, and caretakers.

Limitations

This investigation faced many limitations in its methodology. The study was limited to maternal deaths who died later in pregnancy and during or shortly after delivery. This limitation is common in studies on maternal mortality due to the inability in low resource settings to identify pregnancy status early in pregnancy (AbouZahr, 2003; Somigliana et al., 2010). Further research to assess the contributing factors to deaths for these women is necessary to gain a full understanding of the burden of disease of maternal mortality.

The potential for social desirability and recall bias is present in this study. The knowledge that a local NGO associated with non-community members who support western medicine could have led participants to inappropriately cite activities that they were asked about. This could have affected discussion of women seeking ANC and going directly to health facilities after the initiation of labor pains. The study attempted to mitigate this bias by using community leaders to ensure participants felt safe and by training interviewers in non-coercive and non-leading questions. In all retrospective investigations there is the possibility of recall bias. This study limited deaths to two years before the study start which has been shown to minimize this bias (Campbell & Ronsmans, 1994; Webber & Chirangi, 2014). The rare occurrence and significance of a maternal death increased confidence by researchers that recall bias would be limited.

One of the largest limitations of this study was the inability to qualitatively interview the women themselves on their experience. The study used the proxy of a care taker in order to better understand contributors but we are unable to assess the true perceptions and behaviors of women through these methods. Often time participants may not have been present for the entire illness or may not have been present at all and have heard the story from other family members. This led to gaps in the timeline and events, as well as, variations in data quality and availability. Staff attempted to mitigate this limitation by finding the most knowledgeable care taker available. This limitation is undeniable in a study on maternal death.

In qualitative investigations it is important to reach a point of saturation in which new interviews or cases bring no new information. In this study we were unable to reach saturation due to the limited timeframe and resources available. This research brings to light important aspects of the contributors to maternal deaths in this region but does not provide a complete

picture. Due to the rare occurrence of maternal deaths a surveillance system that investigates maternal deaths as they happen would be the most effective way to reach this saturation point.

Other methodological limitations include interviewing using mid-level interviewers and translation using a one step process. Both of these methods were chosen due to limited resources. The ability to ensure that no data was lost due to translation was not possible in all cases. The use of more experienced interviewers could have led to richer descriptions of the cases. Additionally, the primary investigator conducted all of data analysis in Atlanta, GA. This surely has led to cultural misinterpretations. During transcription and translation some of these cultural misunderstanding were discussed with local staff members to allow the primary investigator to better understand unique cultural components. Future studies of this kind should employ using multiple researchers for data analysis to ensure intercoder reliability. Additionally, using at least one local researcher during the data analysis portion would reduce cultural misunderstandings.

The initial protocol for this investigation attempted to use tablet based survey and interview guides to ease the burden of data collection. However, in this setting difficulty with the ability to access Wi-Fi and electricity were present. Also, the chosen data collection software was not suitable for qualitative investigations. It is important to understand the context and technology needs of a research study and to employ study techniques that are suitable to both of these factors.

Conclusions

Maternal mortality is still a significant problem in Uganda. To achieve global goals on reducing maternal mortality more understanding of the contributors to maternal death at the

community level are necessary. By understanding these contributors we can work to develop interventions that meet the needs of women in these communities. Qualitative social autopsy is one way to begin to understand the complex chain of events and barriers that women face on their pathway to death.

It is apparent that many women do seek ANC and skilled delivery care. The interaction of social, behavioral, and health systems contributors affect the ability for these women to reach appropriate care. Behavioral contributors such as not preparing financially for the cost of emergency care and a lack of knowledge of obstetric danger signs among women and caretakers are significant contributors to maternal death. Social contributors including community perceptions of health facilities, women's status, thoughts about traditional illness, and the availability of appropriate transportation are barriers to reaching appropriate care. Lastly, health system contributors such as poor provider training, low availability of EmOC and essential medicines, and a poorly functioning referral system all prove to be insurmountable obstacles for women.

Improving the quality of care and ability of providers to recognize obstetric emergencies at all levels of health facilities is important to reducing delays. In places where referral systems are in place it is important to ensure that these referral systems are operating effectively and to enact changes to increase their efficiency. These referral systems enact a large effect on the barriers that women face during obstetric emergencies and should be treated with more importance. Increasing access and number of facilities with EmOC should be considered as a solution to reduce delays in transportation and receiving appropriate treatment. Not only is more research on maternal death and care seeking needed but a more nuanced understanding of how

women are interacting with the health care system is necessary. This research should bring with it a tailored combination of interventions to assist women in overcoming barriers. Only by increasing resources devoted to understanding and overcoming barriers women face during delivery and obstetric emergencies can maternal health for all women be realized.

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