LIFE AND DEATH OF VILLAGE WOMEN A COMMUNITY BASED MATERNAL DEATH REVIEW IN SOROTI DISTRICT TESO SUB REGION UGANDA

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Operational definitions

Maternal death: “the death of a woman while pregnant or within 42 days of the end of the pregnancy, irrespective of the duration and the site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes.”

Direct maternal death: a death resulting from obstetric complications of the pregnant state (pregnancy, labor, and the puerperium), from interventions, omissions, incorrect treatment, or from a chain of events resulting from any of the above.

Indirect maternal death: is a death resulting from previous existing disease, or disease that developed during pregnancy, and which was not due to direct obstetric causes, but which was aggravated by the physiologic effects of pregnancy.

Late maternal death: is a death occurring between 43 days and one year after abortion, miscarriage or delivery. It can be due to direct or indirect causes.

Pregnancy-related death: is a death occurring in a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the cause of the death.

Fortuitous or Incidental maternal death: is a death from unrelated causes which happen to occur in pregnancy or the puerperium.

A verbal autopsy for maternal death: is a method of finding out the medical causes of death and ascertaining the personal, family or community factors that may have contributed to the death in women who died outside of a medical facility.
Maternal death review (MDR): is a type of medical audit. It is a qualitative in-depth interview of the causes and circumstances surrounding maternal death in health facilities, in the community, during or after transport from the community to a health facility, or from a lower level health facility to a referral hospital.

Qualitative research: is primarily exploratory research. It is used to gain an understanding of underlying reasons, opinions, and motivations. It provides insights into the problem or helps to develop ideas or hypotheses for potential quantitative research.

Quantitative research: emphasizes objective measurements and the statistical, mathematical, or numerical analysis of data collected through polls, questionnaires, and surveys, or by manipulating pre-existing statistical data using computational techniques.

Qualitative Descriptive Research: The goal of qualitative descriptive studies is a comprehensive summarization, in everyday terms, of specific events experienced by individuals or groups of individuals.

Thematic analysis: is one of the most common forms of analysis in qualitative research. It emphasizes pinpointing, examining, and recording patterns (or "themes") within data. Themes are patterns across data sets that are important to the description of a phenomenon and are associated to a specific research question.

Theoretical saturation: is the phase of qualitative data analysis in which the researcher has continued sampling and analyzing data until no new data appear and all concepts in the theory are well-developed.
**Grounded Theory:** is an inductive methodology. Although many call Grounded Theory a qualitative method, it is not. It is a general method. It is the systematic generation of theory from systematic research. It is a set of rigorous research procedures leading to the emergence of conceptual categories.
## List of Acronyms

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<th>Description</th>
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<td>Sustainable Development Goal</td>
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<td>MDG</td>
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<td>TSM</td>
<td>Tesosafe Motherhood</td>
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Chapter One: Introduction

1.1 Brief background

Maternal mortality remains a challenge to health systems worldwide. Information about rates and trends in maternal mortality is essential for resource mobilization (Hogan, M. et.al,1980-2008) towards meeting the challenge and ending preventable deaths to pregnant, birthing, and post-partum women.

The researchers of this proposed study are associated with Soroti Regional Referral Hospital (SRRH) and Teso Safe Motherhood Project (TSMP) in Soroti District, Birth and the Human Future of Dexter, Oregon, USA, and International Midwife Assistance of Boulder, Colorado, USA.

Soroti Regional Referral Hospital is a public hospital funded by the Uganda Ministry of Health. It is one of thirteen regional referral Hospitals, and one of fifteen internship hospitals, in Uganda. There are over 600 births a month at SRRH. The hospital has 274 beds and offers services to approximately two million people.

Teso Safe Motherhood Project is a maternity center where comprehensive nurses and midwives provide full service maternity care with over 100 births most months. Emergency obstetrical services are accessed at SRRH.

Providers of maternity care received special attention in the World Health Organization sponsored Millennium Development Goals (MDG) from 2000 to 2015. The 2015 goals for safer motherhood were however not met, though progress was made. The Millennium Development Goals were then replaced by the Sustainable Development goals (SDG’s). (WHO,2015)
Building on the momentum generated by the Millennium Development Goals, the Sustainable Development Goals establish a transformative agenda for maternal health towards ending preventable maternal mortality. Goal number 3 is to ensure healthy lives and provide health and wellbeing for all ages. Target 3.1 is to reduce the global maternal mortality rate (MMR) to less than 70 per 100,000 live births by 2030. (WHO & UNICEF, 2015)

The Safe Motherhood Initiative is a loosely organized world-wide effort to reduce maternal mortality. It was started when a UN Conference for Women, in Nairobi, in 1987, made known the wide spread epidemic of preventable deaths occurring among childbearing women. In 1990, it was calculated that there were half a million maternal deaths globally per year. Advances in measurement now show that throughout the Safe Motherhood years, steady progress has been made. (Kassebaum, N. et al., 2016)

The world population and the total number of births have increased, and yet the number of deaths worldwide in 2015 was substantially reduced to 303,000. The maternal mortality ratio, throughout the Safe Motherhood years, steady progress has been made. (Kassebaum, N, et al., 2016)

The world population and the total number of births have increased, and yet the number of deaths worldwide in 2015 was substantially reduced to 303,000. The maternal mortality ratio, which is the number of deaths per 100,000 live births, decreased from 385 to 216. Sub-Saharan Africa including Uganda also made progress: the regional change went from an MMR (maternal mortality ratio) of 987 and total maternal deaths of 223,000 in 1990 to an MMR of 546 and total deaths of 201,000 in 2015. (WHO & UNICEF, 2015.)
1.2 Problem statement

Sub-Saharan Africa, though rich in natural resources, is the world’s poorest region in terms of gross national product; the area also has the highest maternal mortality. Despite considerable progress in 30 years of Safe Motherhood projects since 1987, women still die unnecessarily.

In 2015, deaths in developing regions were estimated at 302,000, with an over-all MMR of 239. The number of maternal deaths in developed regions was 1,700 for an MMR of 12. (WHO & UNICEF 2015).

The MMR of Uganda was 687 in 1990 and 343 in 2015. (WHO, et al., 2017.)
1.3 Research questions:

a) Why do childbearing women die?

b) Where do maternal deaths take place?

c) What are the stories of the mothers who die and the families who are left motherless?

d) What else do we need to know about maternal mortality?

e) What could health care workers and others in Soroti District do to advance knowledge of what might save women’s lives?

1.4 Research objectives - (broad and specific)

a) To perform an ongoing case seeking and review at the village level of women who die as a result of pregnancy and birth.

b) To understand the underlying factors that lead to maternal deaths. To learn from the stories of survivors of women who die while pregnant or within one year of the end of pregnancy on what might have helped the women and their families, or what might have eased their passing.

d) To analyze the information from many people and gain a better understanding of why women in the reproductive cycle die.

e) To determine possible ways of helping mothers access emergency obstetrical care in a timely manner.
1.5 Significance of study

Pregnancy is a normal, healthy state to which most women aspire at some point in their lives. Yet this normal, life-affirming process carries with its serious risks of death and disability. Maternal deaths worldwide have been reduced by one-half through efforts to achieve Safe Motherhood goals. However, ninety-nine percent of these deaths still occur in developing countries, 85% in sub-Saharan Africa and south Asia. Among developing regions, sub-Saharan Africa has the highest MMR with 500 deaths per 100,000 live births, compared to a global MMR of 210. (DeBrouwere, Vincent et al., 2013).

DeBrouwere &, Vincent et al 2013, in the FIGO guidelines on conducting maternal death reviews list community based maternal death review as part of a package to advance the efforts of local professionals and their teams to reduce preventable maternal deaths.

The purpose of this study is to learn about the deaths of women in pregnancy, birth, and the post-partum period, especially those which are out of hospital, those which occur in transport, and/or shortly after admission to the hospital.

The purpose is to learn from the circumstances of the deaths and not to lay blame or guilt on any individual or institution.

1.5 Limitations of Study

The study design does not enable us to calculate the maternal mortality ratio or rate for our district.

The study design does not enable the diagnosis of specific cause of death in all cases.
Chapter two: Literature Review

2.1 introduction

A key resource in the study of maternal mortality is the WHO publication *Beyond the Numbers, reviewing maternal deaths and complications to make pregnancy safer.* (WHO, 2004)

The following statement from the introduction to the book explains its usefulness.

Today, with better understanding of the difficulties involved in measuring levels of maternal mortality, there is increasing interest in directing a larger share of limited resources into efforts to understand why the problem persists and what can be done to avert maternal deaths and cases of severe morbidity. Answering these questions is vital for planners and service providers. Different strategies and tools have been developed to help find out why mothers die. This document describes the main existing approaches and provides practical guidance on how to generate information that looks *beyond the numbers* to the underlying avoidable causes of maternal death. (WHO, 2004)

Later in the introduction there is a word of encouragement to researchers like ourselves, clinicians in the fields of obstetrics and midwifery and concerned citizens.

The approaches described in this guide . . . . can be implemented by safe motherhood advocates or, indeed, by any individual or institution committed to reducing maternal mortality and morbidity. Experience has shown that although the initial implementation is often on a small scale by a few committed individuals, the approaches can subsequently be implemented on a broader scale, even at the national level (WHO, 2004)

Another useful and thought-provoking reference is an extensive historical study by Irvine Loudon, a British doctor, medical historian and artist who died in 2015 at the age of ninety. In *Death in Childbirth, an international study of maternal care and maternal mortality (Charlot G, Borst. 1800-1950)* we learn useful facts about how and when the maternal mortality was reduced in countries now constituting the “developed world”. Considering things which accompanied maternal mortality reductions in the past point towards things which might help in today’s high MMR areas. A useful example is from Sweden, a country with a small population spread out over a large, rugged area. They kept birth and death records from the early days.
Between 1800 and 1850, the maternal mortality rate there dropped by half, from 1,000 per 100,000 births to 500. The author investigates historical records to learn why. Increased training and use of midwives occurred in those years. Social and economic improvements also occurred. He speculates on how these trends all related, so many years ago. (Ibid, p. 409 – 411)

The Swedish MMR dropped by half once more from 1850 –1900; from 500 to 250/100,000. Increased training of midwives is cited, along with, in 1880, the development of the germ theory and the use antiseptic technique in childbirth.

The years from 1900 to 1950 show the MMR dropping by more than half once again, to 100/100,000 and less. New factors which saved lives were safe blood transfusions, antibiotics, safe anesthesia, and other factors which provide for safe surgery an important preventive of maternal mortality. (Colleen D Acosta & David A Harrison et al.,2016)

Loudon shows us in Death in Childbirth that the causes of maternal death are multifactorial. Its remedies probably are too. The above two references are of unique interest in the study and prevention of maternal mortality.

The Safe Motherhood Initiative is also important with its extensive literature. This initiative has inspired work on many fronts to reduce maternal mortality. In Maternal Mortality – A Neglected Tragedy: Where is the M in MCH? Rosenfield and Maine, (1985) give a view on obstetrical realities in. The article was an important influence on the birth of the Safemotherhood Initiative. For an overview of the successes and difficulties of the 30-plus years of the initiative see Generation of Political Priority for Global Health Initiatives: a frame work and case study of maternal mortality (Jeremy Shiff man, Stephanie Smith et al.,2007).

Measurement of the phenomenon of maternal mortality has been difficult from the start of the Safe Motherhood Initiative and before. As soon as maternal deaths were studied, more maternal deaths were found, so the reported rates began to rise.

In the last years of the 20th century it was thought that despite years of work, no progress was being made. As the 21st century began, advances in measurement techniques incorporating more and varied types of data showed that steady progress had indeed been made throughout the years of the Safe Motherhood Initiative. (Akema, et al. 2015.)

Community based maternal mortality review and verbal autopsy are used interchangeably in earlier literature. In Beyond the Numbers (WHO, 2004,).
a comprehensive guide to studying maternal mortality, the terms are at times used interchangeably. However, verbal autopsy is more strictly a quantitative method. It deals with things which can be measured by numbers. An autopsy is a post-mortem examination of a body, often involving dissection. In verbal autopsy, factors surrounding a death dissected, through the use of words to arrive at a diagnosis. Most medical studies are quantitative.

“Verbal autopsy is a method of gathering health information about a deceased individual to determine his or her cause of death.

Verbal autopsy has been found valuable in deaths of infants and children. It has been found less useful in maternal death. Perhaps there is more complexity. “Data on causes of maternal death obtained from verbal autopsies lack precision and should only be used to obtain a general impression of causes of death in a community”. (WHO, 2004)

The World Health Organization has published guidelines for creation of the interview tool which is used in verbal autopsy/community maternal death review. (WHO, 2016.) We made use of this resource in creating our interview tool.

Qualitative analysis gives us a look at the subject’s story. Who was the subject, the one who died during pregnancy, birth or the post-partum period? What about those she left behind? How are they doing? We interview them to learn her story, and we also learn their story. And we gain new understanding from their answers to the open-ended questions. What happened? Looking back at the death, what might have helped? What needs did the interviewee have which went un-met? “The purpose of qualitative analysis is to look at the factors which may have led to the woman’s death in more detail”. (WHO, 2004,)

“Whose faces are behind the numbers? What were their stories? What were their dreams? They left behind children and families. They also left behind clues as to why their lives ended early.” (Berg C et al., 2001)
Chapter three: Methodology

3.1 Study design.

We will perform a retrospective mixed methods study, containing both quantitative and qualitative elements. The qualitative elements are in the form of “verbal autopsy” for maternal death, to find the medical causes and other factors that may have contributed to the death of a woman who died outside of a medical facility, or soon after admission. The in-depth interview results are necessary information for facilities that cater to these women in order to continue lowering rates of death. Much is known about causes of death within facilities. TSMP works hand in hand with the medical authority in this region to reach women deep in the village. The goal is to help them freely choose to seek care at a health center. The verbal autopsy is the tool that reveals possible causes of delay to seek help.

Names of survivors of women who died during pregnancy, birth or in the year after giving birth between 1 January 2015 and 31 December 2018 will be obtained from local village councils. Contact with local leaders will be by a local gentleman, fluent in both Ateso and Kumam as well as English. Only after the consent and information from local leaders will contact be made with the individuals identified by those leaders. Only individuals who are freely interested and willing to participate will be recruited.

Research will be carried out by interviews conducted in our office in Soroti which provides a private and comfortable space for interviews and counseling. Personnel will consist of interviewer, interpreter, and transcriptionist, in addition to consultants, data analysts, and writers. (new content replaces previous paragraph #1.18/11/18)

We have prepared consent forms and a form introducing and describing the researchers and the research in English, Ateso and Kumam. (see appendix).

We have created a questionnaire with both specific and open-ended questions about causes of death and about personal, family and community factors that affected the pregnancy, birth, and the time after for up to one year from the time of birth.
3.2 Study population

Informants are survivors of women who have been pregnant and who died during pregnancy, birth, or in the year after giving birth. The death must have taken place between Jan. 1, 2015 and December 31, 2018. We would like to talk to anyone who was intimately involved in the pregnancy, birth, or the postpartum year; family members, neighbors, traditional birth attendants, medical people who cared for her, village health team members, and others in the villages or towns who knew her well and/or were present at the time of birth. We may interview more than one person regarding a particular woman’s death.

The person who seeks out and recruits eligible participants for the study does not decide if a death was pregnancy related or incidental, but simply enrolls willing participants who are survivors of women who had been pregnant and who died during pregnancy, the birth process, or during the year after birth.

Informants will be given assurance both verbally and in written form of the absolute confidentiality of their information. They will sign the confidentiality form by signature or by X assenting that they understand the methods being used to protect their private information.

Interviewees will be given a 20,000 Ugx transport allowance to cover costs of traveling to and from the research office for their interviews.

3.3 Data collection methods

Interviews will be performed in a private place. We have an office with a waiting room and an interview room in a secure compound. It is sturdily built, so that voices in the interview room cannot be heard in the other room. The interviews will be conducted with an English-speaking interviewer, who will ask the questions. The questions will be translated into Kumam or Ateso by an interpreter who is fluent in all three languages. The reply will then be translated into English, and the interview will proceed.

The English part of the interview will be transcribed for further study. Each interview will be tagged with a unique code and the name removed for storage in a password protected computer. Paper records will be stored in a locked drawer or file cabinet.
3.3.1Data analysis

Analysis will take place after all the interviews have been conducted. Methods used will be grounded theory and thematic analysis. The narrative synthesis approach may help us understand the evidence and explore relationships between the stories of the various subjects.

Quantitative data including participant characteristics will be analyzed with descriptive statistics, including means, standard deviations, ranges, frequencies, and percentages. A medical team will review all the interviews to determine diagnosis for the cause of death when possible.

3.5 Study limitations

In determining the maternal mortality rate, the numerator, total number of maternal deaths found, is divided by the denominator, number of live births among which the deaths occurred, to determine the rate. We have sought out deaths of childbearing women to study. We cannot make a claim to have located all of the deaths in the time period we are studying, so the numerator would be an inaccurate number. And since there is no civil registration of births or deaths in Soroti District, we have no way of obtaining the denominator for our equation for the maternal mortality rate.

It is not possible for our study to determine a maternal mortality rate or ratio. We have potential figures for the numerator in the equation, but the numbers are incomplete. We have no accurate values for the denominator.

The data used in diagnosing the cause of death comes from the quantitative sections of our questionnaire, or verbal autopsy. Verbal autopsy is not considered a reliable method for determining diagnosis of death in maternal mortality. (Hooman K, Arash E, et al., 2010)

Never the less, our data will be reviewed in attempt to obtain diagnosis when possible.

“Different assessors may arrive at different medical causes”.

“Verbal autopsies should not be used to examine the contribution of technical aspects of care delivery.”

This is probably because the information in the verbal autopsy in community based maternal mortality review comes from the observations of non-professionals who are experiencing loss. They may be emotionally distraught and do not have an in-depth knowledge of pregnancy and childbirth.

“The verbal autopsy aims to identify general areas for improvement rather than quantifiable indicators.” (WHO,2016)
Our study will not be able to obtain a diagnosis of cause of death in all subjects.

### 3.6 Ethical considerations

We hope to submit our study for Institutional Review Board consideration both in Uganda and in the United States. Informed consent will be sought from all respondents. Participation in the study is voluntary and refusal will not affect any services that the subject might receive from Teso Safe Motherhood or Soroti Regional Referral Hospital. All information collected will be used only for research or educational purposes. All information regarding the informant and the one who died will remain confidential. Respondents will be identified by a code of numbers and letters to protect their identity. Their names will not appear on their interview or on any of the information they have shared.

All the data collected will be stored in a password protected computer which is owned by the research group, and/or in a locked drawer or cabinet in a secure facility.

Acknowledging the power differential that goes along with educational and economic disparities, and the endemic nature of racism, sexism, and classism in the global and national society, we will make a conscious effort to treat all involved in our project respectfully and avoid harm to the less powerful, less educated participants. Especially the village people, both men and women. We will respectful of those who have died and will not release their personal information in everyday life or in any other circumstance.

### 3.7 Dissemination

Local dissemination may encourage vigilance to prevent maternal mortality at local facilities including Teso Safe Motherhood and Soroti Regional Referral Hospital. We will prepare a report for the general public, and copies will be disseminated to the local library, the hospitals and interested practitioners and officials.

We hope that the results will be presented and discussed both locally and internationally. We are hopeful that some interesting and useful results are can be for published, and that the researchers might present the results and conclusions at conferences.
Bibliography


Charlot G,borst (1800-1950) Death in child an international study of maternal and mortality (p.g 1)DO 110.1056/nejm19931183292123.


Berg C et al. (Eds) *Strategies to reduce pregnancy-related deaths: from identification and review to action.* Atlanta, GA, Centers for Disease Control and Prevention, 2001


*verbal autopsy.* https://en.wikipedia.org/wiki/verbal_autopsy

1 WHO, 2004, op cit. p. 34