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Barriers to Achieving Good Fetal, Infant, and Early Childhood Health
in the East Central Region of Uganda

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Bachelor of Arts
Clark University
2012

Thesis Committee Chair: Dawn Comeau, PhD, MPH

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Behavioral Sciences and Health Education
2016

Abstract

Barriers to Achieving Good Fetal, Infant, and Early Childhood Health
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By Julia Greenspan

Poor maternal and child health (MCH) can have many causes and both short- and long-term impacts on individuals and entire communities. In the East Central Region of Uganda, the current status of MCH is dire. High morbidity and mortality rates are directly related to poor MCH outcomes. A theory that has studied maternal mortality is the Three Delays Model, which outlines three delays related to the household, transportation, and medical care. Beginning at conception and ending at a child's second birthday, the First 1,000 Days has been shown to be a pivotal time to positively influence the health of fetuses, infants, and young children, and the impacts of this period can have life-long implications. This study aimed to examine if, in the East Central Region of Uganda, the Three Delays Model was applicable to the First 1,000 Days, and to identify the emic understandings of health and illness throughout the First 1,000 Days. With a local non-profit, seventeen in-depth interviews were completed with men and women through a systematic random sampling method. All three delays were found throughout pregnancy, infancy, and early childhood. Similar themes relating to the emic understandings of health and illness were found throughout the First 1,000 Days. Future interventions could use the Social Ecological Model, as it can address the complex barriers that participants identified. Interventions should focus on the first delay first, and can include the information gathered on emic understandings to ensure culturally appropriate language is used.

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Acknowledgements

There are so many individuals I would like to thank for helping me get to this point. First, I'd like to thank my thesis committee members, Dr. Comeau and Dr. Yount, for the invaluable feedback you've given me throughout this entire process. I truly would not have been able to produce this piece of work without your guidance. Next, I would like to thank all of those I worked with at SAFE, both in the United States and in Uganda- Jacquie, Medie, Rachel, Debbie, Britton, Sandra, Irene, Ronald, and Jacob. It has been incredibly rewarding to spend the last year working alongside such inspirational individuals who are also passionate about maternal and child health. Next, I would like to thank my interview participants. The seventeen individuals who shared their experiences and insights provided me with important and insightful data, and I hope that programs can ultimately be developed as a result of this study to benefit the men, women, and children living in the East Central Region of Uganda. Finally, I'd like to thank my emotional support system, including my friends and family. In particular, I would like to recognize my mother Debbie, my father Neil, and my boyfriend Shawn. Thank you for your never-ending love and support.

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Introduction

Problem Statement- Global Impacts of Poor MCH

Maternal and child health is one of the most important topics in discussions of public health. In addition to providing insight in to the health of the next generation, maternal and child health (MCH) outcomes are a common indicator for the health of both individuals and communities as a whole (Pincus, 2005). In order to understand the complete picture of MCH, the impacts of morbidity and mortality, influencing factors, prevalence, and preventability of poor health must be examined.

Poor MCH outcomes are multifaceted and are influenced by complex biomedical, economic, and socio-cultural factors. However, many poor outcomes are due to causes that could have been prevented or avoided with education and interventions. The vast majority of maternal deaths (80%) are due to obstetric causes (UNICEF, 2012). As proper education and access to healthcare would have eliminated them, many of these deaths are categorized as "preventable" (USAID, 2014). Similarly, implementing effective health measures at birth and during the first week of life could prevent approximately two thirds of newborn deaths (The Partnership for Maternal, Newborn and Child Health, 2011).

Beyond the biomedical factors that lead to death, there are also many socio-cultural and economic barriers that contribute to mortality. A lack of knowledge contributes to poor maternal health outcomes, and in developing countries, only half of pregnant women attend sufficient antenatal care (UNICEF, 2012). Therefore, although access to appropriate healthcare facilities and increased education about pregnancy and childbirth can decrease the risk for pregnant women, these resources are unavailable or

underutilized (UNICEF, 2012). Being unable to access adequate care during pregnancy is another barrier to achieving good health and having a healthy pregnancy (US Department of Human and Health Services, 2015). Inadequate resources are an enormous issue, as 50% of women in developing countries deliver without a skilled provider (UNICEF, 2012). When women are not attending antenatal care, they are missing not only a time to be seen by a medical professional and have potential complications identified, but also an opportunity for general health education (Wilson, 2013). The number of fetal, infant, and early childhood deaths could be reduced in a similar manner. Interventions directed at increasing education and access to healthcare would positively influence the health of this population (United Nations, 2015).

When mothers become sick or die, there are many negative outcomes. The children of the 500,000 women who die in childbirth each year are less likely to survive their first year of life than their counterparts who have living mothers (UNICEF, 2012). Babies whose mothers die within the first six weeks after childbirth are ten times more likely to die themselves (Wilson, 2013). Beyond this direct relationship between maternal and infant mortality, there are large impacts on a community as a whole when a mother becomes very ill or dies. Mothers are more likely than fathers to encourage their children's education. As education is vitally important to helping communities, a society where mothers are missing due to illness or death will remain stuck in the cycle of poverty (Wilson, 2013).

In addition to maternal morbidity and mortality, the long term impacts of poor infant health are also well established. Common proxies for infant health are fetal growth and birth weight (Figlio, 2013, Royer, 2006). Previous studies have established links

among sibling or infant pairs that show that the child with worse infant health is more likely to experience a range of long-term, negative outcomes. These outcomes include less schooling, more frequent and long-term use of social welfare systems, less income, and, when they are older and have their own children, they give birth to babies that are smaller and have more birth complications (Oreopoulos, 2006, Black, 2007, Royer, 2006). Therefore, when infants that are in poor health grow up, they are predisposed to face additional barriers. For example, adult women who were unhealthy as infants are less likely to be able to break out of the cycle of poverty than their healthier counterparts. Moreover, they are more likely to have risky pregnancies, putting themselves and their future children at risk, thus perpetuating the cycle of mortality and poor MCH outcomes.

As the impacts of poor MCH are well established, there has also been extensive research conducted on ways to improve health during this pivotal time. Beginning at conception, a woman's health is instrumental to the health of the fetus (Centers for Disease Control and Prevention, 2006). After an infant is born, ensuring good health through the first few years of his or her life is very important for long term growth and development. This time, from conception through a child's second birthday, is referred to as the "First 1,000 Days." Discussed more in detail in the Literature Review, the First 1,000 Days represents an incredibly important period for maternal and child health.

Maternal and Child Health in Uganda

In Uganda, the current status of MCH is dire. Approximately 6,000 women die every year in Uganda from pregnancy-related causes, resulting in a lifetime risk of maternal mortality of 1 in 44 (Women Deliver, 2013). For every woman who dies,

another 20 women are injured or disabled (Uganda Bureau of Statistics and ICF International Inc, 2012). Approximately 45,000 babies are stillborn every year, and 90 of every 1,000 live births die before they turn five (Samuelsen, 2013, Waiswa, 2010). A staggering 60% of all under five deaths occur during the first year of life (infant mortality rate of 54 per 1,000 live births), and half of those deaths occur before one month of age (neonatal mortality rate of 27 of every 1,000 live births) (Waiswa, 2010). In other words, 1 in 19 children dies before they turn one (Waiswa, 2010, Requejo, 2014).

For women and children living in Uganda, the First 1,000 Days is a time that is rampant with illness and death. Many women and children succumb to health issues that could have been avoided or treated in a different context, but socio-cultural and economic barriers prevent them from accessing adequate care. One way to explain these barriers is through the Three Delays theoretical model.

Theoretical Framework

Many theories have been developed to attempt to explain the poor MCH outcomes that have been observed worldwide. One theory that addresses both the complex individual and structural obstacles to adequate care in low resource settings is the "Three Delays" (Thaddeus 1994). Developed by Thaddeus and Maine, the Three Delays are identified as: 1) a delay in deciding to seek care; 2) a delay in reaching the health facility; and, 3) a delay in receiving adequate care at the health facility. The theoretical framework was originally developed around maternal mortality in sub-Saharan Africa, and is therefore applicable in Uganda.

Purpose

It has been established that poor MCH has numerous negative impacts, that the current state of MCH in Uganda is dire, that the time from from conception through a child's second birthday is a pivotal time frame, and that theoretical frameworks have identified barriers to receiving vital healthcare. Therefore, the purpose of this study is to examine, in the context of the East Central Region of Uganda, if the Three Delays model can be applied to the First 1,000 Days. The research questions examined in this study are:

1) How do different barriers to achieving good health impact fetuses, infants, and young children?
2) What are the emic understandings of fetal, infant, and early childhood health and illness?

Literature Review

First 1,000 Days

Although many interventions focus exclusively on either health impacts while a mother is pregnant or improving health once an infant is born, it is vitally important to look at both of these time frames. Often referred to as the "First 1,000 Days," this includes the time from conception through age two.

To date, most research on the First 1,000 Days has focused on the impact of proper nutrition. A mother's diet and weight status during pregnancy has been directly tied to birth outcomes (Adair, 2014). It is important not only that a mother receives adequate food, but also that it is nutritionally dense (Christian, 2015). In addition to showing that diet during pregnancy is important, previous studies have also highlighted the impact of a mother's nutrition at the time of conception (Adair, 2014). After conception and pregnancy, the final time frame in the First 1,000 Days is infancy and early childhood. In many environments, proper nutrition for this age group is composed of breastfeeding and a high quality weaning diet (Adair, 2014). The impacts of proper nutrition throughout pregnancy, infancy, and early childhood are evident throughout the life course.

The First 1,000 Days are critical not only to a child's immediate growth, but can also have life-long implications on adult physical growth, which effects education and income (Black, 2013, da Cunhaa, 2015). Adult height is dependent on both genetic and environmental factors, but "growth failure is largely confined to the intrauterine period and the first few years of life" (Victora 2008). Therefore, reduced adult height can be expected if there is early growth failure and no period of "catch-up growth." If a child

experiences stunting during the First 1,000 Days, there is an association with worse educational achievement as adults, specifically "delayed school entry, greater grade repetition and dropout rates, decreased graduation rates from primary and secondary school, and lower school performance" (Victora 2008). Finally, there is an association between better health as a young child and increased earnings. Healthier children do better in school, which helps to remove them from poverty (Victora 2008). However, children that do well during the First 1,000 Days grow up to be taller and stronger adults, which is also associated with increased income. This association remains even after adjusting for education (Victora 2008).

The numerous studies that have focused on the First 1,000 Days show that interventions focused on the time frame are designed to be population-based (da Cunhaa, 2015). In other words, they should not be implemented at the individual level, but rather, are most appropriate for entire geographic areas (da Cunhaa, 2015).

Based on previous research focusing on nutrition from conception through the second birthday, it is clear that the First 1,000 Days is a pivotal period. It is a time that provides an opportunity to promote positive health outcomes.

Maternal and Child Health in Uganda

As previously mentioned, women, neonates, and infants in Uganda face extremely high rates of mortality. The First 1,000 Days has been established as an important time frame in studies in the United States for MCH. However, the environment and context of a pregnancy in Uganda is drastically different than the United States. Previous research has worked to identify if those who face barriers to good health in each of these countries

can expect similar health outcomes. Although standards for prenatal care and education are very different, a similar link between maternal nutrition during the First 1,000 Days and health outcomes has been previously observed in other areas of Africa (Wrottesley, 2015).

Three Delays Model

The Three Delays Model was originally developed around maternal mortality in sub-Saharan Africa, but it has also been used in other contexts. Findings from studies highlight that although Delay One and Three are most frequently cited as representing the biggest barriers to care, all three Delays are contributing factors to high rates of maternal death (Lori, 2011, Mselle, 2011, David, 2014, Combs, 2012). Other studies have shown that the Three Delays model is applicable across maternal mortality in many other cultural contexts, including the Middle East, South America, and Asia.

Over time, the Three Delays model has been adapted and applied to other subjects, including perinatal (month five of pregnancy to 28 days after birth) deaths. A systematic review of other studies using the Three Delays to examine perinatal and neonatal (birth to 28 days after birth) deaths was able to estimate the prevalence of each delay. Delay One was found in 28% of deaths, Delay Two was found in 18.3%, and Delay Three was found in 38.7% of deaths, making it the most common delay (Upadhyay 2014). Upadhyay et al. (2013) completed a study in India focusing on newborn deaths. Through a verbal autopsy, Delay One and Two were found to be the most common, but 74% of the neonatal deaths were found to have had experienced at least one delay (Upadhyay 2013). Within Africa, a study in Gambia found that all three delays were

present when discussing stillbirths (fetal loss after 24 weeks of pregnancy) and early neonatal deaths (death within the first week of life) (Jammeh 2011). The second delay was found to be associated with 50% of deaths, and while less common, the first and third delay were also contributing factors to the deaths (Jammeh, 2011).

To date, there has been one study examining infant mortality within the Three Delays framework in eastern Uganda. Published in 2010, the study used a combined social and verbal autopsy questionnaire, health facility survey, and maternal and newborn care knowledge questionnaire (Waiswa, 2010). Sixty-four infant deaths, occurring between January 2005 and December 2008, were studied. The first delay was most prevalent, with 50% of the infant deaths having a delay in realizing there was a problem, or a delay in deciding to seek additional care. Delay Three was the second most common occurring in 30% of the cases, and Delay Two was noted in 20% of the deaths. The survey found that health facilities were woefully unprepared, lacking adequate numbers of trained staff and equipment. Of those health providers who completed the maternal and newborn care knowledge questionnaire, only 58% answered the questions correctly. This study was the first to examine newborn deaths in eastern Uganda using the Three Delays theoretical framework.

Limitations of the Three Delays Model

A criticism of the Three Delays model has been that the framework understates the importance of gender-based risk factors, as these may influence maternal and child morbidity and mortality in developing countries. Interpersonal violence (IPV), decisions related to labor and delivery, and reduced care seeking for children are all directly related

to gender and health outcomes, but are not discussed in the Three Delays model.

Beyond creating poor health outcomes for women, IPV also impacts female infants and children. Infant and child mortality was found to be significantly higher among females whose mothers experienced IPV compared to those whose mothers did not experience IPV, but this relationship was not found to be significant among male infants and children (Silverman, 2011). Although it is a relatively new area of study, preliminary reviews have found that having a mother who experiences IPV has considerable implications on a child's height and weight status (Yount, 2011). As previously discussed, these measurements of growth are directly related to future physical growth, increased educational attainment, and higher incomes.

Throughout labor and delivery, women are highly influenced by expected cultural gender roles, to the point where their own health is put in danger. In Bangladesh, women preferred silence over sharing that they were in labor (Head, 2011). Therefore, experiencing prolonged labor was driven, in part, by power dynamics (Head, 2011). This trend was also observed in Nigeria. Patriarchy influences women's abilities to make decisions about their own labor, including deciding to have a Caesarean section (Ugwu, 2015). Cultural norms dictate that a woman isn't a "real woman" until she delivers vaginally. It makes sense that when women did have the autonomy to choose their delivery method, 22% of them elected not to have a Caesarean, even when it was medically indicated (Ugwu, 2015). As both prolonged labor and refusing medically necessary Caesarean sections place a mother in danger, the impact of gender-based risk factors are evident throughout labor and delivery.

Reduced care seeking and medical treatment for female children has been noted

across many different cultures (Jehan, 2009). A study completed in Nepal found a significant relationship between parents accessing health treatment for their child and the sex of the child, with 94.2% of sick males being taken for treatment compared to 70% of females (Shrestha, 2015). Similarly, across other parts of Asia, female children are subject to healthcare neglect, including being less likely to undergo recommended surgeries and having lower immunization rates (Khera, 2013). Although she is less likely to be taken for care in the first place, if a young, sick female is brought to a health facility, she is less likely to receive the medical treatment she needs than a male counterpart.

Research Purpose

There is a growing pool of research that uses the Three Delays model to explain deaths beyond maternal mortality. However, the earliest in pregnancy that the research begins is the fifth month, and it only extends to include infants that are one year old. As the First 1,000 Days highlights that long-term impact of health from the time of conception through age two, it is important that there is information about the barriers to care throughout this entire time frame. Therefore, this study aims to examine the First 1,000 Days through the Three Delays model in the East Central Region of Uganda.

Methods

The purpose of the study was to understand the barriers influencing good health for fetuses, infants, and young children in Uganda. Barriers were defined as the motivators, perceptions, previous knowledge, physical structures, and delays in care that contributed to the decision to seek medical attention. The time frame was identified as beginning whenever the interviewee believed a pregnancy began, to the child's second birthday. A qualitative approach was utilized in an attempt to better understand participant's opinions, behaviors, and perceptions of complex health topics, as well as "identify[ing] the social […] context in which activities take place" (Hennick, 2011, p. 10). Due to varying literacy levels and language barriers, a qualitative approach was identified as the most appropriate study method. A quantitative measure such as a survey could have been read to participants, but qualitative interviews provided richer data by allowing participants to share their personal opinions and experiences. Additionally, as the interview included questions about health and illness that could have been sensitive topics, a qualitative approach enabled interviewers to be flexible in conducting the interview, while establishing rapport with participants.

Host Organization

The study was conducted with the support of the host organization, Safe Mothers, Safe Babies (SAFE). SAFE is a non-profit that has worked in Uganda since 2007, and it is well known in the East Central Region of Uganda by the local community. SAFE uses an integrated approach to MCH problems in which they combine community-based participatory action methods with health facility strengthening to identify and improve

barriers related to the Three Delays.

Study Setting

The study was conducted in the East Central Region of Uganda, in the Iganga and Namatumba Districts. These districts were chosen as the study sites due to the existing relationships SAFE has in the area.

Research Team

To ensure cultural competency and minimize the risk of coercion, an in-country team was trained and conducted the interviews. The study author, who is CITI certified, recruited, interviewed, and selected a team consisting of two Ugandan men and two Ugandan women. Interviewers were recruited from their previous work with SAFE and other local non-profits, and from advertisements at local universities. Part of the interview process was ensuring that candidates were from the same districts as the study communities. A comprehensive, four-day training was developed by the study author. All of the research team was required to undergo the training, which included informed and ongoing consent, confidentiality, probing for more information, and creating an open environment for the participant to respond honestly. Throughout this training, the research team received constant feedback on their interviewing skills to ensure mastery of the concepts.

Sample and Recruitment Methods

Participants were recruited through systematic random sampling. Using

systematic random sampling allowed the researchers to minimize the potential for bias, as all possible participants had an equal chance to be included in the study (Laerd, 2012). Inclusion criteria include: women ages 15-49 who have been pregnant at least once, and men ages 18-49 who have fathered at least one child. Participants must live a majority of the time each year in either Iganga or Namatumba Districts, and speak either English or Lusoga, the local language. There were no additional exclusion criteria. It is important to note that in Uganda, individuals who are pregnant, have a child, are married, or are responsible for their own livelihood are considered emancipated adults (Uganda National Council for Science and Technology 2007). Therefore, only young women between the ages of 15-17 who are currently pregnant or have a child, and therefore locally considered to be adults, were eligible to be included in the study.

Participants were recruited with the help of community groups with whom SAFE already works. These community groups are primarily made up of community members, including men and women of all ages, who collectively learn about MCH from SAFE trainings and then impart the same education to their communities through culturally-appropriate venues, such as dramas and songs. Their first language is Lusoga, and only some can speak English (to varying degrees).

The research team held a meeting with approximately fifteen leaders representing all of the community groups, explaining the purpose and methods of the study. It was made clear that there were no additional incentives available to community groups or individual community members if they participated in the study. All questions from the community groups were answered. Then, the community groups advertised to local community members about the research being conducted, and helped the researcher

obtain permission from informal village leadership to work within each village. This entailed providing a short description of the study, and indicating that a research team would be in the village on a specified date asking for participants. Community groups were asked to emphasize that participation was voluntary.

Following these announcements, the research team traveled to a village on a set day. The team started in a randomly selected place and traveled to each subsequent 10^{th} house. If, at the 10^{th} house, there was not someone available, willing, or qualified to participate, the interviewers would continue to the next house until they could conduct an interview. After completing an interview, they would they repeat the process of traveling to the 10^{th} house. Male interviewers recruited only male participants and female interviewers recruited female participants.

Data Collection Methods

The study consisted of in-depth, open-ended interviews, using semi-structured interview guides. For each participant, there was also a short, quantitative demographic section. Interviews were conducted in private, with only the interviewer and interviewee present whenever possible. Participants' names were not recorded. After the study was explained, verbal consent was obtained. This was due to low literacy in the population, and to protect confidentiality. Participants were also asked if they were comfortable with the interview being audio recorded. All participants were comfortable with this, and thus, all interviews were audio recorded.

There were two interview guides: one for female interviewees and one for male interviewees (see Appendix I and II). The interview guide went through review and

revisions by SAFE staff and faculty at Emory University. Questions focused on the Three Delays relating to the most recent pregnancy and the Three Delays relating to an illness experienced by a child less than two years old. There were also questions focused on the respondent's general impressions of what constitutes good MCH. Both guides were originally developed in English, and translated into Lusoga using organization-provided translators. The interview guides were also reviewed by the trained research team to review the accuracy of the translation and to ensure that the guides were both culturally sensitive and comprehensive.

Interviews were recorded on hand-held audio recorders. The research team recorded the demographic information on paper, and was also trained on and expected to hand-write notes during and after each interview. Interviews were conducted on June 9-18, 2015, and lasted between 38 minutes and 1 hour and 58 minutes. In total, there were seventeen interviews conducted. Nine interviews were conducted with female participants and eight interviews were conducted with male participants.

Analytic Methods

After the interviews were conducted, all interviews were translated and transcribed verbatim in full. They were transcribed by a member of the research team, and spot-checked for accuracy by a SAFE employee who is a native Lusoga speaker. All transcripts and notes were de-identified. Participants have been given pseudonyms, all of which were selected from a list of common Ugandan names. A table outlining select demographic information is available in Appendix III.

Coding was completed by the PI using MAXQDA, which is qualitative data

analysis software. The analytic process began with memoing to identify major topics that participants discussed. Through thematic analysis, a code tree and code book (see Appendix IV) were developed. Codes were both deductive and inductive. Deductive codes (such as transportation barriers and breastfeeding) were found in the literature and were used in the creation of the interview guide. Inductive codes (such as traditional medicine and avoiding discussions about the fetus) developed out of major, unexpected themes that came out of the interviews. After coding the interviews, the PI again reviewed the data to identify any additional patterns or themes that became evident throughout the analytic process.

Evolution of Methods

The only change in method of recruitment, data collection, and analysis that occurred during study implementation was changes to the interview guide. Changes were made to the interview guide to ensure that questions were clear and relevant to the population. For example, the original interview guide included only two questions directly related to maternal health definitions: “How would you define good maternal health?” and “What does it mean to say that a mother is healthy?” The final guide included two additional questions: “How can a woman keep herself healthy after having a baby?” and “What are some barriers to staying healthy while pregnant?” These questions were added after discussions with the in-country research team highlighted the need to explicitly ask participants about health expectations and barriers at specific times during the First 1,000 Days.

Ethics/Protection of Participants

The PI submitted the research protocol and interview guides to the Emory IRB. The study received exempt approval on May 29, 2015. No major ethical issues arose during the course of the study. Interview recordings and transcripts were stored on a password-protected computer, and backed up on a password-protected external hard drive. They were coded with a unique numerical identifier, and the master key of the identifiers was stored separately from the interviews. Confidentiality of participants was assured as identifiable information was removed from the interviews as soon as they were transcribed. Identifiable information included, but is not limited to, information about health facilities, ages of children, and names of villages. Participants were informed that the PI, faculty at Emory University, and select staff at SAFE would review the transcripts.

Results

A note on language

As all interviews were conducted in Lusoga, there is some uncertainty with regards to the language used throughout the transcripts. In Lusoga, there is not a clear distinction between what constitutes a midwife, nurse, or doctor. Therefore, although several interviews were spot-checked for accuracy, due to the structure of the language, some uncertainty remains. This extends to the use of the terms "health facility" and "hospital." In Uganda, there are four levels of health facilities (level one being able to handle only the most basic medical problems and level four having extensive resources, including personnel), followed by hospitals. Although some participants explicitly stated the level of health facility that they visited, many others spoke in general terms. Due to these variations in language, it is impossible to speak with certainty as to the level of care given by certain types of medical professionals, and at different medical facilities.

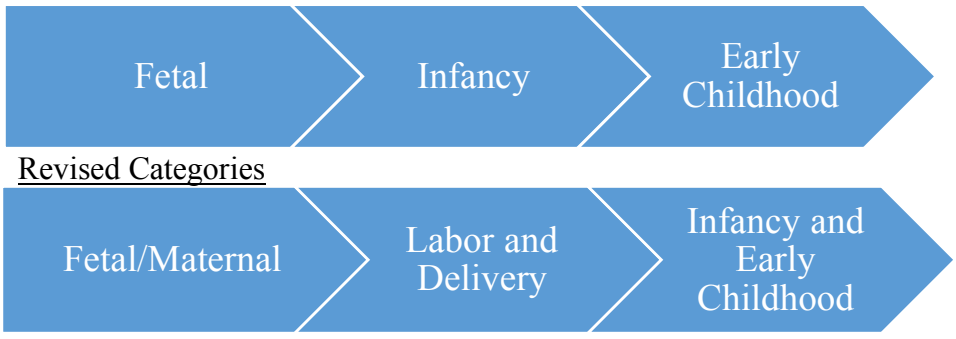
A note on timeframes

In examining the First 1,000 Days, the time from conception through a child's second birthday can be divided into three time frames: 1) pregnancy, 2) infancy (birth through age one), and 3) early childhood (age one to two). However, after examining the transcripts, it became clear that in the context of Uganda, this divide was not possible. Many men and women avoided talking about the fetus while a woman was pregnant. Some participants didn't acknowledge that a woman was pregnant with a child until delivery, instead referring to the fetus as a "thing." Limited resources were prioritized for children and adults. Although pregnant women did receive some special treatment, it was

directed towards them, and was not intended for the fetus. Due to this cultural norm, questions related to fetal health were answered from the perspective of maternal health. As covered in the literature, maternal health is closely related to fetal health. Therefore, throughout the analysis, when information about the pregnancy was not available, maternal health was often used as a proxy for fetal health.

Another cultural difference that impacted the interviews was the lack of distinction between the infant and early childhood time frame. Parents never distinguished if their child was less than or more than one year when discussing health and barriers. However, there was an extensive amount of valuable information available about labor and delivery. Therefore, the second time frame became labor and delivery, and infancy and early childhood were collapsed to become the third and final time frame (see Figure 1).

Figure 1- Cultural differences in language



RESEARCH QUESTION ONE: How do different barriers to achieving good health impact fetuses, infants, and young children?

Delay One

The first delay is a delay in deciding to seek care. Each of the seventeen interviews had at least one mention of the first delay during the First 1,000 Days. Although there were very concrete reasons behind the first delay such as fear, a lack of knowledge, and prioritizing traditional health resources, larger cultural factors like gender roles also influenced the delay in seeking care.

Fear

As fear and shyness can act as both a motivator and a deterrent to receiving care, they are important emotions to consider as part of the first delay. Susan, one of the two single participants, chose not to attend antenatal care (ANC) because she feared that others would judge her. She was eighteen and believed that she was younger than many of the other pregnant women she would see at ANC. Although she never confirmed if she was the youngest patient at ANC, she feared other women would refer to her as "that young girl." As her own shyness was a barrier, Susan never felt comfortable attending ANC. Joan, a Protestant with two other co-wives, decided that after her sixth pregnancy, she would have a tubal ligation. However, it was unsuccessful, and she became pregnant. Although she hadn't attended ANC with her first six pregnancies, Joan was motivated to attend for her post-tubal ligation pregnancy. Although she did not mention specific individuals, she did share that her motivation stemmed from advice she had received from other people.

Fear of HIV also makes women more likely to access care. Isaac, a Muslim man with one wife, encouraged her to deliver in the facility, as opposed to with a TBA. He felt that in cases where a woman was HIV+, the facilities were better equipped to deal with the prevention of vertical transmission, as "the treatment is always there." While pregnant, women expressed that their decisions related to seeking care were motivated by fear and shyness.

Gender Roles

Complex gender roles between men and women influence the decision to seek care. Often, certain responsibilities fall to one particular gender. When they do or do not live up to those expectations, decisions regarding seeking care are effected.

From conception through early childhood, men make almost all of the decisions regarding accessing healthcare. Men are frequently cited as being the first in the family to bring up the conversation about going to the health facility, and being the ones who ultimately determine if it is the appropriate treatment. Irene, a Muslim woman who had been pregnant eight times, explained that "it is always your husband who has to decide" when to go for ANC. Husbands also made the decision regarding which health facility or hospital to access when it was time for their wife to deliver. Often, men talk about this as a responsibility they have when their wife is pregnant, as they are the "owner of the family." When deciding if and when his laboring wife could go to the health facility, Andrew said it was his decision as "it is my responsibility. This is all my responsibility."

There are also other times when the role that men play is explicitly clear. Doris, a Muslim woman who had nine pregnancies, explained that when she needs to talk to

someone about her pregnancy, she must talk with her husband. Sharon, who used a mix of traditional and biomedical care, was bleeding during the pregnancy, and only accessed care after her husband "told me to go to the hospital." Brenda, a woman who had two co-wives and had experienced eight pregnancies, voiced her concerns about one of her pregnancies to her husband. She was fearful because she hadn't felt the fetus move, so her husband told her he would watch her one night and check for fetal movement. It was only after he determined that there was, in fact, no movement, that he took Brenda to the hospital.

Mothers often have the primary role in caring for ill children, and identifying when they need to access additional care. Although some fathers did identify that it was their job to take their child to the facility, participants also voiced a dependence on mothers. Henry, a Protestant with a currently pregnant wife, explained:

> It is the wife who tells you that "this child has a fever," so it is her to tell you, then you hurry up, and bring the treatment, like that. Because it is the wife who understands her baby most. […] The women understand that most. The men don't understand it [...] I just see when she [the child] is a bit older, that is when I know that this person is sick or not. But if she is still young, I can't know.

No participants explicitly stated the process to decide to access care for ill children. However, based upon the central role that mothers play in evaluating if the children are sick, it is possible that mothers play a larger role in decisions related to children than they do in making healthcare decisions related to their own pregnancy.

Delay in recognizing health problems

Throughout pregnancy and incidents of childhood illness, a delay in recognizing there is a health issue or problem due to a lack of knowledge was common. When pregnant, several women delayed attending ANC because they failed to realize they were pregnant. Joan and Florence felt ill and experienced pregnancy signs, but failed to recognize them as such and instead tried to self-treat. Eventually they both went to the health facility and were informed that they were pregnant. Irene explained that when she was pregnant, she delayed going to the health facility for "around three days, because I thought I was over-working myself." For both men and women, they felt that they could visually tell if a pregnant woman was sick and needed to go to the health facility. By being dependent on the idea that a healthy woman "looks well," men and women neglect to realize that many health issues for pregnant women are internal and cannot be visually recognized.

When dealing with a sick child, a lack of knowledge, failing to recognize or incorrectly recognizing symptoms, and a delay in recognizing illness all contribute to the delay in deciding to seek care. Susan spoke about her sick daughter needing to go to the facility. However, she turned to her "parents […] for she is my first born," and she felt like she had inadequate knowledge to make the decision. Joan also had her decision to access care for a sick child influenced by an older relative. However, instead of offering encouragement about when to access the facility, this older relative represented a barrier. Joan had dropped the child off with the relative, and when she returned "[...] the baby was seriously ill […] she was staying with her grandmother who has aged. And, as you know, people who are aging do not know about children." Since the elderly grandmother

didn't recognize the illness, she did not bring the child to the health facility. She was also unable to tell Joan when the child started to display signs of being sick. Joan felt that having an older relative care for the baby was an issue, as the relative failed to recognize when the baby was sick, leading to a delay in the decision to access care.

Many parents listed signs that they use to determine if their child was ill enough to go to the health facility. A high temperature, excessive crying, sunken eyes, and sleepiness were all identified as cues for participants to take their children to see a medical provider. However, other participants stated that it took multiple signs before they decided to pursue healthcare. One woman said it wasn't until the child started crying, stopped breastfeeding, and grew smaller that she took the baby to the health facility. Grace, a woman who had a history of delivering with a traditional birth attendant, took a very long time to take her child to the health facility. Her child stopped defecating, stopped eating, grew cold, and developed diarrhea before Grace decided the problem was urgent enough to require care. For other parents, going to the health facility was decided because they could no longer explain the child's illness, or treat it with traditional medicine. Being unable to correctly evaluate or recognize signs of illness represent a major barrier to deciding to access care.

Prioritizing alternative care

A very common reason for individuals to delay accessing the health facilities or hospitals was because they prioritized other care options over biomedical care. This included over-the-counter drugs, and traditional and spiritual medicine. Throughout pregnancy, labor and delivery, and child sickness, woman and men would access herbs,

Traditional Birth Attendants (TBAs), or traditional healers to fix medical aliments.

While pregnant, many women would mix herbal, traditional medicine with ANC that they received at the health facility. They would not use either exclusively, but rather "keep on mixing here and there, traditional herbs and the hospital." For several women, their mother-in-law was a major source of encouragement to use herbal or local medicine. Doris shared that her mother-in-law gave her herbs so she could be "strong" (presumably for labor), and when Sharon was asked about who provided care during her pregnancy, she explained that she would discuss with her mother-in-law, who would also give her local medicine.

Several participants openly shared that they had delivered previous children in places other than the health facilities. Joan had been taught by her mother about delivering children, and she chose to deliver at home, by herself. For her six previous children, she had delivered in this manner. It was only due to a fear that the botched ligation would produce a drastically different labor and delivery than the experiences she had previous had that motivated her to plan to deliver in the health facility. Due to poor timing, Joan ended up delivering en route to the facility. Sharon used a TBA because of previous poor experiences with medical providers. She explained that long wait times can be expected with doctors in the hospitals (a component of Delay Three), but she felt that she received high quality care from a TBA. As they had not personally experienced any poor health outcomes as a result of not using biomedical care, participants were open to using alternative birthing supports.

Discussions about using traditional medicine were most common when referring to childhood illness. Samuel, a member of a local village health team, stated that the

biggest challenge in his community was that the first resource accessed when a child fell sick was a traditional healer. Many participants spoke specifically about "showering" their child with herbs. Irene explained that "when the temperature is high, when it is not time to go to the facility, you shower him with lubirizi [an herb]. If it [the temperature] is not too much, the temperature will come down and she will be fine."

Needing to appease ancestors and demons was cited as a reason to use alternative treatment options. The typical process would involve visiting the traditional healer, and being told that their ancestors need food. Although she had been having seizures, it was not until Susan's daughter began to "change her eyes" that she was able to identify that her daughter had an issue with clan things. After taking her daughter back to her ancestral home, Susan explained that the convulsions stopped. Despite recognizing the health facility and hospitals as a place to receive care, parents continued to prioritize using traditional care because they felt that it was a viable treatment option.

Several parents used over-the-counter medications before deciding to go to the health facility. In Uganda, many drugs that would require a prescription in the United States can be purchased without any authorization from a medical provider. Therefore, although they are being referred to as over-the-counter, they include drugs like antibiotics that would need a prescription in the United States. Regardless, parents would go out and buy these medications and give them to their children. Sharon thought her child was suffering from worms and bought the corresponding medication, while Joan explained that buying "syrup and tablets" was an important step that would help a child to quickly improve. It was only after these drugs failed that they would consider the health facility.

Parents chose to access biomedical care as a last resort for their children. Daniel, a

man with one wife and one child, explained that it was only after his daughter developed a fever, lost her appetite, had diarrhea, and was unsuccessfully given over-the-counter medication that they brought her to the facility. Doris shared that they used a traditional approach to cure her child. A common belief in the area is that babies will get ill because they were named incorrectly. In order to cure the baby, the traditional naming process must be repeated. The traditional naming process involves taking two chickens and taking a piece of paper with a name on it to each of their legs. Then, both chickens are thrown on the roof. The child will be named after the chicken that falls off the roof first. Doris's family's first choice of treatment was "throwing a hen thinking it [the illness] was because of the name but it also failed. Then we took the baby to the hospital and got some treatment." Unfortunately, that child ultimately passed away.

Delay Two

The second delay is a delay in accessing a health facility. In the context of the East Central Region of Uganda, the second delay is most often caused by transportation issues. Although this delay was mentioned the least frequently out of all the interviews, the experiences shared by participants encompassed all of the First 1,000 Days, including pregnancy, ANC, labor and delivery, and infant/childhood illness. Although the factors that contribute to the second delay are often overarching, large, structural issues, the resulting poor health outcomes are very evident. Brian, a Protestant who worked in farming, described a story of his neighbor's wife going in to labor with twins, but only being able to birth one child. As they were unable to immediately reach a health facility, by the time they accessed proper medical care, the second child had died. The provider

told them that the transportation barrier was a "'small thing that did not require this child dying.'" The intersection of the second delay and the First 1,000 Days can be examined by analyzing the distance from the health facilities, transportation issues including trouble locating transportation, financial barriers, and road conditions, and access issues related to health problems arising at night.

Distance

Distance was discussed as a barrier to accessing health facilities primarily during pregnancy and labor and delivery. Often, distance is one of the primary guiding factors in deciding where someone goes for ANC or delivery. Several men noted a relationship between being located far from the health facility and increased usage of TBAs. Isaac explained that when women have to travel far distances to the health facilities for ANC, "the woman hates it. And fails to finish their doses of ANC. And that causes so many of the women to give birth from the TBA, just because of the distance." Other men supported this claim, explaining that their decisions about where their wife should deliver were based primarily on distance. Distance could impact the decision in multiple ways. Samuel had observed men directing their wives to a TBA instead of a nearby health facility because the TBA was closer. For other men like Andrew, the option was choosing between two health facilities: one that was close by but poorly stocked with medication/equipment, and one that was farther away but had more amenities. The closer health facility with inadequate supplies was chosen because the distance represented a larger barrier than the risk of going to a poorly stocked facility.

The reality of being far from a health facility was reinforced by many participants.

They frequently identified the biggest barrier to healthcare in their community as distance from the health facility. Participants requested that new hospitals or health facilities were opened in closer proximity to their community, to allow easier access. A lack of nearby facilities prevented Ugandans from being able to access care for both routine and emergency situations.

Transportation

For those that live far from health facilities and require a car or boda boda (motorcycle, also referred to as a boda) to reach them, being unable to access transportation in a timely manner represents a major delay. In the East Central Region of Uganda, most individuals do not own a reliable transportation method that would allow them to travel far distances to reach a health facility. While just over half (53%) of participants reported owning a bicycle, only two (11%) had a motorcycle or scooter, and none owned a car or a truck. Issues related to transportation were evident from labor and delivery through the period of early childhood. There are several reasons why transportation may be difficult to access, including financial barriers, having no transportation present, and having drivers who are rude.

Having inadequate money for transportation delayed both men and women who were trying to reach healthcare facilities during labor. Multiple men explained that bodas are more likely to pick up those who clearly have money. For those who call for a boda but are only able to afford a fraction of what the driver expects, it is inevitable that the driver will take a long time to arrive to pick them up. Because of this, Isaac suggested that once it is clear that the driver will be late to pick up and transport your laboring wife,

the next best choice is to locate a bicycle, "get a hold of it, put on your wife, and take her to the facility." The importance of timely transportation cannot be understated, and it is recognized by men and women as vitally important. As Florence explained, financial compensation for the driver is necessary because "even if it is your brother, [if] it is in the night, you still have to appreciate and give him some money, because that person has saved your life, because if he would have refused, [your] life would have gone." In crisis situations, participants were able to find funds for transportation. When her young child was having seizures, Grace's husband was able to arrange transportation. However, she reflected that she was unsure of the source of the money, and "did not know whether he […had to…] borrow money […as…] he did not have the money." Financial barriers are also connected to distance from the health facility. There is a direct relationship, as the cost of transportation increases as distance increases, and many individuals are located far from the nearest health facility. A lack of finances for transportation make it a challenge for men and women to reach health facilities.

Financial barriers with transportation extended beyond labor and delivery. Andrew explained that he had syphilis and wanted to get tested for HIV. However, in order to be tested, the health facility required that he "be tested together with my wife. But because of the poverty, I can't go together with my wife for the checkup." Once he was able to gather enough money, he found that he had other financial responsibilities that left him unable to take him and his wife to get tested. As the financial requirements were too much of a burden, neither Andrew nor his wife were able to get tested for HIV.

For young children that were ill, their families faced the problem of having no transportation options available. When Grace's son was having a seizure, she and her

husband searched for a boda. Eventually, they walked to a lower level health facility, where they were able to flag down a motorcycle. This motorcycle took them to a higher level health facility, where they were able to get a car. The car then transported them to a hospital, which was their desired treatment center. At the hospital, Grace's son was able to get the necessary treatment. Since there was initially no motorcycle and no car available to take the sick child to the hospital, a lack of transportation options is a barrier.

Even if a woman in labor is able to locate an affordable boda, there are no guarantees that she will be able to reach a health facility. As her husband did not have his own boda, Grace and her husband hired a man to drive them. They were headed towards a health facility as Grace was in active labor, but the driver noticed that she was bleeding onto the boda. He "got rude" and insisted that her husband wash the boda. The boda driver refused to continue driving them, so it was not until Grace's husband cleaned the boda that they were able to get a car and finish their trek to the hospital. Despite Grace being in active labor, the driver's disgust at her bleeding, and subsequent insistence on her husband cleaning the boda, created a significant delay. The man's reaction to her blood as dirty demonstrates larger cultural understandings related to labor and delivery, HIV, and gender roles. Grace's labor experience shows that even if a boda or car is present, transportation can still be a barrier.

Finally, the impacts of being unable to access adequate transportation are evident. Brian explained that although he was trying to get his laboring wife to a health facility, "when it started raining and the motorcycle lost pressure, we said, 'let's go here,'" referring to a woman who Brian believed had some medical training. Although the woman's level of training was unverified, she aided Brian's wife in a successful delivery.

Participants were also acutely aware of the poor health outcomes that are related to transportation delays. Without affordable, reliable transportation, Robert, a Muslim farmer, explained that "you are in for it [...] your person, in time, can die." However, Samuel also recognized that it is possible to "avoid death of mothers, [and] children dying at early stages" by having transportation options available from their homes.

Road Conditions

Poor road conditions are a major obstacle in reaching a health facility when a woman is in labor and when children are sick. If transportation can be arranged during a health crisis, citizens still may suffer due to the status of the road. Sometimes, the condition of the road is so bad that patients can be delayed to the point that they die en route to the facility. Individuals that live on roads that are in very poor shape can also expect to be overcharged by drivers, which can lead to additional financial hardship.

Rain was mentioned as a factor which complicated access to health facilities via the roads. Robert and Brian explained that while trying to transport their wives who were in labor, it was raining. Although the roads are passable when it is dry out, "the road is not good when it rains […] the road gets washed out." This is in part due to the sugarcane trucks that drive through the area, which have detrimental effects on the condition of the roads. A side effect of poor road conditions is that slower, less reliable transportation methods must be used. Andrew mentioned the roads as a barrier when transporting a sick child. As his daughter was suffering from what he referred to as her head "rotting," he wanted to bring her to a health facility with a car. However, because of the road conditions, neither a car nor a boda could access the sick child at home to bring

her to a health facility. Therefore, Andrew was forced to use a bicycle, as "a vehicle cannot pass where a bicycle can." Although he was ultimately able to reach the facility, he was greatly delayed due to the road conditions.

Accessing care at night

The final facet of transportation barriers are delays related to traveling at night. As Uganda is located on the equator, sunlight is present for almost exactly half of every day throughout the year. Therefore, considering that medical emergencies are random, there is a chance that an emergency will occur at night. Delivering at night is a source of fear for individuals, and causes women who originally planned to deliver in health facilities to change their plans and deliver at alternative locations. Andrew was fearful that his wife would have to deliver at night, as "it is difficult for us to get transport at night." Although he didn't share if this caused him to make other plans, Andrew did say that this was a source of anxiety for him throughout the pregnancy. Joan had planned to give birth from the health center if she had "felt the labor pains during the day." However, she "felt them at night, and I was far from people, so that is the problem as to why I did not give birth from the health center." Joan ended up successfully delivering without any medical help. Finally, one sick child was unable to receive the healthcare he needed because of nightfall. Although she doesn't explain why, Florence and her mother were unable to access transportation that night, so instead they "sat, […] applied tepid sponges, and by the time it came to 6 in the morning, […] rushed him to the facility." Without a reliable transportation method, women in labor and sick children face delays in accessing health facilities at night.

Delay Three

The final delay occurs after a patient reaches a health facility, and they are unable to receive adequate healthcare in a timely manner. This delay was present in fifteen of the interviews, making it the second most frequently identified delay. Additionally, Delay Three was related to healthcare issues from conception through age two. The factors that contribute to the third delay include long waiting times, a lack of medicine or supplies, multiple referrals, difficulties with health facility personnel, financial issues, poor quality care, and misdiagnosed medical problems.

Long Wait

When attending a facility, participants often had to wait to be seen by a provider. The expected process when you went to a health facility involved having to wait in a long line to see a health provider. Joseph explained that "you may reach [the facility] and sit and wait for them, like for a while." Participants often complained of long waits when attending prenatal care, which is usually a less urgent, non-emergency appointment. There were very few stories of having a long wait at a health facility when a woman arrived to deliver, or with a sick child. However, the delays could be lengthy, as "you may be there from morning to evening. They come at around 7PM, and attend to you." Despite being told that she needed emergency surgery, one woman who arrived bleeding and in labor still had a significant wait. Therefore, even if a patient reaches a facility in a timely manner, there is no guarantee that they will be quickly seen by a provider.

Lack of medical supplies

Having inadequate medical supplies, including medication, affected treatment of patients during labor, delivery, and early childhood. Blood and other equipment were mentioned as missing from the health facilities, but drugs and medication were most frequently cited as lacking. Samuel succinctly explained that "the facilities have no drugs." After battling Delay Two and managing to travel far distance to reach a health facility, participants became frustrated with the lack of medical supplies. The facilities "have medicine, for a few days, and then suffer for the rest of the days" after the medicine runs out. When medication is available, it is often distributed for free. However, once the facility has no more medication, participants need to find other places to purchase necessary drugs, creating a financial barrier and a delay in treatment.

Participants expressed a lack of medical supplies as a barrier during labor, delivery, and periods of childhood illness. When his wife traveled to deliver, Andrew explained that despite a health facility being nearby, it didn't have equipment. It was instead necessary to travel to a farther away health facility that had equipment, raising issues related to Delay Two, such as being unable to locate adequate transportation in a timely manner. If medication is available when sick children are brought to the health facility, it is sometimes offered to parents for free. However, if it is not in the facility, the doctors instruct parents to "run and buy them until she [the child] is fine." One mother told the story of bringing her sick child that required medicine and blood to a health facility that didn't have either resource. After hearing this, they chose to leave the health facility and go back home. When Grace and her son reached the hospital, they were instructed to buy medication. However, as they "did not have money," the child

continued to suffer. Despite its importance, medicine and other supplies in the health facilities are a limited resource that quickly run out, leaving participants without treatment options.

Referrals

Many participants who arrived at health facilities in the midst of medical crises were referred to other facilities, creating a massive delay in accessing care. Sharon traveled to a health facility after she bled for three days while pregnant. She feared she was dying, but the first health facility she went to didn't treat her at all; rather, they referred her to a second facility. Florence had a similar experience, but while she was in active labor. She had decided on delivering at a certain health facility, but was directed to go to a different hospital. Once she arrived at the hospital, she was directed to another health facility that was different from her original, planned site of delivery.

Child illness stories also echoed these experiences. Parents told stories of being referred between multiple hospitals and health facilities, and often were not given any treatment at the first medical facility they reached. When participants were unable to receive care at a facility and were instead referred, they were again faced with the issues related to Delay Two as they attempted to locate adequate care.

Issues with staff

A major issue found throughout pregnancy, labor and delivery, and sick children visits were health facility staff problems. This included issues with both medical and non-medical health facility staff, and included nonexistent staff, a lack of motivation, and

abuse.

Participants would often tell horror stories about midwives during ANC appointments. Daniel shared that sometimes when women would try to go for appointments, they would be told that the midwives couldn't see them and they should "'come back tomorrow.'" After returning to the facility on the second day, the women would again be told that the midwives were unavailable. Then, when the women attempted to return to the facility to deliver, they would be refused admission to the health facility, since they didn't attend ANC there.

Beyond being refused care, women were also mistreated by midwives at their ANC appointments. Florence expressed how thankful she was that she had a midwife who she considered a friend, as other patients at the facility would be neglected or treated poorly by providers. Although his wife didn't experience it, Brian retold a horror story of provider abuse that his wife had observed. It began with health workers who mocked and taunted the pregnant women, judging them for things like their education level. Brian went on to explain that he personally believed that when women gather together, they tended to gossip and laugh. One time when this occurred, a health worker assumed that the pregnant women were laughing at her. She took a patient's ANC book, which is used to record information from each visit, and started hitting the woman with it. The final story Brian shared was when a woman went to get her medication, and a health worker threw the pills at her instead of handing them to her. The patient protested, explaining that she was a human just like the health worker and therefore deserved to be treated with respect. In retaliation, the health worker "got a grudge," and told the woman that "'if you ever dare to deliver from here, I will do something to you that you will never forget.'"

The patient stood up for herself, told the health worker that she was not above the law, and eventually returned to deliver from that health facility. Understandably, Brian explained that hearing about these abuses contributed to his "hatred [of] government facilities."

Issues with providers were also present when women reached the facility to deliver. Isaac explained that as his wife "always gives birth clearly [easily], she is not hated by the midwives." In comparison, he'd observed midwives who wanted to avoid having to care for multiple patients in labor at once, so they would disappear to shower and take an unnecessarily long time to avoid interacting with the patients. There were also instances where doctors walked right by patients and ignore them, because the providers were too busy with other patients. After dealing with the rude boda drive, Grace arrived at the health facility in the midst of a medical emergency. She was in active labor, but the doctors failed to ever explain to her what was happening. Grace was told that she needed surgery, but it took a very long time for the surgeon to arrive. In the meantime, she lost consciousness several times. When she came to, the doctors assessed her, but failed to use colloquial language and explain to her what was happening, as they just continued to "[speak] in their languages." It was only after Grace's husband bribed the doctors that they operated on her. Even during medical emergencies, participants received poor quality care for providers.

Midwives also made medical decisions that were not the most appropriate treatment for women in labor. When Irene's sister presented at a health facility, "the midwife who was there told her that "'it is your time to push now. You push.'" However, Irene's sister's water had not yet broken, so the midwife got a razor and ruptured her

amniotic sac. Afterwards, the midwife immediately disappeared, and her condition deteriorated. They were referred to another facility, and had to arrange transportation. Although the baby was born alive, it was a difficult birth and it took her sister a long time to recover, which Irene attributed to the midwife's actions.

Barriers related to health facility staff and poor infant and child health included concerns about both medical staff and non-medical staff. Some participants found that when they brought their sick child to the facility, the non-medical staff made the experience very negative. Guards would deny participants entry at the gate to the facility. Once they were inside and their child was receiving treatment, family members continued to be treated poorly. Henry explained that the only place for parents to sleep overnight in the hospital was on the floor next to their ill child. However, when the floors would be washed at 1AM, the parents would simply be woken up by having water poured on them. Henry explained that there is "nothing I can do. You just have to wake up, get aside, [and] after mopping, you again sleep." The mistreatment from medical staff was no less appalling. Brenda voiced her concern that health workers "ignore cases when they take their children to these nearby health facilities." This is reflected in the experience Grace had when she took her sick child to a facility. The facility did not have the necessary medical treatment. Her child ended up receiving the medicine he needed only because a doctor took pity on the family, and instructed them to go to a location outside the hospital where they could buy the necessary treatment.

Participants also voiced concerns about the number of providers at facilities. They expressed frustration at traveling to health facilities, and then having no provider available. Brian succinctly stated his ideal solution, which would be increase the number

of providers, so that "if someone works during day, the other can work at night." However, it is clear that the issues with health staff extends beyond just an inadequate number of providers.

Financial/Bribes

Although they also contribute to Delay Two, finances after a family has arrived at a health facility represent a major barrier throughout the First 1,000 Days. These financial issues are typically related to bribes and the cost of medication. Bribes were most commonly mentioned with regards to labor and delivery. Henry explained that with his experience, bribes were not directly discussed. A provider would not tell you exactly how much they wanted, and when you gave them money, it needed to be under a different pretense. His preferred approach was to encourage the provider to take a break. Then, he would give them the bribe money and jokingly tell them they should use it treat themselves to a soda. Henry shared that after his wife delivered and the midwife approached him and informed him that his "'wife has given birth very well,'" he responded back with bribe money and told her, "'here is a soda.'" Many other participants had to provide bribes in order to receive care. After Irene's sister amniotic sac was broken and she rushed to a second facility, they finally encountered a health worker who offer to help. However, the health worker also explicitly asked for money before beginning to help the patient. When Grace showed up having an emergency during active labor, she found that she was being ignored by the providers. It wasn't until her husband gave them money, that "they now started attending to me quickly and every doctor now came." Henry also had to bribe a guard in order to get information on the

status of his wife, who was separated from him and was inside the hospital. Despite being government facilities, bribes were readily utilized. As a result of this, Samuel explained that he preferred private clinics, as there was an official, established system for payment. The widespread Ugandan culture of corruption and financial bribes extends to healthcare, even in the face of medical emergencies.

Quality

Issues related to quality of care influenced participant's healthcare decisions. This concern for accessing quality care was most often reflected when deciding which health facility to access. When choosing where he wanted to take his ill and pregnant wife, Robert explained that "if I put her in the clinic, she may fail to get the right treatment, so I took her to the facility." Later, when referencing his wife's delivery, Robert again stated that he felt an obligation to have his wife deliver from a high quality health facility. When caring for a sick child, there was also a concern related to the quality of care received. Susan prioritized a health facility that was farther away because she felt it had better care. If you took your sick child to the closer, poorer quality facility, "just know that you are going to bury her. Maybe, they help you make a referral, and you rush quickly. But if you put [her] there […] She can even die from there." As men and women have personal experiences with different types of healthcare facilities, they perceive the quality of the care they receive. Then, once they have identified the facilities where they receive higher-quality, they prioritize going to those facilities, even if they are more difficult to access. Therefore, a desire to access higher quality care delays getting medical treatment.

Misdiagnosed

Several participants had the experience of taking their sick child to a facility and receiving the wrong diagnosis. There were two instances where children were originally diagnosed with one ailment (anemia and malaria, respectively), but after returning to the facility, they were subsequently diagnosed with a different disease (worms and measles). Sharon shared that at the first hospital they went to, they were told that her daughter had "lost blood," and they were referred to a second hospital. At that hospital, she was informed that the original diagnosis was incorrect and her daughter had not, in fact, lost blood. That hospital told them to access traditional care for treatment, which relates back to Delay One. Even if participants can access healthcare, if they are given multiple, wrong diagnoses, there will be a delay in achieving health.

RESEARCH QUESTION TWO: What are the emic understandings of fetal, infant, and early childhood health and illness?

Fetal/Maternal

It is incredibly important to examine the emic understandings of fetal health as they vary greatly from what is valued and prioritized when compared to areas like the United States. As resources are highly limited in the East Central Region of Uganda, fetal health was not often discussed by participants as a point of concern. Rather, maternal health and the health of a woman when she was pregnant was prioritized. As the state of a mother's health has a direct impact on fetal health, it will be used as a proxy to examine emic understandings.

Participants often explained that cleanliness was key to a woman having a healthy pregnancy. Keeping oneself clean through showering, working to "maintain hygiene," and washing your hands after using the bathroom were all mentioned. However, participants also advised that the household be clean. Keeping the compound, clothes, and food clean were all listed as important contributing factors to a pregnant woman's health.

Being able to rest while pregnant was often mentioned by men as being important for their pregnant wives' health. Many men also responded that women should not be required to do strenuous labor. Rather, they should be "relaxed, sleeping, in the morning, having tea and cooking for her children, only that," and not worrying about manual work. Avoiding lifting heavy loads, specifically jerry-cans, was also mentioned by several participants as being key to maintaining health. Overworking a woman may cause her to become sick, so removing that responsibility lowered the risk.

Food was described by many participants as an important part of a healthy pregnancy. Although participants listed specific foods that should be eaten, they varied greatly. Local fruit, protein, dairy, carbohydrates, and drinks were all suggested as being healthy foods. Giving a mother the food she craved was also identified as a way to ensure health. Conversely, denying a mother a certain food, often because of financial constraints, was seen as harming her health. Supplying a mother with a certain food was often a responsibility that fell to the father. Additionally, participants formed opinions about what was considered healthy food based on their individual diagnosis and what they were told by the providers. In other words, if one participant believed the healthiest possible food was mango while another thought it was rice, it is possible that based on the context, they were both correct. Finally, a healthy pregnant woman could be identified by eating sufficient quantities of food. When a woman is "feeding well," it was a sign that she was healthy.

Participants viewed a woman as healthy if her pregnancy felt or looked "good." Samuel said that a mother can be identified as healthy if "she feels good." Another husband stated that a woman's health can be categorized "given the way she moves." For example, a sick mother will "move slowly. She cannot move speedy, like you, a normal person. She is always slooow, like pleading for it. She is only forcing her body to move." By using clues from a woman, it can be determined if a pregnant mother is healthy.

Going to the facility and getting diagnoses from medical providers was cited as a way to ensure health. Sharon explained that in order to be considered healthy, "you must go to the facility for treatment." Without going, a woman chances diseases going undiagnosed. Once at the facility, a husband explained that the doctor must identify if the

woman is healthy or not. He felt that a doctor was more credentialed, and it's "not me, but the doctor" who can decide if a pregnant woman is healthy. For some participants, in order to be seen as "healthy," women had to use biomedical care. A dependence on biomedical care was viewed as important to being healthy.

Issues related to sex and HIV were closely tied to a pregnant mother's health. An important key to a mother remaining healthy was ensuring she only had sex with her husband. Susan explicitly stated that to stay healthy, pregnant mothers should not "fornicate, or practice prostitution." Florence reinforced this idea by sharing that mothers should "be only two people with your husband," or that they should remain faithful and only have sex with their husband. Infidelity was identified as an issue because of HIV. By sleeping with someone other than their own husband, the woman could chance that he is HIV positive and they would be exposing both themselves and their unborn child. Sex between a husband and wife was also mentioned by several participants as being a factor related to health. Henry explained that as a husband, he was responsible for sleeping with his wife, and that providers at the hospital would ask him if he did. He credited her easy deliveries to their active sex life. Irene, however, argued the opposite. She stated that sleeping with her husband while pregnant harmed both herself and the baby. HIV was also mentioned as a determining factor for health, as a woman cannot be considered healthy if she has not been tested for HIV. Although complicated, sexual relationships impact cultural understandings of maternal health.

Healthy relationships were cited as an important contributing factor to a mother's health. This included both ensuring the mother had what she needed, and that she was in a supportive relationship. Men viewed themselves as responsible for getting their wives

"whatever they need." For Isaac, regardless of if it was "clothes, beddings, and […] to sleep in a mosquito net […] she has to have everything she needs, [to] not being in a bad condition because it hurts her health when she is pregnant." Participants also discussed the impact of abusive relationships. Physically and verbally abusive relationships were viewed as creating a broken home, which would then "hurt the mother." However, when it is a good, supportive relationship, it is beneficial to the woman's health. A mother who is treated well was viewed as being a healthy mother.

Labor and Delivery

The emic understandings of maternal and child health throughout labor, delivery, and early infancy are highly dependent on acquiring certain resources. Food and financial resources must be planned for, but help to ensure health. Accessing biomedical care, even though it provides very different benefits than care in the United States, is also viewed as important. Finally, cleanliness through labor, delivery, and the postpartum period helps to ensure that a mother and infant remain healthy.

Similar to maternal health during pregnancy, food was often mentioned as important during labor, delivery, and the period immediately after in order to maintain health. Many different foods were identified as being important for health, but there was no consensus as to what was the "best." Participants explained that variations on certain food were acceptable if a certain ingredient was unavailable. For example, women are supposed to eat "porridge, mixed with milk. If you don't have milk, you take plain porridge." Mothers were only expected to eat the special foods/diet for a certain time frame after birth, approximately two to three days. Additionally, two participants made

an explicit connection between maternal diet, breastfeeding, and child health. When asked about maintaining health for the newborn, Daniel mentioned some material things that should be prepared for the baby, but also that he "prepared what the mother could eat, [so] that the baby could also get the nutrients." Robert expanded on that idea, by clarifying that a breastfeeding mother who is with her child needs "coffee […] to keep her warm." Even after labor and delivery and through early infancy, food was identified as being key to achieving good health.

Adequate financial preparations were considered to be a requirement to ensure a woman had a healthy labor and delivery. Gender roles again became evident as participants explained that men were responsible for saving and providing women with the necessary funds. Saving for labor and delivery often began early in the pregnancy, as a way to ensure health. Samuel explained that it when someone was pregnant, "everything has to change," including saving patterns. Transportation to the health facility was one facet of preparing for a healthy birth. Money that was saved could be used to pay for transportation like a boda to bring a laboring woman to the facility. Once they arrive at the facility, women are required to provide their own medical supplies, including items like sheets, a razor, gloves, an a capella (tarp to put over the delivery table), and thread (for an episiotomy). Some participants mentioned a "mama kit," which are either donated or sold by local organizations and health facilities, and include many of the items that are needed for delivery in a health facility. Many men and women discussed the importance of bringing these items to the facility. For those who viewed biomedical care as the key to health, these items were a necessity, as a biomedical provider wouldn't attend to a patient who had inadequate supplies. For those who didn't

clearly identify biomedical care as a requirement, they instead viewed the resources as a way to ensure the woman would "give birth in a good condition." Providing the needed physical resources was viewed as a way to ensure a healthy delivery. Soap, baby clothes, clean sheets, and a basin were also items that were mentioned as being required, but they related to ensuring the infant was healthy after birth.

Accessing biomedical care for labor, delivery, and postpartum care was shared as important by some participants in order to be considered healthy. Even when acknowledging all of the barriers that exist when accessing a health facility, including transportation issues, bribes, and varying treatment by providers, the benefits of accessing care outweighed these factors for many participants. Despite encountering a delay in accessing the appropriate care due to a referral (Delay Three), Grace explained that she still "got transport very fast," as she understood the importance of going to the health facility to have the healthiest delivery possible. Accessing the health facility was seen as a vital step to achieving good health as it was a location to get tested for diseases. Many participants explained that both a mother and newborn child need to be tested for HIV and malaria in order to be considered healthy. As testing is not possible with a TBA, going to the health facility was a necessary step. Although they understood the barriers that exist, many participants viewed accessing a biomedical health facility as key to ensuring maternal health through labor and delivery, and child health during the period of infancy.

When discussing health during labor and delivery, two participants shared experiences of having trouble during delivery, and troubleshooting ways to fix their problems with religion and medication. Irene explained that when she reached the time to

deliver, she didn't have the energy. She was given a shot which helped her, but never identified in the interview what was in the shot. Joseph stated that the only delivery complication his wife had was that she "lost the strength" that was needed. Unlike Irene, Joseph's wife stated that God helped her to deliver the baby. A lack of energy is a common theme from both of these stories that help to better explain the emic understanding of health.

Similar to how it was emphasized during pregnancy, cleanliness was viewed as key to being healthy immediately after delivery. Frequent showering for the mother was often mentioned by participants. Susan explained that after giving birth she would "shower in the morning. And I shower at around noon. I showered at three. And then shower at six." Other participants reinforced the idea of frequent bathing, by sharing that the ideal number of times a mother should bathe daily was between three and four times, to ensure health. Finally, when discussing cleanliness, women described part of their shower routine as using a hot compress on their abdomen. By putting it where they felt pain, several women explained that doing this for a week or two after childbirth "helps to avoid blood from clotting inside the body." Cleanliness remained an important contributing factor to be healthy after childbirth, but participants also viewed the ritual as being medically important.

Infancy/Early Childhood

Compared to understandings of maternal health during pregnancy, labor, delivery, and the postpartum period and infant health, perceptions of child health varied greatly by participant. Although most participants could identify important factors, there was little

consensus between participants as to what criteria should be used to evaluate child health. Some identified things that were physical and measurable, such as vaccines, HIV testing, and new clothing. Others viewed social factors as more important, such as having a united family and someone who was responsible for caring for the child.

Having a strong, supportive family was viewed as a requirement for a child to be healthy. There was significant variation in the family structure of the participants interviewed (including polyamorous relationships, father of the child not being present, and living with in-laws or grandparents), but participants failed to specify what a strong family entailed. However, they did clarify that having "unity […] in the home, will ensure the health of the child." Florence explained that the duty of promoting health fell specifically to the parents, while another clarified that this responsibility was very broad. Protecting the health of the child included bathing, providing an education, and giving the child "everything he requires." Parents were responsible for being both proactive, and taking "good care from the day she is born," and also being reactive, and taking the child for care when they recognized that there was a problem. Despite the fact that it was not clearly defined, having a supportive family was an important factor for child health.

Being attentive to biomedical healthcare needs was a vital facet of childhood health. Many parents felt that taking their child to a health facility when they were sick was an important step to achieving health. They also believed that having a medical professional acknowledge the child was in good health could be an important achievement. As "the doctor cannot discharge you when the child is sick," when participants were told by a medical provider that they could leave the health facility, they understood that their child was healthy. Many participants also mentioned keeping up-to-

date on immunizations as being a milestone in achieving childhood health. Having their immunizations was viewed as being important for helping protect a child against common diseases. Infectious disease testing was another key to achieving good health that biomedical healthcare could offer. When a medical provider could reaffirm parents that their child was HIV negative, parents felt they could label their child as "healthy." Malaria was also mentioned as a barrier to health, and participants explained that proactively using a mosquito net to protect a child could prevent an infection. The final biomedical "key" to achieving child health was ensuring that there was adequate birth spacing. Several participants mentioned discussions with their spouses and how birth spacing was planned for both financial and health reasons. Poor child health was believed to be partly attributed to inadequate birth spacing. Although it is complex and there were varying beliefs, participants felt that accessing biomedical healthcare helped to ensure a child was healthy.

Parents felt that the way their child looked, both every day and while playing, was an indicator as to their health status. The actions and movements of a child was an easy way for parents to gauge health. A newborn crying upon birth and an infant being able to sleep soundly were both mentioned as signs of a healthy child. Interestingly, several participants focused on hand movements. An infant who frequently moved its hands was viewed as having good health, and Brenda specified that a healthy child could be identified by reacting to temperature changes by moving its hands. The full body movement of a child, beyond just its hands, was also an indicator. Judging by the child's "movement, you will just know that she is healthy." Both men and women shared that movement and health were judged based on how a child would play with its peers. This

was an obvious indicator for parents, because when a "child is playing, running around, that shows that, at that time, that child is fine." Similarly, a child showing enough strength to "run and embrace" his or her parents could be deemed healthy. A lack of physical signs of ill health, and being able to appropriately play and move their body indicated to parents that a child was healthy.

A child having an adequate appetite was a way to identify if he or she was healthy. Starting from infancy and breastfeeding, both mothers and fathers shared that a healthy baby was one that was nursing well. Multiple participants stated that a baby should be exclusively breastfed for the first six months, after which solid foods could be introduced. They also stated that after a baby is weaned, in order to be healthy they must drink and eat enough. Robert shared that when observing a child with a poor appetite, "you just know that this child is sick. But if she is eating, you will say that this girl is fine." Having a good appetite, both while breastfeeding and after they are weaned, are cues used by parents to identify if a child is healthy.

New clothing, cleanliness, and religion all contribute to a healthy child. Immediately after birth, a child should be put in new clothes, which helps to ensure that they will be healthy. Similar to maternal health during pregnancy and the postnatal period, cleanliness remained important for children. Ensuring the house is clean, by making sure to "sweep around, put the rubbish in the dustbin and in the toilets," was one way that parents could promote this. Finally, religion was used to keep children healthy. When a child falls ill, a parent can pray on their behalf to heal them. Although not mentioned as frequently, clothing, cleanliness and religion were all identified as facets of good child health.

Discussion

This study sought to examine the First 1,000 Days in the East Central Region of Uganda. Seventeen women and men were interviewed regarding their or their partner's pregnancy, labor and delivery, and experiences with caring for young children. The interviews focused on the Three Delays Model, or examining the barriers that exist to receiving care. Participants were also asked about their emic understandings of health and illness. Several major themes emerged from each research question, which provide important insight for future interventions.

Findings for each research question

How do different barriers to achieving good health impact fetuses, infants, and young children?

This question is most effectively examined through the lens of the Three Delays Model. Overall, the first delay was mentioned by all 17 participants, the second delay was mentioned by 10 participants, and the third delay was mentioned by 15 participants. Therefore, it is clear that all three delays are present throughout the First 1,000 Days for those living in the East Central Region of Uganda.

The Three Delays Model is an excellent theoretical framework to use for this research question as the numerous identified barriers are complex and interrelated. Many of the issues that participants shared were related to multiple spheres of influence, as they extended beyond individual control, and were impacted by larger societal norms and policy decisions.

As the first delay is the delay in the decision to seek care, it is logical that the

barriers participants identified are related to the household. Fear, gender roles, a delay in recognizing health problems, and prioritization of alternative care were all barriers related to this delay.

Barriers related to the second delay, a delay in accessing a health facility, were all closely connected to transportation. The barriers mentioned by participants are larger, structural issues, including difficulties encountered due to distance to the health facilities, road conditions, and accessing care at night.

The third delay, a delay in receiving adequate healthcare in a timely manner, occurs after participants reach a health facility. Barriers in the third delay included having to wait a long time to be seen by a provider, a lack of medical supplies, multiple referrals, issues with staff, financial issues like bribes, poor quality care, and misdiagnosed ailments.

Despite a general dearth of literature regarding the Three Delays throughout the First 1,000 Days, the results from this study aligned very well with existing research. As previous studies focusing on stillbirths, perinatal, and neonatal deaths found that all three delays were present, the current study supports previous research. Additionally, an earlier study by Waiswa (2010) that focused specifically on infant mortality in eastern Uganda also aligns with the current research. In addition to all Three Delays being present, Waiswa found that health facilities were unprepared and understocked, and staffed with inadequately trained providers. All of these factors were also found in the current study. Despite the current study including a wider range of ages, the similarities between these studies highlights that the issues related to infant mortality extend before and after infancy, as they effect all of the First 1,000 Days.

What are the emic understandings of fetal, infant, and early childhood health and illness?

When sharing their personal understanding of health and illness through the First 1,000 Days, participants repeatedly mentioned several concepts. However, these concepts were understood differently depending on if they were referring to pregnancy, infancy, or early childhood. For example, multiple participants discussed food as being key to remaining healthy from conception, through labor and delivery, and until a child reached age two. During pregnancy and immediately post-partum, this could be measured by the type and variety of food available to the mother and newborn. However, throughout the rest of infancy and early childhood, the emic understanding was that a child needed to have a hearty appetite in order to be considered healthy. Although food was important throughout the First 1,000 Days, participants focused on different aspects depending on the time period. In addition to food, emic understandings of cleanliness, accessing biomedical care, the way someone looks or feels, and relationships also varied across the First 1,000 Days, and were mentioned by participants as important.

Results of the second research question highlight that there are complex ways that individuals understand health concepts throughout the First 1,000 Days. Even a topic that is as seemingly straight forward as food has a very different meaning when discussing the health of a fetus versus a two-year old. Therefore, this research question shows that understandings of health vary greatly depending on age, and there is not one clear definition of any health concept.

Limitations

The most significant limitation of this study was using Ugandan interviewers.

Since having an American conduct the interviews would have been seen as coercive, having an in-country team helped to ensure cultural competency. However, the in-country team had varying levels of previous experience with qualitative interviewing. All team members underwent an intensive training and received feedback throughout the research study, but some of the interviewers had trouble mastering concepts such as probing. With a longer study period and the opportunity for additional training, the research team may have been able to gather richer information.

Another limitation is that cultural differences related to use of language required that data be regrouped during analysis. The First 1,000 Days can be broken into three time periods that are roughly equal in length- pregnancy, infancy, and early childhood. As the interview guide was developed around these three time frames, the initial analysis of the data worked to categorize the results accordingly. However, after examining the transcripts, it became clear that in the context of Uganda, this categorization was not possible. Many men and women avoided talking about the fetus while a woman was pregnant, so it was not possible to include pregnancy/fetal health as its own category. Instead, questions related to fetal health were typically answered from the perspective of maternal health. Therefore, the pregnancy/fetal health category was adjusted to include information about maternal health. The third time frame, early childhood, was also not culturally relevant. Participants failed to specify if their children were younger or older than one year. To address this issue, infancy and early childhood were collapsed into a single time frame. As there was a lot of unexpected, but valuable information on labor and delivery available, this replaced infancy and became the second time frame. Therefore, although the original time periods were fetal, infant, and early childhood, they

were adjusted to become fetal/maternal, labor and delivery, and infancy and early childhood (see Figure 1 on page 20). Although changing the time frames did not impact the quality of the data, it is important to note that the cultural differences in language were unexpected and required additional study.

As with many studies, there is a chance that the research results were impacted by bias. As participants were asked about specific events, recall bias is possible. While some questions focused on their most recent pregnancy, a different section of the interview guide asked about a time their child was sick. It is possible that some participants were recalling stories that were over a decade old. Additionally, many of the questions focused on medical decisions. As many participants had overwhelming experiences at the health facilities, it would not be unreasonable to expect that participants incorrectly remembered some details. Social desirability bias also may have influenced participants to not share their true experiences and beliefs. Despite the general knowledge that women should deliver at health facilities, some participants revealed that they had given birth at home or with a traditional birth attendant. However, as the interviews were conducted in person, it is possible that other participants feared they would be judged by the interviewer if they shared similar information.

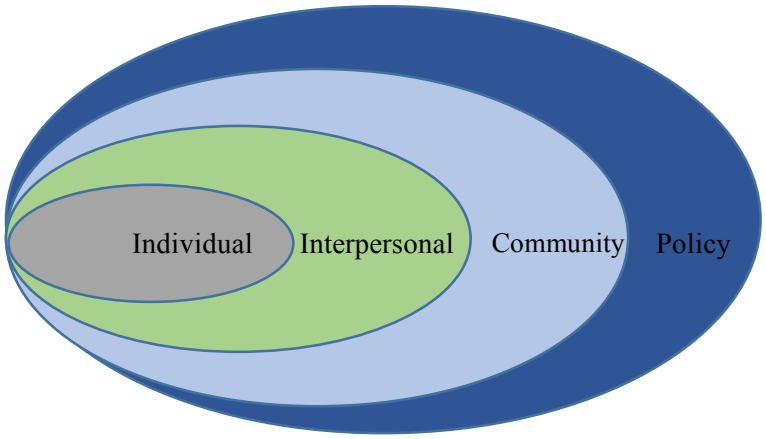
Finally, as the study was designed to be qualitative, the results are not generalizable. Despite the First 1,000 Days being a pivotal period across the world and the Three Delays being pertinent in many different settings, the information collected is only relevant to the East Central Region of Uganda. However, the research study could be conducted again in a different setting, using the same interview guide, to gather additional information that is specific to a different culture.

Future interventions

This study provides important information that could be used for future public health programming. The barriers identified by participants through the Three Delays Model were related to individual behaviors, the balance of power in relationships, societal norms, and policy. These four categories closely align with the framework of the Social Ecological Model (see Figure 2). Therefore, to account for the interactive nature of the levels of influence, the barriers identified through the Three Delays Model could be addressed through future interventions based on the Social Ecological Model.

As the barriers that participants face in the Three Delays Model are evenly split between the individual, interpersonal, community, and policy levels, future interventions that target all of these levels will be the most effective. Education programs that focus on normalizing biomedical care and recognizing signs of poor health would help to change individual behaviors. Improving interpersonal relationships, including those within the household and the interactions individuals have with medical professionals, would lead to better health outcomes. Changing larger structural issues at the community level would allow participants to feel more confident that they will receiving high quality, timely care at a health facility. Finally, working on policy changes that minimize the second delay will

Figure 2- Social Ecological Model



ensure that those who need medical services are able to reach facilities. In Figure 3, all of the identified themes in the data are divided by the appropriate level of the Social Ecological Model. As these issues are complex and multi-faceted, an intervention that could address multiple spheres of influence at once would be most effective.

Using the Social Ecological Model would also provide an opportunity to focus on gender-based risk factors. As it is designed to address the multiple influencing layers that contribute to health decisions, issues related to power and gender can be effectively addressed through the Social Ecological Model. Although the Three Delays Model lacks an explicit focus on power dynamics, designing interventions that emphasize solutions and behavior change from the individual to policy level could address these gender-based risk factors.

Figure 3- Themes from the data sorted by level of the Social Ecological Model

Individual
- Fear (Delay One)
- Delay in recognizing health problems (Delay One)
- Prioritizing alternative care (Delay One)

Interpersonal
- Gender roles (Delay One)
- Issues with staff (Delay Three)
- Misdiagnosed (Delay Three)

Community
- Referrals (Delay Three)
- Financial/bribes (Delay Three)
- Quality (Delay Three)
- Long wait (Delay Three)

Policy
- Distance (Delay Two)
- Transportation (Delay Two)
- Road conditions (Delay Two)
- Accessing care at night (Delay Two)
- Lack of medical supplies (Delay Three)

Out of all the barriers mentioned by participants, those related to the first delay should be addressed first in future interventions. As these are largely individual-level behaviors, education could have an enormous impact in directly improving health. Next, gender roles, which are a barrier related to the interpersonal sphere of influence, could be best addressed through

promoting empowerment. If an intervention aimed at educating women in this region included information on normalizing biomedical care and gender empowerment, progress could be made towards addressing many of the barriers that contribute to poor health throughout the First 1,000 Days.

For future studies done in this setting, it is important to remember the cultural context. As discussed above, emic understandings of different time frames within the First 1,000 Days influence the use of language. Therefore, future research should recognize that it is difficult to discuss fetal health with participants, and infancy and early childhood are not normally recognized as distinct time periods. Using a trained, in-country team will help to maximize the success of future research studies.

Conclusion

Although the current state of maternal and child health in Uganda is austere, this study's data provides important context for the situation. The Three Delays Model provides an excellent framework to examine the barriers to accessing health that exist from conception through age two. Although participants experienced a wide variety of delays, all three delays were present throughout the First 1,000 Days. Studying the emic understandings of health and illness in the East Central Region provide a better understand of the cultural context for health issues. Although some concepts were evident across multiple time frames, they were understood differently depending on the age of the patient. By examining the complex factors that contribute to poor maternal and child health outcomes, barriers can be addressed through culturally competent and effective interventions, which will eventually lead to better health outcomes.

Appendix I- Female Interview Guide

INTERVIEWER READ THE FOLLOWING TO RESPONDENT: Hello. My name is [_____] and I am working with a nonprofit organization called Safe Mothers, Safe Babies.

1. Are you between the ages of 15 and 49?
2. Have you ever been pregnant with a child?

INTERVIEWER READ THE FOLLOWING TO RESPONDENT:
Thank you. We are conducting interviews throughout the Iganga District to better understand community perspectives on maternal and child health. Between 25 and 35 interviews will be completed, and your household has been selected for participation. Most interviews will take 45-75 minutes to complete. If you participate, you will be asked to answer questions related to your family, your wives' pregnancies and births, the health of your children, and your thoughts and opinions about healthcare and pregnancy. There are no right or wrong answers. You can ask me to skip any question for any reason at any time.

Because we are asking about your health and the health of your children, it is possible that you could experience emotional discomfort; however, we do not foresee any risks beyond that. This study is not intended to benefit you personally, but will be used to benefit women, children, and families in this region in the future. You will not be offered payment for being in this study.

Your privacy is very important to us. We will assign a number to the information we collect, but won't record your name so it won't be able to be linked to you. The only personal information collected will be your parish name. Your name will not be recorded and your information will remain anonymous. Some of the information we speak about may be shared with other people or organizations, but it will have no information linking it back to you. There is the possibility of the risk of loss of privacy, but every measure has been taken to prevent this from occurring. The only other time any information would be shared with anyone is if we are required to share it by law. Participating is voluntary. You do not have to participate if you don't want to, but we hope you will agree because we think that your views and experiences are important.

If you have any questions about:

• This study and your part in it, or concerns or complaints about the research, contact Julia Greenspan at Julia.Leigh.Greenspan@Emory.edu

• Your rights as a research participant; questions, concerns, or complaints about the research; or would like to let the IRB know about your experience as a research participant, contact the Emory Institutional Review Board at irb@emory.edu

• If you become uncomfortable at any point, contact Mukalu Mohamed at +256 782 961097

3. Do I have your permission to record the interview?
4. Do you have any questions about the interview?
5. Are you willing to participate in the interview?

BEGIN RECORDING THE INTERVIEW

Warm-up Questions:

1. Tell me a little bit about yourself.
    - What is a typical day like for you?
    - Do you work?
        i. PROBE: Where? What do you do?

2. Tell me about your family.
    - How many people live in your household? How are you related to them?
    - Spouse? Children?
        i. PROBE: Number of children? Age/gender of children?
        ii. PROBE: How many times had you been pregnant before? How many births have you had? How many living children do you have?

INTERVIEWER SAY TO RESPONDENT: "It's great to hear about your family and your daily life. Now I would like to ask about your experiences from your most recent pregnancy."

Care Seeking Decision-Making:

3. Tell me about your pregnancy.
    - PROBE: How did you feel about the pregnancy?
    - How did you feel **during** the pregnancy?
    - IF SHE HAS HAD PREVIOUS PREGNANCIES: How did this pregnancy compare to other pregnancies?
        i. PROBE: How was it different? How was it the same?
4. During the pregnancy, did you discuss **your** health with your husband?
    - IF YES, PROBE: Tell me more about that discussion. When during the pregnancy did you talk about it?
5. During the pregnancy, did you discuss the **baby's** health with your husband?
    - PROBE: Tell me more about what you discussed. When during the pregnancy did you discuss it? Why did you discuss it?
6. During the pregnancy, did you discuss what could go wrong with the pregnancy?
    - PROBE: Tell me more about that discussion. What was decided if something did go wrong?
7. What do you think about antenatal care?
    - PROBE: Who do you think should get antenatal care?
    - PROBE: Did you receive antenatal care during your last pregnancy? Did you discuss it with anyone else? Tell me more about that decision.

i. IF SHE DID RECEIVE ANC: How many antenatal care appointments did you attend? Did anyone attend the appointments with you?
   - What was your experience like with the midwife during your ANC appointments?

8. Tell me about planning for the birth.
   - PROBE: Were decisions made about: where to deliver?; childcare responsibilities?
     i. PROBE: Tell me about how these decisions were made. Who was involved in the decision?
   - Were any purchases made ahead of time for the delivery?
     i. IF YES: Tell me more about [item].
        1. PROBE: **Where** did your purchase it? What did it **cost**? **When** before the birth did you buy it? **Why** did you buy [item]?
     ii. Tell me about financial planning related to other things for the delivery.
9. Were there any things that you wanted to do to prepare for the birth that you could not do?
   a. FOR ANY ACTIVITY NAMED, PROBE: What prevented you from doing that?
10. Tell me about what happened when you reached the time to deliver.
   - PROBE: Where did you want to deliver? Why did you want to deliver there?
     i. Where did you actually deliver?
     ii. IF DISCREPANCY BETWEEN INTENT AND ACTUAL: I noticed that you wanted to the baby to be delivered [LOCATION] but that the baby was actually delivered in [LOCATION]. Why did that change?
   - Were there any problems accessing the care that you wanted?
     i. PROBES:
        1. IF BABY WAS NOT BORN AT HOME: Tell me about how you got to [location where baby was born].
   - Tell me about the delivery.
     i. PROBE: Were there any problems with the delivery?
        1. IF YES: Why was this a problem? How was the problem managed?
   - IF DELIVERED IN A HEALTH FACILITY: Tell me about your experience with the midwife.
     i. PROBE: How were financial decisions made related to transportation to the health facility?
   - IF DELIVERED WITH A TBA: Tell me about your experience with the TBA.
     i. PROBE: How were financial decisions made relating to paying the TBA?
11. How did you feel about the care during the labor and delivery?

INTERVIEWER SAY TO PARTICIPANT: "Thank you. I only have a few more questions that I'd like to ask. These questions are about the health of your child/ren."

12. Was there ever a time before (any of) your child/ren's second birthday that they were very ill?
    - IF YES:
        i. Please tell me about the illness.
        ii. When did you decide the child was sick?
        iii. What did you do once you decided the child was sick?
            1. IF THEY WENT TO A HEALTH FACILITY: How did you decide that you should go to the health facility?
                a. How did you get to the health facility?
                b. What was your experience like at the health facility?
            2. IF THEY DID NOT GO TO A HEALTH FACILITY: Tell me more about that decision.
13. IF CHILD IS STILL ALIVE: How did the illness resolve?

INTERVIEWER SAY TO PARTICIPANT: "Thank you. I only have a few more questions that I'd like to ask. These questions are about health and pregnancy in general."

<u>General Questions</u>

14. Who do you talk with about pregnancy and birth?
    - PROBE: What do you talk about? What are some things they told you that were helpful? What was unhelpful?
15. While you were pregnant, did you discuss your health with any of your family members?
    - PROBE: Who?
    - How was your family involved in your pregnancy?
        i. PROMPT: Who was involved? What was their role?
16. Was there ever a time during one of your pregnancies that you were concerned about **your health**?
    - PROBE: Tell me more about **why** you felt that way. Tell me more about **what happened.**
17. Was there ever a time during one of your pregnancies that you were concerned about the **health of the baby**?
    - PROBE: Tell me more about **why** you felt that way. Tell me more about **what happened.**
18. How would you define good **maternal health**?
    - PROBE: What does it mean to say that a mother is healthy?
    - PROBE: How can a woman keep herself healthy after having a baby?
    - PROBE: What are some barriers to staying healthy while pregnant?
19. How would you define good **child health**?
    - PROBE: What does it mean to say that a child is healthy?
20. What do women need to stay healthy during a pregnancy?

- DEPENDING ON ANSWER, PROBE: How should this be provided? Who should provide this?

21. Are there any special ways that a father can help to make sure his baby is healthy?
    - IF YES: Tell me more about this.
22. Are there any rituals or ceremonies that women participate in related to the health of their babies?
    - IF YES, PROMPT: Tell me more about this.
23. Are there any things that you think should be done to improve the health of mothers, children, or families in your community? What are they?

INTERVIEWER SAY TO RESPONDENT: Thank you so much for all this information. Before we end the interview, is there anything else would you like to tell me about pregnancy, birth, or maternal and child health?

INTERVIEWER SAY TO RESPONDENT: Those are all of the questions I have about maternal and child health. Thank you for your help. I have a few final questions about your personal background and household.

[Quantitative Section]

Appendix II- Male Interview Guide

INTERVIEWER READ THE FOLLOWING TO RESPONDENT: Hello. My name is [_____] and I am working with a nonprofit organization called Safe Mothers, Safe Babies.

1. Are you between the ages of 18 and 49?
2. Have you ever fathered a child?

INTERVIEWER READ THE FOLLOWING TO RESPONDENT:
Thank you. We are conducting interviews throughout the Iganga District to better understand community perspectives on maternal and child health. Between 25 and 35 interviews will be completed, and your household has been selected for participation. Most interviews will take 45-75 minutes to complete. If you participate, you will be asked to answer questions related to your family, your wives' pregnancies and births, the health of your children, and your thoughts and opinions about healthcare and pregnancy. There are no right or wrong answers. You can ask me to skip any question for any reason at any time.

Because we are asking about your health and the health of your children, it is possible that you could experience emotional discomfort; however, we do not foresee any risks beyond that. This study is not intended to benefit you personally, but will be used to benefit women, children, and families in this region in the future. You will not be offered payment for being in this study.

Your privacy is very important to us. We will assign a number to the information we collect, but won't record your name so it won't be able to be linked to you. The only personal information collected will be your parish name. Your name will not be recorded and your information will remain anonymous. Some of the information we speak about may be shared with other people or organizations, but it will have no information linking it back to you. There is the possibility of the risk of loss of privacy, but every measure has been taken to prevent this from occurring. The only other time any information would be shared with anyone is if we are required to share it by law. Participating is voluntary. You do not have to participate if you don't want to, but we hope you will agree because we think that your views and experiences are important.

If you have any questions about:

• This study and your part in it, or concerns or complaints about the research, contact Julia Greenspan at Julia.Leigh.Greenspan@Emory.edu

• Your rights as a research participant; questions, concerns, or complaints about the research; or would like to let the IRB know about your experience as a research participant, contact the Emory Institutional Review Board at irb@emory.edu

• If you become uncomfortable at any point, contact Mukalu Mohamed at +256 782 961097

3. Do I have your permission to record the interview?
4. Do you have any questions about the interview?
5. Are you willing to participate in the interview?

BEGIN RECORDING THE INTERVIEW

Warm-up Questions

1. Tell me a little bit about yourself.
    - What is a typical day like for you?
    - Do you work?
        i. PROBE: Where? What do you do?

2. Tell me about your family.
    - How many people live in your household? How are you related to them?
    - Spouse? Children?
        i. PROBE; Number of children? Age/gender of children?

INTERVIEWER SAY TO RESPONDENT: "It's great to hear about your family and your daily life. Now I would like to discuss your thoughts about health and healthcare services in this region."

General Thoughts Health

2. Tell me about your community.
    - Tell me about the leaders in your community.
    - What do members of your community do for work?
    - What are the most important cultural traditions?
3. What are the biggest health issues facing your community?

INTERVIWER SAY TO RESPONDENT: "Thanks for telling me more about your community and the health challenges that your community face. Now, I'd like to hear more about your experiences with maternal health by talking about your wife's most recent pregnancy."

Care Seeking Decision-Making:

4. Tell me about your wife's most recent pregnancy.
    a. PROBE: How did you feel about the pregnancy? How did she feel about the pregnancy?
    b. How did she feel **during** the pregnancy?
        i. PROBE: How many times had she been pregnant before?
    c. How did this pregnancy compare to other pregnancies?
        i. PROBE: How was it different? How was it the same?
5. During the pregnancy, did your role change in the house?
    a. IF YES, PROBE: How did your role change?
6. During the pregnancy, did you discuss your **wife's** health with her?

a. IF YES, PROBE: Tell me more about that discussion. When did you talk about it?

7. During the pregnancy, did you discuss the **baby's** health with your pregnant wife?
    a. PROBE: Tell me more about what you discussed. When did you discuss it? Why did you discuss it?
8. During the pregnancy, did you discuss what could go wrong with the pregnancy?
    a. PROBE: Tell me more about that discussion. What was decided if something did go wrong?
9. What do you think about antenatal care?
    a. PROBE: Who do you think should get antenatal care?
    b. PROBE: Did your wife receive antenatal care during her last pregnancy? Tell me more about that decision.
        i. IF YES: Did you discuss this ahead of time? Do you know how many antenatal care appointments she attended? Did you ever go with her?
            1. IF HE WENT WITH HER: Tell me about the antenatal care appointment. How did the midwife treat your wife?
10. Tell me about planning for the birth.
    a. PROBE: Were decisions made about: where to deliver?; childcare responsibilities?
        i. PROBE: Tell me about how these decisions were made.
    b. Were any purchases made ahead of time for the delivery?
        i. IF YES: Tell me more about [item].
            1. PROBE: **Where** did your purchase it? What did it **cost**? **When** before the birth did you buy it? **Why** did you buy [item]?
        ii. Tell me about financial planning related to other things for the delivery.
11. Were there any things that you wanted to do to prepare for the birth that you could not do?
    a. FOR ANY ACTIVITY NAMED, PROBE: What prevented you from doing that?
12. Tell me about what happened when your wife reached the time to deliver.
    a. PROBE: Tell me about what your role was during the labor.
    b. Where did you want her to deliver? Why did you want her to deliver there?
        i. Where did she actually deliver?
        ii. IF DISCREPANCY BETWEEN INTENT AND ACTUAL: I noticed that you wanted to the baby to be delivered [LOCATION] but that the baby was actually delivered in [LOCATION]. Why did that change?
    c. Were there any problems accessing the care that you wanted?
        i. PROBES:
            1. IF BABY WAS NOT BORN AT HOME: Tell me about how you got to [location where baby was born].
    d. Tell me about the delivery.

i. PROBE: Were there any problems with the delivery?
1. IF YES: Why was this a problem? How was the problem managed?

e. IF DELIVERED IN A HEALTH FACILITY: Tell me about your experience with the midwife.
i. PROBE: How were financial decisions made related to transportation to the health facility?

f. IF TBA: Tell me about your experience with the TBA.
i. PROBE: How were financial decisions made relating to paying the TBA?

13. How did you feel about the care during the labor and delivery?

INTERVIEWER SAY TO PARTICIPANT: "Thank you. I only have a few more questions that I'd like to ask. These questions are about the health of your child/ren."

14. Was there ever a time before (any of) your child/ren's second birthday that they were very ill?
a. IF YES:
i. Please tell me about the illness.
ii. When did you decide the child was sick?
iii. What did you do once you decided the child was sick?
1. IF THEY WENT TO A HEALTH FACILITY: How did you decide that you should go to the health facility?
a. How did you get to the health facility?
b. What was your experience like at the health facility?
2. IF THEY DID NOT GO TO A HEALTH FACILITY: Tell me more about that decision.

15. IF CHILD IS STILL ALIVE: How did the illness resolve?

INTERVIEWER SAY TO PARTICIPANT: "Thank you. I only have a few more questions that I'd like to ask. These questions are about health and pregnancy in general."

16. Tell me about when you first learned about pregnancy and childbirth.
a. Tell me more about that education.
i. PROBES: Who provided it? Where? What topics did they teach about?
ii. Did you get this education with your wife at the same time, or was it separate from her?
b. Are there any health topics that you'd like to know more about?

17. How do you think men like you should receive health education?
a. PROBES: Tell me more about the ideal setting to receive this education. Tell me more about who should be present to receive this education.

18. Was there ever a time during one of your wife's (wives') pregnancies that you were concerned about **her health**?

    a. PROBE: Tell me more about **why** you felt that way. Tell me more about **what happened**.
19. Was there ever a time during one of your wife's (wives') pregnancies that you were concerned about **the health of the baby**?
    a. PROBE: Tell me more about **why** you felt that way. Tell me more about **what happened**.
20. How would you define **good maternal health**?
    a. PROBE: What does it mean to say that a mother is healthy?
21. How would you define **good child health**?
    a. PROBE: What does it mean to say that a child is healthy?
22. What do women need to stay healthy during a pregnancy?
    a. DEPENDING ON ANSWER, PROBE: How should this be provided? Who should provide this?
23. Are there any special ways that a father can help to make sure his baby is healthy?
    a. IF YES: Tell me more about this.
24. Are there any things that you think should be done to improve the health of mothers, children, or families in your community? What are they?

INTERVIEWER SAY TO RESPONDENT: "Thank you so much for all this information. It has been very helpful. Before we end the interview, is there anything else you would you like to tell me about pregnancy, birth, or maternal and child health?"

STOP RECORDING THE INTERVIEW

INTERVIEWER SAY TO RESPONDENT: Those are all of the questions I have about maternal and child health. Thank you for your help. I have a few final questions about your personal background and household.

[Quantitative Section]

Appendix III- Participant Demographic Information

Participant pseudonyms	Religion	Highest level of education completed	Marital status	Live in the same house as mother (male participants) or mother-in-law (female participants)?	Do you have more than one wife (male participants)? Do you have co-wives (female participants)?	How many wives are there total?	Number of pregnancies	Number of living children
Brenda	Protestant	Some primary	Currently married	No	Yes	3	8	7
Grace	Protestant	Some primary	Currently married	No	Yes	2	6	6
Joan	Protestant	Some primary	Currently married	No	Yes	3	7	6
Isaac	Muslim	Secondary	Currently married	No	No	1	7	6
Joseph	Protestant	Some primary	Currently married	Yes	No	1	4	N/A
Daniel	Protestant	Primary	Currently married	Yes	No	1	1	1
Brian	Protestant	Some primary	Currently married	No	No	1	N/A	3
Doris	Muslim	Some primary	Currently married	No	No	1	9	6
Florence	Protestant	Some primary	Never married	N/A	N/A	N/A	1	1
Henry	Protestant	Some primary	Currently married	No	No	1	3	2
Robert	Muslim	Primary	Currently married	No	No	1	3	2
Andrew	Muslim	Primary	Currently married	No	No	1	8	8

Samuel	Muslim	Secondary	Currently married	No	No	1	7	7
Sharon	Muslim	Some primary	Currently married	Yes	No	1	2	1
Irene	Muslim	Some primary	Currently married	No	Yes	2	8	6
Susan	Muslim	Primary	Never married	N/A	N/A	N/A	1	1
Josephine	Muslim	Some primary	Currently married	No	Yes	2	5	4

Appendix IV- Code Tree and Code Book

Code Tree

1. Things not going as planned
2. Food
3. Father's feelings
4. Father's responsibilities during pregnancy
5. Culture
6. Fear
7. Husband not being present
8. Monetary/physical prep for birth
9. Government
10. No provider available
11. Prioritize health of those outside fetus
12. Financial barriers
13. Gender roles
14. Emotional support sources
    a. Community members
    b. In-laws
15. Work
16. Pregnancy numbers
17. Family descriptions
18. Spirits/traditional medicine
19. Maternal death
20. God/religion
21. Problems effecting the community
22. Home delivery/TBA
23. Education
24. Birth control/birth spacing
25. Bribery
26. Labor and delivery
    a. Surgery
27. Sex
    a. Husband and wife
    b. Infidelity
28. Wife's responsibilities in the home
29. HIV testing
30. Female health
    a. During pregnancy
    b. After childbirth
    c. Bathing/cleanliness
31. Good child health definitions
    a. Breastfeeding
    b. Father's responsibilities
32. Child illness

a. Decisions to access health facility
b. Parents recognizing child is sick
c. Malnutrition
d. Malaria
e. Child death
f. Multiple referrals
g. Multiple diagnoses of one illness
h. Lack of trust in healthcare facilities
i. Vaccines
j. Measles

33. Avoiding discussions about fetus
34. Healthcare decisions and discussions
    a. Lack of discussion
    b. Mother-in-law
    c. Wife's parents
    d. Doctor
    e. Avoiding discussion with others
    f. Wife
        i. Wife making decision about child
        ii. Wife encouraging husband to make a certain decision
        iii. Making decision by herself
    g. Husband
        i. Husband making decision about child
        ii. Husband deciding with his mother
        iii. Husband doesn't discuss with wife
        iv. Husband and wife make the decision
        v. Husband makes the decision
35. Delay in access care at health facility
36. Unexpected birth outcomes
37. Delay in reaching healthcare facility
    a. Night
    b. Process to reach healthcare facility
    c. Road conditions
    d. Distance from health facility
    e. Unable to get transportation- person
    f. Unable to get transportation- mechanical
38. Quality of care received
    a. Refused care/referred
    b. Lack of physical resources
    c. Trust
    d. Rude/mistreated
    e. Timeliness
    f. Ignored by providers
    g. General beliefs
    h. Individual experiences
39. Antenatal care

a. Experiences
b. Perceptions

Code Book

Code	Definition
Things not going as planned	Stories where participant expected a certain outcome and what actually happened was not what they expected
Food	Information about certain types of food women or children consume. Also includes information about not having food
Father's feelings	A man discussing how he feels about general health, a pregnancy, his wife, gender roles, or his child
Father's responsibilities during pregnancy	Discussions of a man's role when his wife is pregnant
Culture	Instances where participants identified something as a part of the culture or a cultural norm
Fear	Times when a man or woman expressed they or someone they were with was experiencing fear
Husband not being present	Husband being absent due to death, work, or family obligations
Monetary/physical prep for birth	Any mentions of saving money or buying things to prepare a mother or child for labor, delivery, and childbirth. Also includes mentions of being unable to secure certain things
Government	Any mention of government involvement (local or national)
No provider available	Not having a provider available when they were needed at a health facility
Prioritize health of those outside fetus	Participants focusing on the health of the mother as opposed to the health of the fetus
Financial barriers	Any discussion of a lack of money being a barrier to receiving care
Gender roles	Discussions about men or women having certain roles or responsibilities due to their gender
Emotional support sources	Individuals that participants mentioned as being sources of emotional support
Community members	Anyone that was mentioned as an emotional support that the participant was not related to or lived with
In-laws	Discussions of a husband's parents as being a source of emotional support
Work	Information about paid or unpaid work
Pregnancy numbers	Number of pregnancies and live births
Family descriptions	Descriptions about family and living situation

Spirits/traditional medicine	Any mention of traditional or spiritual medicine. Includes herbal medicine
Maternal death	Stories that were told where a woman died while pregnant, during labor or delivery, or post-partum
God/religion	Any mention of God or formal, organized religious institutions
Problems effecting the community	Issues that were identified by participants as problems that effected the whole community (as opposed to individuals)
Home delivery/TBA	Stories that involved giving birth at home or with a traditional birth attendant, as opposed to in a biomedical facility
Education	Any discussion about formal education
Birth control/birth spacing	Information about using any sort of birth control. Can include barrier methods (condoms) or non-barrier methods (rhythm method). Also includes the reasons why individuals choose to use birth control (like needing adequate birth spacing)
Bribery	Any mentions of needing to provide money to receive a resource
Labor and delivery	Stories about individual's experiences with labor and delivery
Surgery	Labor and delivery stories involving surgery (emergency or planned)
Sex	Information about any sort of sexual contact
Husband and wife	Sexual interactions between a man and wife
Infidelity	Sexual interactions referring to a couple that are not married
Wife's responsibilities in the home	Obligations that a wife has in the household. Can include specific, discrete tasks (cleaning) or broader obligations (caring for children)
HIV testing	Any mention of biomedical HIV testing
Female health	Beliefs of what contributes to a woman's health
During pregnancy	Discussions about what makes a woman healthy/unhealthy while she is pregnant
After childbirth	Discussions about what makes a woman healthy/unhealthy immediately after childbirth
Bathing/cleanliness	Explanations about the appropriate frequency for a woman to bathe while pregnant/postpartum
Good child health definitions	Explanations of what makes a child healthy
Breastfeeding	Examples of child health that mention breastfeeding
Father's responsibilities	Examples of child health that specify the father's role and responsibilities
Child illness	Stories of a child under the age of two falling ill
Decisions to access health facility	Contributing factors that influenced the decision to take a sick child to the health facility

Parents recognizing child is sick	Contributing factors that helped a parent to recognize the child may be ill and some sort of corrective action needs to be taken
Malnutrition	Child illness stories that involve a child being malnourished
Malaria	Child illness stories that involve a child having malaria
Child death	Child illness stories that involve a child dying
Multiple referrals	Child illness stories that involve a child being referred to multiple health facilities
Multiple diagnoses of one illness	Child illness stories that involve a child's illness being incorrectly diagnosed
Lack of trust in healthcare facilities	Child illness stories that involve parents not trusting healthcare facilities or drug shops
Vaccines	Child illness stories that involve vaccines or a lack of vaccines
Measles	Child illness stories that involve a child having measles
Avoiding discussions about fetus	Participants avoiding discussions about the fetus while it is in utero (as opposed to being out of the body)
Healthcare decisions and discussions	Stories related to decisions about accessing healthcare
Lack of discussion	Participants who identified that there was a lack of discussion about health or accessing healthcare, or didn't share any stories of discussing it
Mother-in-law	Participants who discussed healthcare decisions with the husband's mother
Wife's parents	Participants who discussed healthcare decisions with the wife's parents
Doctor	Participants who discussed healthcare decisions with the doctor/biomedical provider
Avoiding discussion with others	Participants who explicitly avoided discussing healthcare with family members or community members outside of their spouse
Wife	Healthcare decisions that were made by the woman
Wife making decision about child	Instances where the mother made healthcare decisions about the child
Wife encouraging husband to make a certain decision	Instances where the mother did not explicitly make a choice, but encouraged her husband to make a certain choice
Making decision by herself	Instances where the mother made a healthcare decision by herself. Could relate to her own health or the child's health
Husband	Healthcare decisions that were made by the man

Husband making decision about child	Instances where the father made healthcare decisions about the child
Husband deciding with his mother	Instances where the father made healthcare decisions with his mother about his wife or a child
Husband doesn't discuss with wife	Instances where the father didn't discuss healthcare decisions with the mother because he has no time or interest, or he is not available
Husband and wife make the decision	Instances where the father and mother make the decision together
Husband makes the decision	Instances where the father makes the decision himself (about the child or his wife)
Delay in access care at health facility	Stories where there was a delay in accessing care after participants reached a health facility. Possible reasons include no provider was available or they were ignored once they reached health facility
Unexpected birth outcomes	Any mention of an unexpected birth outcome, including premature births, spontaneous abortions, or planning on delivering at a facility and being unable to reach it
Delay in reaching healthcare facility	Stories where there was a delay in reaching a healthcare facility
Night	Stories where there was a delay in reaching a healthcare facility due to it being night
Process to reach healthcare facility	The process that participants had to go through to reach a healthcare facility
Road conditions	Instances where the road conditions acted as a barrier to participants reaching a health facility
Distance from health facility	Instances where the distance acted as a barrier to participants reaching a health facility
Unable to get transportation-person	Instances where delays related to an individual acted as a barrier to participants reaching a health facility. Included delays like being unable to find someone to drive a car, or someone kicking them off a motorcycle
Unable to get transportation-mechanical	Instances where delays related to mechanical issues acted as a barrier to participants reaching a health facility. Included delays like a car not working or a car not being available
Quality of care received	The level of care received as perceived by the participant. Includes both positive and negative care
Refused care/referred	Stories where participants were refused care or referred to other facilities
Lack of physical resources	Instances where physical resources were missing, include not having enough medicine, or medical providers not being present

Trust	Participants sharing when they did or did not trust providers and the care they were receiving
Rude/mistreated	Instances where participants felt they were being treated rudely or being mistreated. Includes instances of physical abuse
Timeliness	Instances where participants felt they had to wait a long time to be seen by a provider
Ignored by providers	Instances where participants felt that a provider purposefully ignored them
General beliefs	General statements by participants explaining the quality of care in facilities
Individual experiences	Information about an individual's personal experience at a healthcare facility
Antenatal care	Any mention of antenatal care. Although intended to focus on formal care (doctors, nurses, trained midwives), may also include traditional care (due to lack of clarification from participants)
Experiences	Information about what actually occurred during ANC visits. Includes personal experiences (self or wife), as well as second-hand experiences (family members, neighbors, or stories that they've heard). Includes ANC experiences for wife and husband
Perceptions	Explanation of and justification for why women should or should not go for ANC. Includes both individual ideas ("I think...") and cultural expectations ("women should..."). Includes perceptions influenced by others ("my husband told me to go")

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