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Decision-Making Related to Pregnancy and Childbirth in Kabarole District, Western Uganda

by

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Dedication

For my mother, who showed me the importance of mothers all over the world.

Abstract

The focus of this study is to understand why, despite high uptake of antenatal care, women in Uganda continue to deliver without skilled birth attendants. A critical gap in our knowledge is an understanding of the decisions women make during pregnancy and childbirth that determine the services they seek. Using a focused ethnography, we explored cultural knowledge and perceptions related to pregnancy and childbirth in Kabarole district. Interviews and focus group discussions were conducted with women that had recently given birth, their husbands/partners, biomedical and traditional health workers, and older women. HIV was identified as an important reason for seeking antenatal care. Other services used during pregnancy, biomedical and traditional, were accessed based on a complex array of beliefs and advice given to women. Thaddeus and Maine's Three Delays Model provided a framework for analysis of barriers to skilled attendance at birth, which include distance, support from partners, and quality of health services.

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List of Abbreviations

ANC – Antenatal care

DHS – Demographic and Health Survey

EM – Explanatory Model

EmOC – Emergency Obstetric Care

HAART – Highly Active Antiretroviral Therapy

HIV/AIDS – Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

MDG – Millennium Development Goal

MDG5 – Millennium Development Goal number 5

MMR – Maternal Mortality Ratio

MOH – Ministry of Health

PMTCT – Prevention of Mother-to-Child Transmission of HIV/AIDS

SBA – Skilled Birth Attendant

TBA – Traditional Birth Attendant

SMI – Safe Motherhood Initiative

WHO – World Health Organization

Chapter 1

1.1 Introduction

Maternal mortality is defined as the death of a woman during pregnancy, childbirth, or within 42 days of delivery (Hogan et al, 2010). The major direct causes of maternal death are hemorrhage, infection, unsafe abortion, eclampsia and obstructed labor (World Health Organization (WHO), 2010 (a)). A woman is estimated to die every minute due to complications related to childbirth (WHO, 2010 (a)). Approximately 99% of this burden lies within low-income countries (World Bank, 2006). Women in sub-Saharan African face a 1 in 16 lifetime chance of dying during pregnancy and childbirth compared to 1 in 4000 in high-income countries (UNICEF, 2009). With adequate access to family planning services, prenatal health education and skilled care during pregnancy, childbirth and the first month after delivery, almost all deaths can be prevented (WHO, 2010 (a)). Improved maternal health can empower women to have smaller family sizes and increase the intergestational space between births, which, in turn, allows families and governments to invest in education, health, and economic growth. In contrast, poor maternal health outcomes can reduce family income and productively. Costs associated with health care can reduce funds required for other necessities such as food, housing, and education (Global Health Council, 2010).

It has only been in recent years that maternal health has become a prominent issue on the global public health agenda. In 1985 the public health

community recognized that more than half a million women were dying every year due to complications related to pregnancy and childbirth, most of which were avoidable and preventable (Rosenfield & Bardfield, 2009). This finding resulted in the launch of the Safe Motherhood Initiative (SMI) in 1987 (Starrs, 2006). The SMI was an international strategy with the purpose of reducing maternal mortality by half by 2000 through an emphasis on maternal services such as antenatal care (ANC) in order to detect and manage complications. SMI encouraged training of Traditional Birth Attendants (TBAs) through large-scale programs and prioritized professional medical intervention for complications (Starrs, 2006). More than two decades later, this initiative has been deemed largely unsuccessful in reducing maternal mortality. The reasons for this include, among others, inadequate measures of mortality, a lack of consensus around appropriate interventions, insufficient political commitment and poor infrastructure (Berer, 2007).

In 2001, eight international development goals, known as the Millennium Development Goals (MDGs) were agreed upon by the 192 United Nations member states and numerous international organizations. The goals range from reducing maternal mortality to promoting gender equality and were to be achieved by 2015 (UNDP, 2010). The fifth Millennium Development Goal (MDG5) is to improve maternal health by reducing the maternal mortality ratio (MMR) by three quarters from the 1990 statistics and achieve universal access to reproductive health services (UNDP, 2010). Current knowledge shows that 15% of all childbirths will face a life-threatening complication requiring emergency obstetric intervention; these complications are unpredictable, thus women cannot be

screened as “high risk” during antenatal visits (WHO, 2000). For this reason, skilled birth attendants (SBAs) at every birth and access to Emergency Obstetric Care (EmOC) is a key focus of maternal health projects working to achieve MDG5 (United Nations, 2008).

Nonetheless, and despite significant international investment since 2000, countries with the highest burden of maternal mortality are failing to achieve the targets of MDG5. In 1990, there were an estimated 576,000 maternal deaths, and in 2008, almost two decades later, there were 529,000. Although there is some controversy regarding the exact numbers of maternal deaths worldwide, with figures ranging from an annual MMR decline of 0.4% to 1.3%, all evidence suggests we are failing to achieve the 5.5% decline in annual maternal mortality that is required to meet the 2015 MDG target (Hogen at al, WHO, 2010(b)). Moreover, an additional ten million women are estimated to suffer long-term complications and disabilities, such as obstetric fistula, related to pregnancy and childbirth (Rosenfield & Min, 2007; Global Health Council, 2010).

1.2 The Ugandan Context

Sub-Saharan Africa accounts for only 11% of the world’s population but carries half the burden of maternal, newborn and child deaths (Friberg et al, 2010). Like most sub-Saharan countries, Uganda is characterized by a high maternal mortality ratio of 435 deaths per 100,000 live births (UBOS & Macro International Inc, 2007). The key health focus in Uganda has, in the past, been on the HIV/AIDS epidemic. But other issues such as the high maternal mortality,

reproductive health, family planning, child health and gender equality have gained importance through efforts such as SMI and the MDGs (Uganda District Information Handbook, 2005).

Uganda is also a context in which 92% of women seek ANC services at least once during pregnancy but only 42% deliver under the care of a skilled birth attendant. A breakdown of maternal health service uptake shows that despite the rates of ANC attendance, only 47% of women received the recommended four antenatal visits and services are accessed late in pregnancy. Fifty-eight percent of deliveries in Uganda take place outside of a health facility with the proportion of home deliveries being higher in rural areas (64%) and lower in urban areas (21%). Of the births that are not attended to be a skilled attendant, 23% deliver in the presence of TBAs, 25% with family/friends and 10% alone (UBOS & Macro International Inc, 2007).

A critical cap in our knowledge today is why, despite education, health programming, and widespread use of ANC women continue to deliver in unsafe conditions without the assistance of SBAs in Uganda (Berer, 2007; Starrs, 2006). Little is known about the cultural practices and belief systems around pregnancy and childbirth that determine the type of services Ugandan women use. We need to understand why, for example, women choose to access ANC services during pregnancy, but deliver at home with a TBA or another unskilled attendant. It is unclear if delivering at home is a woman's choice or a decision made due to circumstances beyond her control. The impact of ethno-cultural belief systems related to pregnancy and childbirth on the services accessed during pregnancy and

childbirth is critical to fill this knowledge gap. Utilizing work by Amooti-Kaguna & Nuwaha (2000) and Kyomuhendo (2003), the present research aims to address these knowledge gaps. Empirical evidence to help understand and address the gap between high rates of ANC access and low rates of skilled attendance at birth is crucial. This research will provide policymakers and program planners with cultural insight on maternal health services.

Chapter 2

Literature Review

2.1 Search Strategy

The strategy for the review of literature involved searching numerous databases including: Medline, Pubmed, Global Health, Web of Science, Embase, CINAHL and Google Scholar. Sources used included journal articles, newspaper articles, textbooks, and grey literature. The term 'grey literature' refers to papers and reports that are not indexed in major data bases and, in this case, included government websites, maternal health reports and publications by major organizations such as USAID and WHO. Searches were conducted using key words such as *maternal mortality, pregnancy, complications, childbirth, prenatal care, health knowledge, attitudes, practice, explanatory models, Africa and Uganda.* These terms were searched in various combinations and independently. Key journals such as Social Science & Medicine, Reproductive Health Matters and Lancet were also hand searched for any articles that may have been missed and to ensure the latest literature was accessed. Qualitative studies identifying women's knowledge, attitudes, perceptions and beliefs and their role in decision-making at the time of childbirth in western Uganda were not found. Further, evidence that included views of multiple stakeholders such as women, men, community members and health workers were not found. Thus, a gap in what is known was noted. This study aims to fill the identified gaps as well as to

contribute to the knowledge surrounding decision-making during pregnancy and childbirth.

2.2 Maternal health guidelines

Hemorrhage, sepsis, eclampsia, obstructed labor and abortion are the five most common causes of maternal death in developing countries (WHO, 2009). These complications are preventable or can be managed through identification of danger signs and the ability to provide quality care and refer to a higher level of care when necessary (WHO, 2009; WHO 2010 (a)). The World Health Organization (WHO) created recommendations for care that should be provided to all mothers during pregnancy, childbirth and the post partum period. During pregnancy, routine care includes four antenatal visits to confirm pregnancy, monitor progress, detect problems, provide prophylaxis (iron, folic acid, tetanus immunization) and treatment for illnesses (anemia, hypertension, bleeding, malpresentation), provide health education, plan for the time of delivery, and be tested for syphilis (WHO, 2009). In certain areas, such as Uganda, it is also important for women to receive HIV counseling and testing, preventative treatment for malaria and treatment for intestinal worms (dewormer) (WHO, 2009; Bhutta et al, 2010; Horton, 2008; Carroli, Rooney & Villar, 2001). During childbirth, women require diagnosis of the onset of active labor, monitoring of the progress of labor as well as maternal/fetal wellbeing, continuous documentation of findings on the partograph, supportive care and pain management and management of the third state of labor (WHO, 2009. These activities will promote detection of complications and problems associated with labor prolonged

labor, obstructed labor, bleeding), delivery and immediate care of the newborn. After delivery, women must be monitored and assessed in case of complications such as infections and bleeding. During the postnatal period (six weeks after childbirth), the mother and child need to be assessed for well being, prevention and detection of any complications, prevention of anemia and prophylaxis through iron and folic acid supplements, counseling and education on nutrition, safe sex and family planning and health education on danger signs and precautions (WHO, 2009).

Routine antenatal and childbirth care can help identify women who require additional care. In cases where perinatal women are HIV positive, for example, they will require prevention of mother to child transmission (PMTCT), treatment of HIV infection and counseling on infant feeding, mode of delivery and further health education regarding HIV (Horton, 2008; Bryce et al, 2008; Carroli, Rooney & Villar, 2001). In cases of complications during childbirth, such as obstructed labor, women may require labor enhancement or assisted delivery including caesarean sections, blood transfusions and other medical interventions. It is important in all cases to be able to identify the signs of danger through ANC and skilled care at the time of birth so that appropriate interventions can take place in a timely manner (WHO, 2009; WHO, 2004; Carroli, Rooney & Villar, 2001).

2.2.1 Skilled attendant

A skilled attendant is defined as an accredited health professional such as a midwife, nurse or doctor who has been trained and educated in the skills

necessary to manage normal (uncomplicated) pregnancies, deliveries and postpartum maternal/newborn care over six weeks (WHO, 2004). These attendants are able to identify, manage and refer complications in women as well as newborns. Skilled care refers to care that is provided by a skilled attendant who has access to the required technology and the support of a functioning health system (WHO, 2004). Through the Millennium Development Goals, skilled care during pregnancy, childbirth and the postnatal period has been emphasized as an important factor in reducing maternal mortality (WHO, 2004; Bhutta et al, 2010; Bryce et al, 2008). Unfortunately, in spite of the importance placed on skilled attendants being at every birth, many low income countries still lack sufficient human resources to achieve this goal (WHO, 2004).

2.2.2 Traditional Birth Attendant (TBA)

The term 'traditional birth attendant' refers to a person who has been informally trained and provides community-based care during pregnancy, childbirth and the postnatal period (WHO, 2004; Kamal, 1998). TBAs are defined as "… a person (normally a female), who assists mothers during childbirth and who initially learns her skills delivering babies by herself or by working with another, more experienced TBA" (Kamal, 1998, p S43).

In the past, it had been suggested that TBAs could perform the role required of a skilled attendant, however, it has been recognized that even training TBAs does not result in a reduction of maternal mortality and it is hypothesized that this is due to a failure to link them with the health system (WHO, 2004;

Essendi, Mills & Fotso, 2010). In a Pakistani training study, TBAs did not lead to a decrease in maternal mortality (Jokhio, Winter & Cheng, 2005) but they were identified as important partners in safe motherhood to advocate for skilled attendance (Campbell & Graham, 2006). According to some literature (WHO, 2004; Campbell & Graham, 2006), in order to successfully integrate TBAs, they must become a part of the health system and so that they can refer mothers for skilled care while still providing health education, support, and acting as a link between the community and health services.

2.2.3 The health system

It is accepted that in order to successfully implement maternal health programs, a functioning health system is essential. A functioning health system includes transport and referral services for the management of situations requiring emergency obstetric care (WHO, 2004). Policies, procedures and guidelines pertaining to routine and emergency care must, for example, be put in place (Bryce et al, 2008). Moreover, adequate human resources are necessary. This means that sufficient numbers of skilled attendants, with the necessary skills, working in environments that provide sufficient salaries and opportunities to continue training and upgrade skills are needed (WHO, 2004; Bhutta et al, 2010; Campbell & Graham, 2006). Availability of essential medications, supplies and equipment is required to implement maternal guidelines. A transport and functioning referral system, such as ambulances in cases of emergencies and communication between health services must also be in place (WHO, 2004). Moreover evaluation mechanisms to assess the effectiveness of the health system

and patient satisfaction with care provided can assist with the provision of quality care (WHO, 2004). Lastly, partnerships and linkages between the health sector and communities, including traditional care providers and community leaders, can help ensure that women actually know what services are available and needed. Furthermore, these partnerships can promote the integration of health services within the community (WHO, 2004; Campbell & Graham, 2006).

2.3 Maternal Health in Uganda

2.3.1 Overview of health services

Uganda encompasses 241,039 Km^2 and has been divided into 80 administrative districts (see appendix A). While the national government is responsible for security, policymaking, standards and supervision, there is a decentralized system for other matters such as health services, which are allotted to the district health system (UBOS & Macro International Inc, 2007). The Ministry of Health (MoH) provides guidelines, technical support and supervision and the District Health Officer (DHO) is responsible for managing funds, implementing guidelines and supervising health services. Services are provided to the population by a mix from both public and private sectors. As only 6% of the country's GDP is allocated to health services, the population endures a large out-of-pocket cost for care (Pearson, 2000).

Kabarole district in western Uganda has a population of 427,426 and 60 health facilities. There are three hospitals, one of which is a government hospital (Fort Portal Referral Hospital also known as *Buhinga*), another is semi-private

(Kabarole District Hospital), while the third is a faith based private hospital (Virika Hospital). The government hospital provides services free of charge while the private and semi-private institutions charge fees for services rendered. The three hospitals are located in Fort Portal town and are all within walking distance of one another indicating a very centralized system of health care. (Joa Okech, personal communications, December 3rd, 2000).

In addition to the three hospitals, there are 60 health centers throughout Kabarole district. Health centers are numbered I - IV depending on the services that are offered. Health center IV's ideally have a functioning operating theatre, a medical officer present, maternity ward and an ambulance available. Health center III's have midwives available to conduct low risk deliveries but lack operating theatres and doctors. Health center II's conduct ANC and post natal care, but do not conduct deliveries. The term 'health center 1' is used to describe a local village health team. This team does not offer maternity services. Health center IV's are the least common, with only three in the entire district. (Dr. Joa Okech (DHO), personal communication, December 3rd, 2000).

Western Uganda experiences two rainy seasons; the long rains and the short rains. Heavy rainfall can disrupt transport in rural areas particularly in regions with few paved roads. Rural populations often rely on bicycles, small motorcycles and ambulation as their main modes of transport; all of these can be hindered by the combination of heavy rainfall and dirt roads (Uganda District Information Handbook, 2005).

Maternal mortality in Uganda has declined since the mid-1990s. The MMR in 1995 was 557 deaths per 100,000 live births and it was most recently found to be 435 in 2006 (Mbonye et al, 2007; UBOS & Macro International, 2007). This decline can be attributed to the focus on emergency obstetric care, family planning programs and emphasis on skilled attendants at every birth. Although there is progress, reaching the Millennium Development Goal target of 162 by 2015 requires a great deal of intervention (Mbonye et al, 2007). A recent study identifying interventions that are necessary to achieve the goal MMR found that health facilities continue to lack emergency care. Many health units, despite the presence of a midwife, lack running water, electricity and functioning operating theatres (Mbonye, et al, 2007). Women are encouraged to seek institutional care but it is clear that these facilities often lack basic services (Ssengooba et al, 2003).

Surveys in Uganda show that the majority of women access ANC at health facilities during pregnancy. The main reasons for seeking this service have been to get an antenatal card, to make sure the pregnancy is okay and to get an injection for tetanus (Amooti-Kaguna & Nuwaha, 2000). The antenatal card is a precautionary measure in case women need to deliver at health facilities as possessing this card is seen as good behavior (Amooti-Kaguna & Nuwaha, 2000). Women may choose not to access biomedical services during pregnancy because of lack of money, fear of ridicule by health care workers, long distances to health units and lack of drugs and supplies at health units (Amooti-Kaguna & Nuwaha, 2000).

There are many traditional practices that are common during pregnancy and childbirth in Uganda. Women have used herbal remedies for many years and TBAs provide mothers with herbs for cleansing their birth canal, preventing abnormal vaginal discharge and protecting the pregnancy from bad omens (Amooti-Kaguna & Nuwaha, 2000). Women receive herbal treatments from TBAs; meanwhile, biomedical health care workers hypothesize that some herbs may be toxic to the development of the fetus and discourage their use. This results in conflicting advice given to women during pregnancy with regards to herbs and traditional practices (Ssengooba et al, 2003).

A small body of literature identified the perception that, although complications and maternal deaths are sad events, they are considered normal. Pregnancy was a test of endurance for women where survivors are recognized as such and those that do not survive or require external (medical) assistance may be seen as lazy and undeserving of praise (Kyomuhendo, 2003). Thus, medical care is only sought in extreme cases and if traditional therapies are deemed ineffective.

In 2008, the Ministry of Health in Uganda announced its decision to ban TBAs from practicing due to the lack of timely referral when complications occur. It was recognized that women sought care from TBAs because of the insufficient number of skilled professionals, particularly in rural areas, but the ministry of health did not want to be perceived as endorsing the work of TBAs (Malinga, 2010). TBAs in Uganda, like in other countries, have been practicing since antiquity (Kamal, 1998). In Katine, a sub-county in northeast Uganda, an assessment of TBAs found that they are continuing to assist women at the time of

childbirth. Reasons for this include the financial benefit of practicing, poor health infrastructure and a cultural confidence in TBAs (Malinga, 2010). Moreover, if a TBA is approached to help save a mother that is in labor and unable to access to health services, she will not refuse. In many parts of Uganda women are unable to access transport to reach health facilities, and so they utilize TBAs (Malinga, 2010). Kamal (1998) suggested that even if TBAs are banned through laws, it is unlikely that low-income countries will have sufficient health workers and institutional facilities to replace them. Therefore, it is assumed that TBAs will continue to exist and practice, even without recognition or support from the Ministry of Health, because the demand for them will continue to be in place (Kamal, 1998).

The majority of women in Uganda deliver in their homes with TBAs, family members, other non-skilled workers or alone (Amooti-Kaguna & Nuwaha, 2000; Ssengooba et al, 2003; UBOS & Macro International 2007). TBAs are well-known community members with informal training or acquired experiential knowledge (Ssengooba et al, 2003; Amooti-Kaguna & Nuwaha, 2000). Prior to the 2008 ban on TBAs, they were trained in safe delivery, identification of complications and appropriate referral practices by the Reproductive Health Programme in Uganda. TBAs are believed to build better relationships with women and can provide them with culturally appropriate care. TBAs are also preferred because they are flexible, they can negotiate payments, and live in the community (Amooti-Kaguna & Nuwaha, 2000). However, it is not believed that TBAs have contributed to a decrease in maternal mortality and poor referral

practices have been noted (Ssengooba et al, 2003). Since TBAs receive payment for conducting deliveries, they may attempt to manage complications rather than appropriately referring women who are at greater risk for adverse outcomes (Ssengooba et al, 2003). Women seek medical care during childbirth if pregnancies are complicated or if complications such as bleeding arise during labor. If women are advised of abnormalities during pregnancy, they are more likely to seek medical care and deliver in health facilities. Other reasons for home deliveries include habit, lack of money, labor starting during the night, long distance to health units and a preference for TBAs (Amooti-Kaguna & Nuwaha, 2000).

2.4 Explanatory Models

A large body of anthropological literature documents perceived need as a predictor for the type of healthcare sought (Atkinson & Farias, 1995; Chapman, 2003; Chapman, 2006; Kleinman & Mendelsohn, 1978; Kleinman, 1978). Perceived need for health services is determined by the explanatory models (EMs) held at the individual and community levels related to the body, illness and, in this case, pregnancy and childbirth (Atkinson & Farias, 1995). Researchers have only recently begun to assess the relationship between risk perception during pregnancy and the subsequent decisions made by women to manage pregnancy and childbirth (Chapman, 2003; Chapman, 2006). The significance of understanding explanatory models lies within the hypothesis that when EMs of patients, families and practitioners align, clinical communication, clinical management, patient adherence and outcome improve. The different systems of

medical knowledge are anchored in cultural beliefs, sociopolitical arrangements and traditional knowledge (Kleinman & Mendelsohn, 1978). In order to maximize health in a community, it is believed that professional practitioners should be better trained in understanding patient and family EMs, thus enabling them to negotiate the treatment of illness, improve communication and increase patient adherence to the treatment of illness (Kleinman, 1978).

In order for health care professionals to ensure that mothers seek the recommended care during pregnancy and childbirth, it is important for them to understand the mothers' perceptions of pregnancy and childbirth (Kleinman, 1978). For example, a study in Nepal assessing the perception of bleeding during pregnancy and childbirth found that communities look at the complications differently than do health care workers (Matsuyama & Moji, 2008). Vaginal bleeding, according to health workers, is a danger sign and indicator of complication that requires medical follow-up. Community members however perceive bleeding after delivery as a normal event and, at times, even necessary to wash the woman's body of 'bad blood' (Matsuyama & Moji, 2008). In fact, some even perceive that more blood is a positive indicator. In cases of excessive bleeding, traditional medicine is accessed, which can lead to significant delays in identifying the need for biomedical attention. (Matsuyama & Moji, 2008) Thus, it is important to both understand these differing perceptions and to identify knowledge and behavior gaps.

In a Brazilian study, Atkinson and Farias (1995) assessed the relationship between risk perception and motivation for seeking health services during

pregnancy. In this population, local explanatory models did not alter the health services that women seek during pregnancy in a negative manner as they did in Nepal. For example, the risks that women identified included cesarean sections, abortions, high blood pressure, and anemia. Women also perceived that childbirth would be easier with prenatal care because the hospital will identify them as more responsible. In order to avoid the risks and to make sure they are treated well in hospitals, women access ANC and delivery in health facilities (Atkinson & Farias, 1995).

In the above studies, it is illustrated how local explanatory models and local perceptions of risks and complications can result in health seeking behavior or delays in accessing appropriate emergency care (Matsuyama & Moji, 2008; Atkinson & Farias, 1995). Research such as this was not found in Uganda but it is necessary to gain a better understanding of the local values and beliefs that affect health-seeking behaviors. For example, women in Kabarole district seek ANC but the majority does not deliver in health facilities. It is important to take a critical look at the services that are used during pregnancy and childbirth and why. Dissemination of local explanatory models and health priorities during this period in a woman's life is essential. Health care workers and policy makers' awareness of such explanatory models can result in their integration into health education and service delivery policies and guidelines.

2.5 Purpose

Drawing on the Demographic Health Survey data and the maternal health policies in place by the Ministry of Health in Uganda, the purpose of this research is to explore and understand why, despite education, health programming, and widespread use of ANC, women continue to deliver in unsafe conditions without the assistance of skilled birth attendants.

2.6 Specific Research Questions

1. What types of services, biomedical, traditional, or other, do women in Kabarole District use during pregnancy and childbirth?

2. How do Ugandan women decide on the services they will access and utilize during pregnancy and childbirth?

3. What factors modulate the decisions regarding the type of care sought?

2.7 Study Objectives

1. Map local knowledge, perceptions, beliefs, practices and attitudes related to pregnancy and childbirth.

2. Identify and describe the health resources, facilities and treatments (traditional and biomedical) that are used during pregnancy and childbirth.

3. Present policy makers and health care workers with local explanatory models thus providing insights that can enable them to develop health policy and health services that meet population needs.

Chapter 3

Methods

3.1 Qualitative Design

The primary question for this research study involved acquiring an understanding of what services women access during pregnancy and childbirth and how they decide to access these services. This requires an in-depth understanding of women's experiences and behavior. Thus, a qualitative study design, which allows for understanding the 'how' and 'why' questions, was deemed most appropriate.

Qualitative research is based on the acceptance of multiple realities (individual perceptions of a phenomenon are unique), which can elicit values, beliefs, customs, and responses of individuals or populations under study (Donalek & Soldwisch, 2004). This type of research takes into account the interaction of the researcher with the participants and the environment (Key, 1997). Qualitative research is particularly appropriate for our research because it is important for us to understand what women choose to do during pregnancy, how they do it and why this is seen as necessary. Qualitative researchers can explore local knowledge and concepts, which can help, explain and inform quantitative findings (Yoder, 2001).

3.2 Focused Ethnography

The research methodology most appropriate for the proposed research questions and objectives is a focused ethnography. Ethnography, with its anthropological roots, aims to study a particular culture or phenomenon through fieldwork, documenting beliefs and practices emerging from the culture being studied (Riemer, 2008). This is accomplished through the researcher's immersion in the community and the lives of people (Hammersley & Atkinson, 2007). An ethnography requires the researcher to study behavior in everyday situations rather than under experimental or artificial conditions that have been created for the research (Genzuk, 2003). The ethnographer aims to interpret the culture or phenomenon from the emic, "insider's" view of reality and translate it so that outsiders can understand it (Riemer, 2008; Hammersley & Atkinson, 2007).

Focused ethnography is a research methodology designed to explore cultural knowledge and perceptions related to specific illness categories rather than the broad set of findings that can be obtained through traditional ethnography. This method can work towards collecting emic information that contributes to uncovering local explanatory models of illness (Kleinman, 1978; Albrecht, Fitzpatrick, & Scrimshaw, 2003) by asking specific questions (Knoblauch, 2005). Focused ethnography concentrates on small elements of society through short-term field visits, which produce large amounts of data in a relatively short period of time. Data are collected through recording rather then

writing and is analyzed through coding and other analytical methods (Knoblauch, 2005).

3.3 Setting

Data were collected in two areas of the Kabarole district – Fort Portal Town and surrounding villages and Hakibale Sub County. Kabarole district has 60 health units with 75% of the population being less than 5 kilometers away from a unit (Uganda districts information handbook, 2005). The three hospitals in Kabarole district, Fort Portal Referral, Kabarole District Hospital and Virika Hospital are all located in Fort Portal town. We selected Hakibale sub-county based on advice from Mr. Tom Rubaale, the project manager for the Community Based Highly Active Antiretroviral Therapy (HAART) project. Hakibale sub-county was located about 20 km away from Fort Portal town and required either a vehicle or a *boda-boda* (motorcycle taxi) to reach. The road was unpaved and could easily be flooded and blocked during the rainy season. Both Fort Portal Town and Hakibale Sub County had health centers, but only Fort Portal had hospitals; anyone from Hakibale requiring hospitalization or higher-level care would require transport to the hospitals in town. We visited three health centers around Fort Portal town and three health centers in Hakibale sub-county.

As a Registered Nurse in Canada and a student in Public Health Sciences with a specialization in Global Health, the issues of maternal mortality in a developing country including the recommendation for skilled attendants at every delivery, utilization of health facilities, health promotion and health education are

all within my field of study and areas of expertise. Having previous experience in east Africa as both a nursing student and a resident for several years, Uganda seemed an ideal location to conduct this project. Kabarole district was selected given that the School of Public Health at the University of Alberta has long-term connections within the district. Prior to entering Uganda, study approval was provided by the District Health Officer (DHO), Dr. Joa Okech (See appendix B).

3.4 Data collection

Participants for this study were drawn from four groups in the population: 1) women of reproductive age (18-49) that have had a child (non stillbirth) in the last 12 months 2) husbands of women who recently gave birth (in the past two years) 3) older women (over the age of 50) living in the community and 4) formal and informal health care providers in the community (doctors, nurses, midwives, clinical officers, TBAs and traditional healers).

Three main data collection methods were used for this focused ethnography: participant observation, in-depth interviews, and focus groups (Hammersley & Atkinson, 2007). In-depth interviews were conducted with women of reproductive age and older women, either in their homes or outside in the community; these ranged from twenty to forty minutes in length. Due to the demanding schedule of formal health care providers, we did not plan on spending more than twenty minutes with them. In the field however, health care workers actually scheduled an interview into their day and provided us with adequate time to ask the needed questions. The majority of these interviews were conducted in

English by the primary researcher. TBAs were interviewed in their homes or within the community and some showed us the beds upon which women delivered. Interviews with health care workers (traditional and biomedical) were, on average, forty minutes long.

The semi-structured interview guides were created prior to traveling to Uganda and were designed to help illicit local knowledge, attitudes, perceptions and beliefs related to pregnancy and childbirth (Kleinman, 1978; Ulin, Robinson & Tolley, 2005). The initial interview guide was loosely based on the McGill Illness Narrative Interview (MINI) and Explanatory Model Interview Catalogue (EMIC) interview styles because the aim of both is to attain local explanatory models regarding illness (Weiss, et al, 1992; Groleau, Young & Kirmayer, 2006) (see appendix C). Upon arrival in Uganda, the interview guides and information sheets were translated into Rutooro and assessed for clarity and cultural appropriateness by Tom Rubaale, the project manager for the Community-Based HAART project. Tom has a great deal of research experience and has worked with previous masters students from the University of Alberta. This guide was used for the first 3 to 4 interviews and after reviewing transcripts and discussing findings with research assistants, modifications were made to collect more specific information and ask additional questions. This process of reviewing transcripts and making modifications to the interview guide was continued throughout the research process (Ulin, Robinson & Tolley, 2005).

Focus groups, which use group interaction to produce data and insights, were conducted with men to gain insights into their beliefs and knowledge of

services accessed during pregnancy (Rothe, 2000; Ulin, Robinson & Tolley, 2005). We recruited 10 participants and aimed for each group to have 6 to 10 men, as it could not be expected that all potential participants would be able to attend. Focus group discussions included a facilitator who introduced topics, provided information and sought informed consent. The facilitator asked questions based on an interview guide to illicit information regarding community perceptions and gender-based perceptions, beliefs and practices with respect to pregnancy and childbirth (see appendix D) (Rothe, 2000; Ulin, Robinson & Tolley, 2005). There was also a note taker who recorded a simultaneous translation of the session so that the researcher could ask additional questions or clarify the discussion. We conducted four focus groups all together: two with participants living close to Fort Portal town and two with participants living in Hakibale Sub-County. The focus groups had an average of ten participants and were between 40 and 60 minutes in length.

The researcher lived within the community for four months and maintained a journal with notes on observations made at health centers, observations from interviews and further questions that arose from the findings. The researcher also accompanied the research assistants the majority of time that fieldwork was being done but did not always sit in on the interviews because she thought the participants would be more comfortable with only the research assistants. When the researcher was in the field, observations were made of the facilities available, transport methods and living conditions. During field

observations, personal identifying information was not collected and photos, when taken, did not include any people.

Participants were recruited through a snowball sampling approach, which falls under the broader category of purposeful sampling. Purposeful sampling selects participants based on characteristics that are deemed to appropriate for the research question and objectives. Snowball sampling involves identifying a person or "case of interest" and then asking that person to recommend other potential participants who would also be appropriate and asking subsequent participants to recommend more potential participants to be included (Trochim, 2006). In the present study, we identified the first cases through local networks within the health centers, hospitals and through the local council. Each village had a local council leader (LC1) that we approached; we introduced the study to the local council leader through an information letter (see appendix E) and requested permission to recruit participants in the community. We began our study in villages near health centers and then proceeded into villages that were further away based on recommendations from the local council. We also recruited traditional healers and TBAs in far away villages based on recommendations from participants on where to find them.

It is important in qualitative research to focus on understanding an experience rather than understanding individuals, thus sample size must be large enough to identify sufficient themes and ideas to understand the experience of pregnancy and childbirth (Hammersley & Atkinson, 2007). Although sample size in qualitative research is difficult to ascertain in advance, it is important to collect

and analyze data concurrently to determine if saturation has occurred or if no new ideas are forthcoming. Prior to beginning the study, we estimated that about 30 in-depth interviews with childbearing women, 5 to 10 interviews with older women, 10 interviews with health care workers as well as 4 to 8 focus groups with men would be required. We conducted 31 interviews with new mothers, 9 interviews with formal health care workers, 9 interviews with informal health care workers, 10 interviews with older women and 4 focus groups with men resulting in a total number of 104 participants. Data were collected until all members of the research team believed we had reached saturation. However, this was difficult to ascertain because local researchers were not trained anthropologists and may not have been clear on the notion of saturation. Furthermore, as only one person was translating and transcribing a large number of interviews, there was a time lag between interviews and availability of transcripts, thus analysis was also delayed.

All participants were required to be residents of Kabarole district and fit inclusion criteria for age and history of childbirth. Research assistants, fluent in English and Rutooro explained the study verbally and provided an information sheet in both languages (see appendix F). Participants were provided with full disclosure regarding the purpose of the research, potential risks and benefits, confidentiality, freedom to withdraw at anytime, and contact information for the researcher; furthermore, we allowed time for questions and discussion with family members if needed. After explaining the study, all participants were required to provide free and informed consent (see appendix G). No participant declined the invitation to be interviewed.

As all participants were over the age of 18, they provided their own informed consent. Anyone that met the study criteria but was not over the age of 18 was excluded because we believed that teen mothers face a different set of challenges. Due to differing levels of literacy, some participants were unable to sign their names on the consent form; in these cases a thumbprint was accepted.

One interview with a self described TBA was excluded because he was believed to be under the influence of alcohol at the time of the interview. Moreover, this participant wanted to have the interview conducted in English by the primary researcher rather than in Rutooro. There was a clear language barrier and the information acquired was questionable. One interview with a mother was also excluded because she was not fluent in Rutooro and the research assistant that interviewed her was not fluent in the dialect that the mother spoke. After these exclusions, the total number of interviews and participants included in data analysis is illustrated in table 1.

Table 1. Total numbers of participants and interviews

	Number of interviews conducted	Fort Portal and surrounding areas	Hakibale Sub-county
Mothers	30	14	17
Formal health care workers	9	5	4
Informal health care workers	8	1	7
Older women	10	4	6
Focus groups	4 (41 participants all together)	2	2

3.4.1 Research Assistants

A total of four research assistants participated in this study in Uganda. All research assistants were educated, bilingual Ugandans residing in Fort Portal. Three out of the four had previous research experience and training by faculty and/or students from the University of Alberta. All research assistants were trained in issues of confidentiality that can arise in research involving humans and were asked to sign a confidentiality agreement (see appendix H). The primary researcher kept the original copy of the agreement and research assistants were given a photocopy.

Two research assistants conducted interviews with mothers, older women and traditional healers. Only one of them had prior experience but both were given multiple training sessions relating to the purpose of the study, methodology and interviewing strategies; training also included role-play, which helped demonstrate knowledge and skills. When two research assistants were available, one conducted the interview and the other took notes in English so that the researcher could ask for clarification. Research assistants also summarized interviews at the end of the day.

The third research assistant facilitated all four focus groups as she had prior experience with this. She also transcribed the focus group discussions and checked a sample of other transcriptions. She was provided with two training sessions related to the research project and guidelines for focus groups. The final research assistant worked only as a translator/transcriber as she possessed

excellent bilingual skills and was able to explain cultural concepts with ease. This research assistant also translated the consent forms, interview guides and information letters. Furthermore, she checked focus group transcriptions for accuracy. After transcription, another research assistant checked a selection of transcripts for accuracy.

3.4.2 Data Recording

All interviews were digitally recorded. The recordings were transferred onto the researcher's computer at the end of each day. The computer was password protected and original files were deleted from the recorder. Transcribers were either given a copy of the recordings if they had access to a computer or another recorder and headphones with which to listen and transcribe by hand. The recordings were all given a numerical code and, to protect confidentiality, names were not used in transcriptions to protect confidentiality.

3.5 Analysis

The recommendations for analysis of ethnographies were used in this research. Following each interview or focus group discussion, the data were translated and transcribed as soon as possible to allow for continual and iterative data collection and analysis. The researcher continuously analyzed transcripts to identify patterns and emerging themes to help narrow the focus of subsequent interviews and focus groups (Rothe, 2000). Transcriptions were coded using guidelines such as those outlined by Rothe (2000) and Mumtaz (2008). Analysis was conducted through the five interrelated steps of reading, coding, developing

domains, developing themes and interpretation. These five steps were cyclical and repetitious. We began with a surface analysis of transcriptions followed by coding to identify emerging categories and themes (Rothe 2000; Holloway, 1997; Mumtaz, 2008).

The process of coding involves reading and re-reading the transcripts to identify key words and phrases that are important or relevant. These codes were categorized into domains based on the key ideas arising from interviews, focus groups and observations. The domains were then sorted, re-read and developed into themes based on identified connections in the data (Rothe, 2000; Holloway, 1997; Mumtaz, 2008). During the entire process of analyses, the researcher maintained notes containing insights, thoughts, questions and ideas. These notes or memos were used to help understand the findings and develop themes and conclusions (Birks, Chapman & Francis, 2008).

3.6 Rigour

Rigour is an important aspect of qualitative research as it ensures that findings are generated form the data and interpreted appropriately. It is important to maintain an accurate representation of participants (internal validity/credibility), appropriately apply the findings to other settings (external validity/transferability) and ensure that findings are verified through review and audit trails (reliability/dependability) (Mayan, 2009). Although various terms exist for concepts of rigour in qualitative inquiry the concepts are consistent (Mayan, 2009).

Data collection and analyses were concurrent to ensure credibility and reliability (Tuckett, 2005). The findings and data were continuously discussed and verified through conversations with colleagues, supervisors and other research team members to ascertain that appropriate meanings had been identified (Mayan, 2009; Rothe, 2000; Tucket, 2005). An audit trail was maintained throughout the research process to allow other researchers to examine the data and follow the decision trail. This was achieved through personal memos and journaling throughout the data collection and analysis (Ryan-Nicholls & will, 2009; Tuckett, 2005). Moreover, specific steps had been undertaken to ensure rigour: description of the study purpose, explanation of the researcher's interest, justification of purposeful selection of participants, description of data collection methods, justification of data analyses, interpretation and presentation of information, and a description of the various methods used (Ryan-Nicholls & will, 2009). There was also a continual review of methodology, data collection strategies, sampling and analysis to ensure methodological coherence. The researcher achieved this through constant discussion with her supervisor, an experienced qualitative researcher (Tuckett, 2005).

3.7 Ethical Issues

Ethical approval for this research was obtained from the Health Research Ethics Board Panel B at the University of Alberta as well as the Uganda National Council for Science and Technology in Kampala (see appendix I & J). All participants provided informed consent to ensure voluntary participation. There were several ethical considerations that were taken into consideration.

One important consideration was maintaining privacy and confidentiality of all the study participants. Only necessary information was collected: names, age, gender, marital status and residential area (Ells & Gutfreund, 2006). Confidential information was put into a password protected excel spreadsheet on the researcher's computer. The hardcopies of consent forms were kept in the researcher's residence in a locked area for the duration of her stay in Uganda. Upon completion of the research, the consent forms were put into a safe in the community based HAART project office. Each participant was assigned a code and names were never used. Only the researcher and her supervisor, Dr. Zubia Mumtaz, had access to the list of participants' names and associated codes. On completion of the research, all confidential information will be burned onto an external memory storage device and stored in a locked cabinet in Dr. Mumtaz's office for five years according to the HREB guidelines. This issue of privacy and confidentiality was discussed with participants as an element of informed consent. During focus group discussions, all participants were asked to keep information disclosed private (Ells & Gutfreund, 2006).

It was also important to consider that not all participants were fluent in English. Therefore, information and consent forms were available in both Rutooro and English. A research assistant fluent in both languages provided information and was available to answer questions (Squires, 2009). Participants that were illiterate and unable to sign consent forms were able to indicate their consent by providing a thumbprint.

As behaviors and beliefs related to pregnancy and childbirth were assessed, it was important to be prepared in case discussions revealed potentially dangerous health habits. Although the risk of identifying potentially dangerous habits and behaviors was low because women had already given birth, the researcher was prepared to encourage participants to seek appropriate medical attention and seek health education when deemed necessary.

There was a potential for the researcher to feel conflicted in her role as both a researcher and a clinical nurse (Orb, Eisenhauer & Wynaden, 2000). The researcher explained her role as a researcher and clarified that although she was a nurse, she was not licensed to practice in Uganda and would not be practicing nursing in the health facilities. Although a shortage of staff was evident, the researcher did not find that she was expected to assist with the workload in health centers. The researcher was prepared to provide assistance in case of medical emergency but this was not required.

3.7.1 Incentives for participation

Since all of the participants in the study were giving up time to participate in the research, it was deemed appropriate to provide a small token of appreciation. It was important that the incentive be appropriate for the amount of time provided and not large enough to be considered coercive (Grant & Sugarman, 2004). Thus, through discussions with colleagues in Uganda and previous incentives used by students we determined that a bar of soap, costing approximately 1000 Ugandan shillings ($1 CDN) was appropriate. Therefore,

each mother, older woman and traditional health worker was given soap. Formal health care workers were offered snacks for their time that cost approximately the same amount. Past experience with focus groups indicated that it was more appropriate to provide all the participants with the same refund regardless of how far they traveled. Subsequently, focus group participants were provided with 4000 Ugandan shillings ($2 CDN) and a snack and beverage for their time.

Chapter 4

Results

Themes indentified in the data will be presented in this chapter; table 2 provides a summary of these. Direct quotes, where appropriate will be exemplars of emerging themes.

Table 2: Themes and key concepts

Themes	**Key concepts**				
HIV testing as a reason for ANC attendance					
The mixing and merging of belief systems	Position of the baby during pregnancy	Stalled pregnancies, witchcraft and babies hiding in the back	Obuzaire	Being clean inside the womb	Local herbs
Sources of Knowledge during pregnancy and childbirth	Education through health facilities	Advice from 'singays' and traditional health workers			
Role of Men	Support	Knowledge and decision making			
Health care using during pregnancy	Antenatal care and services used	Traditional antenatal care	TBAs and delivering in the village	Delivery in a biomedical facility	Overlap of services
Barriers to skilled attendance at delivery	Reaching health facilities	Poverty	Attitude of health workers	Quality of health facilities	

4.1 HIV testing as a reason for ANC attendance

Our respondent narratives revealed a high degree of sensitization towards the importance of HIV testing during pregnancy. Specifically, women deemed it important and, in some cases, essential, to be tested in order to have a healthy baby. HIV campaigns have educated the communities, not only on the consequences of HIV and AIDS, but also instilled the importance of testing in order to have healthy babies. The majority of women who sought ANC in a biomedical facility consistently identified HIV testing as a key process: "*The first thing they do – they instruct you to first go for HIV testing*" (mother). It is important to note that ANC, as described by the study participants was biomedical care provided in health facilities and did not include traditional services. Women were aware that without testing, they were "*increasing the risk of giving birth to a child who is infected with the HIV virus … if [they had] gone to the hospital for testing, [they would] give birth to a healthy child*" (mother). Partners of women that had recently given birth (identified as husbands) also encouraged their wives to be tested for HIV because "*if the woman is found positive, she's recognized and at the time of giving birth, she delivers a HIV free baby*" (husband). HIV campaigns have provided information regarding the available treatment and the measures that can be taken to prevent transmission of the virus:

> *They also gave me an injection for HIV/AIDS so that the baby is not born with it. When you deliver in the hospital and you are HIV positive, they give the newborn baby a tablet and they also give you a tablet. They even*

stop you from breastfeeding the baby … So that the baby is not infected. (mother).

Despite the apprehension that goes along with finding out one's HIV status, women were willing to face their fear of being tested so that their children could be born disease free. Moreover, when women were identified as HIV positive, they were aware of the need to seek additional ANC services as well as skilled attendance at the time of delivery so that the risk of transmission is reduced.

Health care workers also contribute to the high HIV testing rates during pregnancy. Interviews with mothers revealed the importance of knowing their HIV status in cases of hospital delivery: "*…the nurse cannot touch them (mothers) without putting [gloves] on. She first puts on the gloves and then she touches you … she fears maybe you could be infected with the HIV virus and it is transmitted to her*" (mother). Health care workers, for their own safety ensure that all women are screened for HIV: "*Routinely for every pregnant mother that comes … we screen them for HIV. So before we touch, before we examine, you must have passed through the lab*" (midwife). Women prepare for delivery with a card acquired through ANC, which has their HIV status noted (antenatal card). Even women who plan on delivering at home or with a TBA, prepare for emergencies with this card because health care workers will not deliver a woman without first knowing her status. Health care workers clarified that they do their best not to deliver a woman without first knowing her HIV status:

Interviewer: … What if a woman comes in here to deliver … but she doesn't have an antenatal card, what do you do?

Midwife: She didn't attend (ANC) at all? … The first thing you do … [if] you have time, we do counseling and testing and we remove blood to see your serostatus … but when you come when it is late, like those ones who come when they are dilated, almost pushing … we have to remove that blood … you cannot leave … the hospital before being tested.

In the above conversation, it is evident that an HIV test is essentially required for delivery, even if it is an emergency situation. It is assumed that during ANC, women are made aware of this requirement and thus, women may seek ANC just to be tested for HIV and have their status on the ANC card in case of emergency.

An underlying tone of judgment by research assistants was also noted during interviews towards mothers who had not been tested for HIV. For example:

Interviewer: You have said you have never tested for AIDS?

Mother: No I have never tested?

Interviewer: But why? There is a lot of sensitization going on, why haven't you come to be tested…?

Mother: I will come and be tested … I don't fear to be tested … I am … planning to come and be tested.

Interviewer: Do you know the benefits of being tested? … What benefits do you know of?

Mother: To prevent yourself from dying early…

Women who have not been tested are perceived as lacking knowledge and as being cowardly and negligent towards the health and well being of their child. The research assistant in the above example was an educated woman from a well-off family and the mother being interviewed was a young, single woman whose appearance indicated a lower financial status. The mother in this conversation was the only one who openly discussed the fact that she had not been tested for HIV. An air of condescension and judgment is noted because this mother had not ensured that she was screened for HIV – and the mother became defensive and wanted to prove that she was not fearful and she will be tested soon. The hierarchy that was identified between the mother and interviewer is important because it may be an indication of the underlying attitudes and judgment within the community among those that have and have not been tested.

Overall, our findings indicated that the majority of women were tested for HIV during ANC and that women identified testing as an important reason for seeking biomedical antenatal services in health facilities.

4.2 The mixing and merging of various belief systems pertaining to pregnancy and childbirth

Underlying the actions taken, services used and attitudes portrayed during pregnancy and childbirth are several perceptions and beliefs. Our results suggest

that these belief systems are a combination of traditional and biomedical ideas. Women do not hold either solely traditional or solely biomedical beliefs, but a mixture of both.

4.2.1 Position of the baby during pregnancy

One key reason women access biomedical ANC was to ascertain that their baby was in the "correct position" in their womb. The value placed upon the position of the baby may provide some explanation as to why women often delay coming in for ANC and why they only attend once.

The desired position is with the child's head pointing downwards allowing for vaginal delivery. Women want to ensure that their baby is not in breach or transverse positions, so that at the time of delivery, they can have a 'normal', vaginal delivery. Women noted that if a child is found to be in a position that is not ideal for vaginal childbirth, there could be problems at the time of delivery that a TBA or local village birth attendant would not be able to handle, thus leading to problems:

> *If you have not gone for antenatal care for check up during pregnancy you may give birth to a child who is entangled with the umbilical cord (okwambara). And sometimes there is a time when the baby comes out with the legs first instead of headfirst and this is very bad, and … she (mother) may end up being operated.* (mother).

The women interviewed identified emergency cesarean sections as one of the problems that can occur during childbirth. This procedure was seen as

frightening and something that should be avoided if possible. A child lying improperly in the womb can lead to this procedure and therefore, women take the necessary measures to correct fetal positioning. A midwife or TBA can assess fetal position through palpation at ANC, but it seemed that most women used biomedical services. To confirm the position, women are sent for an abdominal scan (ultrasound). Pregnant women "*usually come in [during] the second trimester, some of them … in the third trimester to [know] that the baby is lying well in the womb … that is their only concern"* (midwife). Once the positioning is confirmed as unsuitable for vaginal delivery, women seek various sources to rectify the situation:

> *When I came here (health facility) for check up the nurse told me that my child was lying diagonally in the womb and when I visited the TBA she gave me some herbs, which I took. When I came back to the unit on the days of next visit … the nurse checked me and told me that the baby had turned and now it was okay, and this happened after drinking the herbs.* (mother).

> *When you go for antenatal care … you know how the baby is lying … there is nothing they can do for you expect they tell you that your baby is not lying properly and they send you to the scan and it is the people who work on the scan that help to turn your child inside the womb.* (mother).

A traditional belief pertaining to positioning of the baby combined with the fear of an operation at the time of childbirth (a biomedical procedure) is

believed to lead to the high use of ANC, at least once, and often late, during pregnancy.

4.2.2 Stalled pregnancies, witchcraft and babies hiding in the back

Another belief arising from the traditional realm concerns stalled pregnancies. A stalled pregnancy is one that has a greater duration than nine months. Its occurrence was described by many women in the study population, and confirmed by traditional health workers and biomedical health workers, who provided their own reasoning for it. In this section, a description of prolonged pregnancy, its causes and traditional interventions for resolution is provided.

Prolonged pregnancy is described as a "*problem some women get … carrying a pregnancy for 12 months … such women keep worried all the time … [they] spend 12 months without delivering*" (husband). The child, in the scenario of a stalled pregnancy, is described as "hiding" in the back or at the side and is alive, but does not grow. This can continue for a period of time ranging from 10 months to 6 years. Furthermore, there are some pregnancies that completely disappear for long periods of time and some that just 'hide' at the time of delivery and require herbal or biomedical intervention to allow for delivery of the child. A TBA explained her beliefs in the following example:

> *It's true the pregnancy can hide in the back and the woman even doesn't menstruate to prove that she is really pregnant. There is a woman who came and the pregnancy had hidden in the back and I thank God because when the woman came [to me], I gave her a herbal medicine … and the*

child came back … [pregnancies disappear] at six months, and I myself … when my mother was pregnant with me at six months, the pregnancy disappeared and my mother spent 4 years still carrying me in her womb. (TBA).

The primary explanation for stalled pregnancies given by women, husbands, traditional healers and older women was witchcraft. Women can be bewitched by anyone that wishes them harm and the pregnancy is described as being "tied", resulting in the baby hiding in the womb or the pregnancy disappearing. An interview with a traditional healer revealed that "*people still uphold witchcraft – those things from our tradition – after the woman becomes pregnant … [they] tie the pregnancy there and it doesn't grow. The woman feels the pregnancy…but it doesn't grow*" (traditional healer). The act of bewitching is often performed by co-wives or those who are jealous of or malicious towards the pregnant woman. The notion of tying the pregnancy is described in the following quote from an interview with a local herbalist:

There are some bad people who have tied the pregnancy … so that she doesn't give birth … if a woman has been bewitched and the pregnancy tied on her, you see the head of the child coming and going back … I hear they put herbs [in her] way and when the pregnant woman steps over these herbs … the pregnancy is tied on her.

None of the participants interviewed were able to provide information on *how* pregnancies were tied. This was perceived as an evil act and it is believed that

none of the participants wanted to share their knowledge of such an action. The only information obtained was related to how to remedy the situation.

Midwives, with biomedical training did not believe that pregnancies can be stalled or that babies can hide inside the womb. According to them, women are either making an error in counting the weeks of gestation or are considering miscarriages or abortions as a stalled pregnancy: "*there is no way that the baby can be in the back … there is no uterus*" (midwife). Furthermore, women experiencing "*constant … abortions [may] relate it to witchcraft, maybe she is married to a co-wife, then she is saying it is because of that co-wife … it is a common belief*" (midwife). Conversations with midwives indicated that they place a sense of inferiority on women who participated in this anatomically incorrect belief.

Similar to other belief systems, the resolution of a stalled pregnancy can be through either biomedical or traditional means. For example:

> *When you go the hospital … [and vaginal delivery] fails … you are operated … but when you are in the village maybe they can give you some herbal medicine … and then the child comes out. But when you are in the hospital, it is a must [that] they operate*." (TBA).

It is clear that with the varying perspectives that were offered, a stalled pregnancy may be delivered through biomedical intervention such as vacuum extraction, a caesarean section or traditionally, through herbs to induce labor.

4.2.3 Obuzaire

Obuzaire, a commonly cited problem after childbirth, was explained by translators as puerperal malnutrition, i.e., malnutrition after delivery. This is caused by blood remaining in the womb (this blood is called *obuzaire* in the local language), which, if not removed, causes women to suffer from malnutrition. Women may experience this potentially life-threatening problem if they are not properly taken care of after childbirth, despite having a normal delivery with no other complications. For example:

> *If you have delivered normally – they tell you to eat enough food and take enough drinks so that you don't suffer from obuzaire. If you don't eat well and take enough drinks, you fall sick…you feel abdominal pain, you feel headache and you feel dizzy … a woman … becomes very weak and if she is not well looked after, she may even end up dying."* (mother).

Women require "*soup from the intestines of cows and goats (ebyenda) … to help her regain energy … after giving birth*" (herbalist). *Ebyenda* helps remove *obuzaire*. In order to remove *obuzaire*, "*the body [must be] pressed with hot water*" (mother). To prevent or resolve *obuzaire* women require a caretaker that can provide them with food, fluids, *ebyenda* as well as someone that can press their body. After childbirth, women are weakened and their bodies are unstable, and therefore, they should not be doing heavy work and require supportive care.

4.2.4 Being clean inside the womb

A common belief described by the study population was that being clean inside the womb ensures delivery of a clean baby. The notion of "clean baby" was difficult for both study participants and local translators to explain. It has been understood as a baby that is not covered with an ash-like substance and has smooth, brown skin. Women's wombs were thought to be 'unclean' or having 'dirty things' things inside. Thus, once a woman is confirmed to pregnant, she is advised to "*start collecting herbs and taking them so that they can cleanse the baby inside the womb … it is like washing the baby inside*" (TBA). Moreover, modern "*drugs cannot wash the baby*" (older woman). There were two commonly described herbs that cleanse the womb: *omweya* (cleanses the baby and makes the skin smooth) and *wankura* (helps the baby's skin be clean and not covered with ash). Women desired to have a clean, brown baby rather than one covered with an ash-like substance (vernix caseosa). There are no biomedical methods to be clean inside the womb and thus, this belief and its remedy are both purely traditional.

4.2.5 Local Herbs

Many of the above beliefs require traditional interventions, such as herbal remedies, in order to resolve commonly occurring problems during pregnancy and childbirth. The majority of women indicated that they had taken some sort of herbal or *kitoroo* (local) medicine. Herbs were believed to both prevent and treat a variety of problems during pregnancy and childbirth. In addition to uses of herbs described elsewhere, they can ease the pain and difficulty of pregnancy: "*there are some herbs which make your limbs flexible, make the … walls of the*

vagina softer … so if you want to avoid [episiotomy], you should be doing these things … so that your vagina walls … soften" (midwife). Herbs can also be taken to alleviate pain during pregnancy and herbal teas can cure certain ailments such as syphilis.

Herbs are believed to be effective because "*even the drugs from the hospitals…come from the herbs*" (traditional healer), therefore, they may be seen as being the same as biomedicine. Furthermore, there is a belief in local herbs: "*before modern drugs came into existence, our great grandparents used to use traditional herbs which cured all diseases at that time*" (husband). TBAs, older women and herbalists tell women which herbs to take and how to take them. Herbs are either collected from gardens or acquired from herbalists and boiled into herbal teas or made into a paste and rubbed on the body. However, as indicated by a TBA it is important to make sure herbs are taken properly: "… *I am saying that this herbal medicine should be used with precautions because some TBAs just prepare the herbs without even first boiling the water and this is unhygienic and I myself don't like them*".

4.3 Sources of knowledge during pregnancy and childbirth

Women receive knowledge, guidance and advice from a range of "experts" or people who are older and therefore perceived as being more knowledgeable. These sources include health workers (both traditional and biomedical), older women and family members. It is important to note that education through various forms of media, such as radio and television were not

mentioned. All the health centers I visited had posters in both English and the local language regarding issues such as the importance of tetanus and malaria prophylaxis during pregnancy. This results in women receiving information from a variety of formal and informal sources, thus leading to a further mix of services that are accessed during pregnancy and childbirth

4.3.1 Education through health facilities

Health care workers, dressed in their white uniforms and their position of authority, are perceived as superior sources of knowledge within the community. The majority of women interviewed access ANC in a health facility at least once during pregnancy. A component of this type of ANC includes health education. Women are advised on the measures that should be taken to care for their growing baby. The advice includes HIV testing, required medications (malaria prophylaxis, folic acid, ferrous sulfate and dewormer), personal hygiene, nutrition, and preparations for delivery.

Health workers advise women to plan for delivery in health facilities. Women are educated during ANC on the benefits of a hospital delivery and the risks of delivering at home:

> *They [nurses] said that it is not good for a woman to deliver in the villages and they explained to us that the TBAs are unhygienic and if a woman has HIV and she delivers in the village, the baby can easily be infected with the virus. The TBAs in the village don't have enough knowledge*. (mother).

This advice also contributes to the fear of delivering a baby with HIV, which further encourages women to be tested for the virus and take any necessary precautions. Through discussions with participants, it is believed that if a woman tests negative for HIV, she may be willing to risk delivering with a TBA, but if she is HIV positive, she is more likely to ensure that the proper precautions are taken at a health facility.

The advice from health care workers is often rooted in the biomedical realm and the majority of health workers advised women to "*avoid taking native medicines, as they may cause some intrauterine and fetal death*" (midwife). Women were told not to drink herbal teas because they may be poisonous in large doses, but smearing herbs on their bodies is less harmful. Health workers did not accept traditional practices and beliefs such as witchcraft and, during interviews, were very firm in their views that women holding such beliefs lacked knowledge and education.

4.3.2 Advice from 'singays' and traditional health workers

Singays are "*old [women] in the village, she does not deliver, but she is an expert*" (midwife); these women, along with TBAs, traditional healers and herbalists are well-known, respected, older people living in communities. They are able to advise women on how to care for themselves during pregnancy and childbirth. An interesting finding from this group was the range of advice that is given. For example, most *singays*, herbalists and traditional healers advised women to deliver in health facilities, while TBAs tell women to come to their

homes to deliver as long as they are HIV negative. The new policy banning the use of TBAs is a contributing factor: "*because of this disease … the government stopped [TBAs] from operating and they explained to them the problems involved in delivering in the villages*" (older woman). On the other hand, all participants unanimously advised women to be tested for HIV. Traditional healers, for example, will not touch a woman that thinks she has been bewitched without her providing documentation of her HIV status.

Older women provide cultural advice such as telling women to:

> *… keep our Tooro culture like sitting position when you are pregnant so that the child sits properly in the womb and telling you to … behave in a good way and sleeping properly … you have to sleep properly on the sides. You cannot sleep on the back or with the stomach facing down."*

Women are told to "*sit with [their] legs straight*" (older woman) and avoid crossing their legs. Older women also assist mothers with herbal remedies and precautionary measures such as herbs to cleanse the womb. Women are also advised to avoid "*lying on [their] back … [because] the baby will be entangled with the umbilical cord*" (mother).

4.4 The role of men

Discussions with husbands provided insight into the male perspective of pregnancy and childbirth. Interestingly, the role of men during pregnancy and childbirth was better understood through interviews with unmarried women who underwent pregnancy and childbirth in the absence of a man. Men play an

important role in terms of support, advice and decision-making. These points will be further explored.

4.4.1 Knowledge and decision-making by men

In Uganda, men are the head of the household and the primary decision makers. Men provide advice and suggestions to women during pregnancy and childbirth. Women are advised, for example, to do a light to moderate amount of work but "*not to keep sleeping because it's not good for her health*" (husband). It is important for women to avoid heavy lifting and heavy work "*because when she's overworked or when she does heavy work the fetus is … overworked also*" (husband).

Focus group discussions with men helped define their role during pregnancy and childbirth. Unsurprisingly, most aspects of pregnancy were a woman's responsibility. The role of men was to:

> *… take responsibility … [and] start sending the woman to the hospital for antenatal services … when the time for her to give birth has reached it is you to suffer if she gives birth from the village you must take her or get any means of transport to take her to a nearby health unit where [the midwives] can help her deliver.* (husband).

The act of men "sending" their wives to health facilities highlights the place of the man as the primary decision maker; he decides that his wife needs health services and he will take her to the facilities that he deems appropriate. Thus, the services

women receive are dependant on the choices made by their husbands, if they are present.

Another responsibility that men have is to offer more attention to their wives because "*when women get pregnant, they always need a lot of care/attention … from their husbands*" (husband) and to provide money to purchase the required supplies for delivery. Men also try to provide women with the food they desire and purchase them expensive items: "*you cannot buy meat everyday, I try to buy for her meat at least twice a wee*k" (husband). Men will also support women by "*[washing] clothes when [they] don't have any other job*" (husband). It is important to note that washing clothes, cleaning the house and preparing meals were all seen as women's jobs and when men weren't busy with their male roles, they would assist their wives.

During the early stages of each focus group discussion, men presented an ideal situation, and emphasized the importance of seeking biomedical care during pregnancy and at the time of childbirth. For example, most men said that when their wives were pregnant, they tried their best to provide them with nutritious foods and to enable them to receive biomedical facilities. Through further probing, however, it was made clear that in reality, men did not know much about pregnancy and childbirth aside from the laws and recommendations advertised. Discussions with men clearly indicated the preference for health facility delivery, but "*in situations whereby they are staying far from hospitals [and] a TBA is around, she can help [women] deliver*" (husband). Health care workers

emphasized the importance of men accompanying their wives to ANC visits but found that men were still not coming.

Men were aware of the law banning TBAs and consequently believed that hospital delivery was the ideal situation:

> *Starting from the area Local Chairman 1 (LC1) there's a strict law which states that 'no one is supposed to help a woman deliver in their homes because they aren't trained and they aren't to do so'. This law was meant for TBAs who give services illegally. Women who were ignorant before the law was put in place, have now realized the mistake hence being forced to go to hospitals because they were educated.*

Men listened to the laws put in place by the government and placed blame on women for not knowing about these laws by calling them ignorant. In cases where their wives delivered at home with TBAs or even alone, men did not appear to understand their wives' circumstances:

> *... it seems there are women who get labor pains when they don't expect them without realizing it. There are some who get them in the middle of the night and ... they become impatient, in the process of becoming impatient, the baby comes out and she delivers.*

Men believed it was a woman's ignorance that led to inappropriate actions during pregnancy and childbirth such as delivering in villages and not in health facilities rather than understanding women's circumstances. Women are unable to make the decision to transport themselves to the hospital or health unit at onset of labor

because "*it is the man who makes the decision. So if the man thinks otherwise … he wont give you the things (money) … so you go to the TBA*" (doctor).

Our findings indicated that the ultimate decision regarding services utilized during pregnancy and childbirth lies with men. However, their involvement is limited, both emotionally and practically; moreover, the situation of polygamy further distanced men from their pregnant wives. As mentioned earlier, women rarely mentioned male involvement unless they were single and had *no one* to care for them. Not only do women require men to provide financial support, but they also need the man's emotional and physical support to reach facilities. Despite their awareness of laws and recommendations, it is clear that men lack knowledge and are often unaware of what women are going through; thus men may not always act in the best interest of the women.

4.4.2 Support

During, pregnancy, many mothers indicated their need for someone to support them emotionally, physically and financially. While pregnant, women are unable to continue working which places them in a situation where they lack finances to sustain them. The man is seen as the one with the financial means as well as the responsibility to provide care: "*When a woman is pregnant, a man should take responsibility … you must take her or get any means of transport to take her to a nearby health unit*" (husband). Single mothers were, therefore, in a dire situation:

But if you don't have a husband, who will give you the service? All the assistance comes from the husband who is the father to your child – isn't it? … If he doesn't care for you … like buying pieces of cloth to cover the child and the child's clothes he buys you what to eat and what to drink. (older woman).

Aside from money, women who are alone during labor are unable to reach health facilities. For example, one mother had the following experience: "*When I started labor pains … I had nobody to bring me here (health center) because I was alone … My husband had gone to see his second wife*" (mother). Polygamous relationships put women in vulnerable situations because they were not receiving *all* of the man's attention. Furthermore, as the above quote shows, if the man was away, women are unable to go to the health centers in emergency situations. At health facilities, they also need someone to take care of them by preparing food and providing emotional support. Therefore, a woman who is left alone will not travel to a health center despite her desire for biomedical services; she is forced to access traditional services, or worse, is left alone with no one to care for her. A young woman that had recently given birth to twins alone in her home illustrates the absence of a man in her life through the following quote:

When I became pregnant, I became very weak and … and was unable to do anything…I delivered the twins myself … during the night … nobody was there to assist me. … I would have liked to get someone like to fetch for me water or if I wanted to eat something [cook] for me and even washing clothes for me. … I was at first employed but when I got pregnant

I had no energy to do any work and … I would just stay seated without eating or drinking and I couldn't manage to stand up by myself without any support. … I really suffered a lot without anybody to take care of me. … I loved a man who had a wife without my knowledge … I was a very beautiful woman, very rich with my money but now I don't even have a fifty-shilling coin … my husband is not caring for me. I am just here suffering with the children. (mother).

4.5 The range of services used during pregnancy and childbirth

Our data suggests that the combination of belief systems and the broad spectrum of advice pregnant women receive results in the use of a continuum of services that span the traditional and biomedical realms. A set of circumstances including availability of services, women's social status, male support system, geography and financial access intertwined with belief systems appear to determine what type of care is sought during pregnancy and childbirth. In this section, we explore how and why women decide which type of care they want to use.

4.5.1 Care during pregnancy

4.5.1.1 Biomedical care during pregnancy

The majority of Ugandan women access biomedical ANC at health facilities at least once during pregnancy, but discussions with participants indicated a difference in the services that should be provided and the services that are received. Observations at health facilities and discussions with health care

workers identified the key components of ANC which includes screening for HIV and other STIs, health education, a physical exam, prophylaxis and treatment of problems. These components are described in detail in appendix K. Women, however, did not describe all these interventions, and instead identified HIV testing and a physical exam as the most important components of ANC and the reasons for which it was sought. Health education and medications for treatment of diseases and prophylaxis were dependant on availability of a midwife, availability of medication and the amount of time women were willing to spend at health facilities.

There are some circumstances in which women expressed a preference for biomedical attention to traditional services. For example, "*the moment [women] feel pain … [they] just go direct to the hospital*" (mother) and require a physical assessment to ensure their baby is all right. Intra partum bleeding or histories of miscarriage are further reasons for women to seek biomedical attention during pregnancy. Moreover, any sign or symptom that may risk the health of the fetus during pregnancy is perceived as a reason to seek biomedical attention. Examples of these signs include bleeding, pain, symptoms of malaria (fever, headache), diagnosis of HIV/AIDS, and diagnosis of an STI. These symptoms are thought to be biomedical in nature and rather than risk the health of their baby women will travel to health facilities using any means necessary and access appropriate services to make sure their child is okay.

4.5.1.2 Traditional services used during pregnancy

Antenatal care, as described by participants was formal, biomedical care provided during pregnancy through a health facility. Through further discussions and probing, it was revealed that the majority of women do access traditional services during pregnancy. Participants did not independently mention herbal and traditional interventions as services used during pregnancy and we actually had to probe and specifically ask if herbal medicines were used. Upon recognizing their pregnancy, women seek the assistance of their mothers, older women in the community and known herbalists to assist with the pregnancy and ease labor. Traditional healers have knowledge of herbal remedies, which are brewed into teas, smeared on the abdomen, rubbed on the walls of the vagina or used to bathe with. Herbs are taken to induce labor, ease labor pains, prevent the need for episiotomies, cleanse the womb and prevent miscarriages. The various herbs taken during pregnancy are described in appendix L.

4.5.2 Care during childbirth

4.5.2.1 Biomedical services during childbirth

Women are advised, by health care workers to plan for a health facility delivery to ensure proper care, particularly in emergency cases such as obstructed labor, maternal fatigue, hemorrhage or situations requiring cesarean sections. Complications during pregnancy such as weakness, bleeding, malaria, breach presentation and a positive HIV status lead to a preference for biomedical attention at the time of delivery. A desire for biomedical care at the time of

delivery was evident through interviews with the participants, but the lengths that women will go to in order to receive this attention varies with the beliefs, values and experiences held by an individual woman. For example, a woman with an uncomplicated pregnancy who experiences labor pains at night is more likely to seek care from a neighboring TBA than look for expensive transport to reach a far-away health facility. Moreover, there are a number of barriers to seeking health services; these are discussed in the next section.

4.5.2.2 Barriers to biomedical services during childbirth

Reaching health facilities

Kabarole district has 60 health facilities, but most facilities do not have the capability to conduct deliveries. Even if a woman lives within 5km of a health facility, there may not be a SBA present who can provide emergency obstetric care. For women living far away in the villages, traveling the distance to an equipped health facility may require going into Fort Portal town:

> *We don't have good hospitals and midwives around, when the woman gets labor pains unexpectedly and she wants to deliver, it becomes a problem getting quick means to take her to the nearest hospitals in town since we don't have good facilities*." (husband).

A doctor at one of the hospitals in Fort Portal indicated that "*health facilities … are located in town, in the rural areas they are scarce … so it is near[er] for a mother to go to a … TBA*".

Another important factor in reaching health facilities is the availability of transport. This involves availability of a vehicle, funds to pay for transport and adequate road conditions. Rural populations often travel by foot and vehicles are not widely accessible; there is also cost associated with hiring private vehicles. Lastly, rural Uganda is predominately comprised of dirt roads; this combined with two rainy seasons results in roads that are closed or not usable. The district does not have a reliable ambulance system; the one vehicle that functions as an ambulance is often under repair, out of fuel or occupied with other errands.

When women are not able to reach an appropriate health facility at the onset of labor, problems can occur as a result of the delay:

> *You find when we don't have any means of transport, and by the time we get means to take the woman to the hospital, she has already had problems just because of transport problems to take her to the hospital at an early stage. Due to such problems, you find yourself taking her to a traditional birth attendant who can give quick services*." (husband).

As mentioned in the section on the role of men, it is important to emphasize that women require the financial, physical and emotional support of their husbands or male partners in reaching health facilities. However, men must have the funds to help women travel to health facilities. Women further require someone to accompany them to the health center and to care for them while they are there. Lastly, men have been identified as the ultimate decision makers and, thus, they must deem it important to seek biomedical services.

Poverty

Poverty was identified as a barrier in skilled attendance at the time of childbirth because although government health facilities are free of charge, there are many hidden costs associated with health care. As described elsewhere, women require financial means to reach health facilities. Women are also told, during ANC, that they must prepare certain items for the time of delivery (see appendix M) and sometimes "*the income is very low ... the mother ... is not able to provide all these things ... so this lady fears*" (midwife) attending health facilities due to her unpreparedness for delivery. Furthermore, if a woman only has dirty clothes and used or older clothes for her new baby, she feels ashamed of her poverty. Health care workers dress in clean, pressed, white uniforms; a mother with torn or dirty clothes feels ashamed of her condition: *"... we go there (health facility) putting on clean clothes*" (husband). This is also a deterrent to seeking a skilled attendant for delivery.

This issue of poverty was discussed in interviews and focus groups with all participant groups. Health care workers, for example, explained a poor mother's dilemma: "*Going to a hospital ... the mother will require transport, to bring herself to the health facility, and ... she is like, if I am in labor, I don't have transport to go to the health facility, even if I get the transport, I don't have food to eat in the health facility, I don't have money to buy food or drinks*" (midwife). In such a situation, most women would rather go to a TBA who will provide a place to stay and food to eat. Women will not be judged by the TBA, nor will they feel ashamed of their circumstances.

Attitude of health workers

Health care workers, midwives in particular, are often described as abusive and mean. Women told stories of abuse, scolding and rude behavior at the time of delivery. They explained their need to be handled with care and emphasized their need to be handled with care and be given comfort during a time of immense pain. Fearing abuse was identified as a barrier for seeking formal health services at the time of delivery:

> *Another reason why mothers don't go to maternity, to our health services [is] that the midwives … the personnel are rude. But if we can start to make sure that … we minimize the rudeness … then the mothers will reach (health facilities).* (District Health Officer).

Men also indicated their frustration at the situation:

> *… we still have a problem, I don't know if it's corruption or something else, we have nurses who are trained but when you seek medical help from her, she doesn't give a patient any attention because there are some health centers you go to and the health workers tell you that 'I've worked all day, I am tired and I've just left work' … do you think you can stop a woman who is in labor pains to hold on and wait for the nurses or midwives to stop having their siesta?*

Husbands also described why women choose to use TBAs:

Some people go to TBAs because they offer good services even though they demand a lot of money, but taking your wife to hospital where they give free services, midwives there should/insult women, they don't advise them, no care, help, attention, they are negligent but TBAs have care. Generally TBAs offer good services because they are paid for the services, they give proper medication to patients unlike in government hospitals.

Although poverty was described as an issue, there was also a belief that paying for services should lead to a higher quality of services. In the above case, this man would prefer taking his wife to a TBA even though there is a fee to be paid because she will provide more care.

Surprisingly, one of the midwives interviewed, was quite aware of the situation:

... mothers say, I don't know how true it is ... that personalities of midwives are rude ... they don't want to deliver in hospitals because the midwives are rude to them, they beat them, they abuse them ... we have to reform, midwives have to change.

Interviews with health care workers provided insight into their work lives including understaffing, stressful work environments and an overwhelming work load. Midwives are expected to live close to a health facility and be on call at 24 hours a day. Moreover, only one midwife is stationed in most health facilities so she becomes stressed and fatigued. The unfortunate result of the situation is described through a conversation with one of the husbands:

> *We live in far villages and maybe the woman experiences labor pains at night, by the time you reach the health unit, you find when midwives are sleeping and they refuse to wake up and help your wife, what you do next is to go to traditional birth attendants.*

The above quote clearly illustrates how poverty actually leads to the use of TBAs despite effort made to reach a health facility; a situation such as this results in a significant delay in reaching a birth attendant and may result in adverse maternal/newborn.

Quality of health facilities

If a woman is able to overcome barriers and reach a health facility, with the required supplies and has a midwife available to assist her, she may still be in a health unit lacking essential resources. For example, emergency cesarean sections require functioning operating theatres, doctors, medications, and supplies for a blood transfusion, but these are rarely present at local health units. Instead, women are referred to hospitals in Fort Portal town, which can result in a significant delay due to lack of ambulances and other means of transport.

Observations made at health facilities identified many limited resources: consistent electricity, running water and adequate supplies of essential medications and supplies such as gloves. Often, women requiring medications for post partum bleeding are given a prescription that must be filled at a drug shop because the health facility does not have drugs in stock. In many cases, women

do not have the financial means to acquire the drugs that could prevent adverse health outcomes.

A preference for private rather than publicly funded government facilities was evident: "*I would prefer going to a private hospital and you pay money and receive enough attention instead of suffering in government hospitals*" (mother). Mothers told stories of adverse experiences in government facilities that included no available doctor, abusive midwives, not enough time with midwives, long waiting times and insufficient space. They could not afford care in private hospitals; if they experienced inadequate or abusive care in government hospitals they could be deterred from seeking formal care for subsequent pregnancies. The quality of health facilities can serve as both a deterring factor to even seeking the presence of skilled attendants at a facility at the time of delivery as well as a barrier to receiving adequate care at the health facility.

Furthermore, the quality of health services can also facilitate seeking traditional services:

> *... there are other traditional birth attendants who stopped helping women because of the government laws which discouraged women seeking ... services from traditional birth attendants but due to our needs, we find ourselves going back beseeching to traditional birth attendants for help ... this is all brought about by someone who is like 'I don't have money to take my wife to Virika hospital [private hospital]*. (husband).

4.5.2.3 Traditional Birth Attendants and delivering in the village

Services provided by TBAs

TBAs explained that they had acquired their knowledge through observing other TBAs (usually family members) and assuming the role once the family member aged and passed away. They also received training through education programs provided through government initiatives prior to the ban against TBAs: "*... whenever there is training for TBAs I am also invited*" (TBA). TBAs provide a range of services including preparing and administering herbal remedies, abdominal palpation and assistance with childbirth. They are able to manipulate the position of the baby:

> *... when the baby is not lying properly inside the womb and they bring them here they show me the results from the scan showing the baby not lying properly then I just touch her and turn the child ... [it] is our secret ... I just rub her womb with some oil and you find the baby has turned inside.* (TBA).

The services provided by TBAs are not free; fees range from 5000 to 15000 Ugandan shillings but if a woman cannot afford the fees, there is flexibility of payment. Although TBAs were initially trained and their use encouraged in Uganda, they are currently banned from practicing. However, women still approach them to assist with delivery:

> *... since 30th July 2009 – that letter I had told you about – I stopped because of the fear of the government policy ... And another thing I would*

like to say is that I stopped doing this job according to that letter I showed you and I am no longer a TBA [but] I still see people coming to me. If they want me to continue working then they should accept me and I resume my work. (TBA).

TBAs indicated that they wanted to learn more in order to treat women effectively. With the understanding that women often face difficulties accessing health services, TBAs want to provide assistance. However, health education and advice from midwives discourages delivery outside of a health facility. TBAs are deemed to be inferior by midwives, as is illustrated here:

They are there and they can deliver, but what I think is that they don't have enough information … they are not well trained to carry out deliveries, they don't know what is complicated, they don't know what is normal, they don't know what drugs to give, they don't know any anatomy.

Interviews with TBAs provided insight into the services they offer:

After knowing that a person has become pregnant … you start giving her herbal medicine up to seven months. And then from seven months onwards you start rubbing the abdomen with herbs in order to prepare the child to lie properly in the womb, you examine how the child is in the abdomen and at the time of birth, you measure where the child has reached and when it is not yet ready for the woman to push the child you stop her until when you see that the child is ready to come out. After

delivery you wait for the placenta to come out and thereafter clean the child and you cut the umbilical cord and then you cover the child.

Negative experiences with TBAs

Some men in focus group discussions indicated a negative perception of the services provided by TBAs:

> *… it's a big mistake letting your wife deliver from the village at a TBA's place. We usually go to hospitals because they handle complicated cases like in situations where the baby inside the womb is too big for the mother to push or she gets other complications during childbirth, the health workers can operate [on] her.*

The problem identified with TBAs is that although they are able to conduct normal deliveries, they lack the knowledge and resources required to handle HIV positive mothers, identify danger signs during labor or manage obstructed labor, and other abnormal presentations:

> *For example, when a couple is HIV positive and the woman delivers from a birth attendant who isn't trained well, the kid ends up being infected with HIV just because the birth attendant has little knowledge on women giving birth.* (husband).

TBAs were also described as unhygienic because they did not always have gloves, used banana leaves to conduct deliveries on and did not always clean supplies

between mothers leading to a higher risk of infection. Some women reported adverse experiences with TBAs:

> *Of all the children I have, it is only one child whom I gave birth [to] at the TBA's place and they put hands in my uterus and destroyed some of my body parts down there … I became very sick and very weak … some of my private parts were tampered with by the TBAs.* (mother).

When problems occur during childbirth, TBAs indicated that they advise women to go to hospitals and health facilities for further management. However, based on insight from midwives, there is often a delay in this referral contributing to adverse maternal outcomes including mortality. For example: "*When the blood comes profusely and we try all means to stop it and it continues coming, then we see this is as a problem and rush the mother to the hospital*" (TBA). Mothers were also aware of the delay that may result in case of a complication when delivering with a TBA:

> *… because you can fail to deliver in the village and when they (TBAs) refer you to the hospital … it is too late they can send you away and you die during delivery or even the baby can die inside the womb.*

These quotes provide evidence that delays that can occur during childbirth in the villages with TBAs.

Positive experiences with TBAs

Despite the limitations of TBAs, women may prefer to deliver with them because they are knowledgeable in traditional medicine, local practices, and are well known members of the community. "*Some people go to TBAs because they offer good services … midwives … shout/insult women, they don't advise them, no care, help, attention … but TBAs have care [and] good services*." (husband). Mothers also explained why they might utilize TBA services:

> *They (mothers) avoid going to hospitals to be abused by the nurses. People opt to go to the TBAs in the villages because for them, they don't abuse women – they handle them carefully and they give tender care to pregnant women. They don't abuse women like how nurses do in the hospitals.*

A husband also explained the following services provided by TBAs:

> *The comfort expectant women get from TBAs helps them to deliver well. Another service the TBAs provide is to correct the poorly positioned fetus in the pregnant women by using their local herbs … TBAs do that work so well, so we shouldn't despise TBAs because they've saved women's lives most especially expectant mothers living in rural areas.*

Despite policies and advice against the use of TBAs, their services continue to be accessed during pregnancy as well as at the time of delivery. TBAs are more financially, geographically, and socially accessible; they also provide better client care. TBAs that we met were all older women and this work

was their primary source of income. It is also believed that they wanted to continue earning their living as a TBA, but wanted more education:

> *But the most important thing I am seeing here is that nowadays we as TBAs we are also confused because we fear to be infected with the disease (HIV/AIDS) … I know if I get infected while assisting women to deliver then I will be bring the disease to my husband and our whole family will perish and that will be the end of it. It would be good for our services to be continued but now … not many women come to us … You can find in a month only one woman comes and sometimes we refuse to assist them because of that fear.* (TBA).

It is important to note, however, that the majority of participants understood the risks associated with TBAs and even though TBAs offered more comfort and would not abuse women, they indicated a preference for health facility delivery. However, in a previous section, we identified the barriers to health facility delivery; these barriers facilitate to delivery with a TBA or deliver alone.

4.5.5 Overlap of services

Discussions with participants indicated "*most [women] use hospital services at the same time [as] traditional herbs*" (husband). Women prefer to seek services from the continuum of providers ranging from doctors at hospitals, midwives at health centers, TBAs in villages, and traditional healers in villages.

For example, a mother diagnosed with syphilis during pregnancy explained her experience:

> *When I went to the hospital they gave me drugs and I decided to use herbal medicine which helped [because] … my blood was not working properly with modern medicine.*

Another mother indicated that she used "*kitooro herbs … and [she] also received treatment from the nurses in the hospital in cases when [she] was feeling fever*". Typical scenarios can be envisioned through the following quotes where it is evident that the two realms of health care cannot be used without some degree of overlap between them. Moreover, if one system appears to fail, the other can always be accessed:

> *I was staying at home and when I became pregnant my mother was the first to recognize [it] … she told me to go to a certain woman near our home…she was also a traditional birth attendant. I went there and she checked me and confirmed that I was pregnant. Then I also came her [health unit] and the nurse checked me.* (mother).

> *Sometimes women can fall sick and they feel abdominal pain and when you feel the baby not moving freely in the womb, you can go to the hospital for treatment and they give you drugs. If you are unable to go to the hospital, you can go to the traditional healers and they can give you herbs and you take them and you feel relieved*." (herbalist).

You find expectant women going for immunization at the hospital but having a TBA who gives her herbs when she's not feeling well. She tells a TBA that 'I am feeling pain here' and the TBA replies 'I know of a certain herb, go to the bush and pick it, it always helps' so you find pregnant women using both hospital and at the same time the TBA health services ... I think ... the two health services are helpful." (husband).

Lastly, traditional health workers believe in the necessity of biomedicine. An example of this is the case of HIV. A traditional healer reported that he asks "*if [patients] have gone to the hospital first, and if they say yes, the hospital has failed them then [he] starts working on them*". This healer understood the risk associated with HIV and ensured that all his patients were tested for HIV, and if the problem was unrelated to biomedicine, such as witchcraft, he was able to treat them. TBAs also acted similarly: "*If she asks me what to do I would just advise her to go to the hospital and they first treat her by either giving her injections or tablets. Sometimes when the womb continues to pain her she can come back to me and I can give her herbs*". Thus, it is clearly that the services women access during pregnancy and childbirth cannot be separated from one another; instead they must be seen as a continuum of care that is provided by a variety of service providers.

Conclusion

Insight on the circumstances of women going through pregnancy and childbirth in Uganda is provided. During pregnancy women seek services that are

perceived as important based on an array of beliefs and values. These beliefs arise from exposure to an array of 'expert' advice given to women. Biomedical ANC, for example, is important in order to be tested for HIV and ensure that their child is in the correct position for the time of delivery. Traditional services during pregnancy are used to ease the process of childbirth. Our findings have indicated a situation in Uganda where women are encouraged to deliver in health facilities through education and shared beliefs related to the risks associated with delivery in villages and the benefits of delivery in the hospital. Although women may prefer or even decide to deliver in a health facility, only 42 percent of women do deliver with skilled health workers. This is the result of the numerous barriers faced by women including transportation difficulties, distance to facilities, poverty, quality of services, attitudes of health workers and a lack of financial support from husbands or partners, which prevent them from doing so. In fact, these barriers are thought to prevent women from accessing formal health care services; instead, they seek the care of TBAs or deliver alone. Thus, the findings provide some insight into the high rates of ANC attendance and low rates of skilled attendance at the time of delivery.

Chapter 5

Discussion

The primary objectives of this research were: (1) to identify the various beliefs, perceptions, attitudes and practices related to pregnancy and childbirth, (2) to identify the type of services, both biomedical and traditional, that are used during pregnancy and childbirth and (3) inform policy makers of the findings so that they can be incorporated into health services. The majority of the findings from this study support previous research pertaining to maternal health in low income or developing countries. There are some new findings that, to the best of our knowledge, have not been previously discussed in literature. The following section will discuss both novel and previously known findings.

5.1 HIV testing and antenatal care

A key finding of this research is that the desire to be tested for HIV is the rationale for at least one biomedical antenatal care visit. This may explain why 92% of women access ANC at least once during pregnancy. A large body of research has been conducted on the uptake of HIV testing during ANC in health facilities. However, pre-existing studies have not indicated that the desire to be tested for HIV is a reason for seeking ANC. This is a new finding that, to the best of our knowledge has not been included in existing literature. It points to a positive and possibly unintended side affect of the HIV prevention program. We argue, based on our empirical findings that the availability of HIV tests and the

knowledge of its importance has become a reason for seeking ANC in Kabarole District, Uganda.

Four primary reasons for seeking ANC in Uganda have been identified through literature: assessment of the position of the baby, treatment when ill, tetanus vaccination and to receive an antenatal card (Ndomugyenyi, Neema & Magnussen, 1998; Tann et al, 2007; Kyonuhendo, 2003; Waiswa et al, 2008; Amooti-Kaguna & Nuwaha, 2000). Research related to ANC and delivery sites has been conducted in Uganda. Presenting an ANC card at the time of delivery provides evidence to nurses and midwives that the woman with the card has been in contact with health services during her pregnancy and is, therefore, a good mother (Waiswa et al, 2008). The antenatal card includes information on women's HIV serostatus (Medley & Kennedy, 2010). This body of research did not specifically indentify HIV testing as a reason for seeking ANC. Our findings suggest that HIV testing should be added on to the list of reasons women seek ANC.

Over one million people are estimated to be living with HIV in Uganda. Although Uganda has been a success story in the management of the HIV epidemic, the population has witnessed devastating consequences ranging from untimely deaths to children being orphaned. By the 1990s, the majority of the Ugandan population knew someone who had died as a result of HIV. The first AIDS control program in Uganda was initiated in 1987; the success of this and other campaigns is believed to be a result of commitment at the leadership and grassroots levels. Many prevention activities also reduced stigma associated with

HIV and allowed communities to witness a healthy life despite diagnosis through involvement of people living with AIDS. (AVERT, 2010).

HIV education strategies have included radio announcements, school programs, training of health care professionals, television programs, films, posters and plays (Albright & Kawooya, 2005). More than two decades of HIV programs and campaigns has resulted in increased awareness of the disease and modes of transmission, including mother-to-child transmission of the virus. The 2006 Demographic and Health Survey found that over 99 percent of the population had heard of AIDS (UBOS & Macro International, 2007) and 73 percent of women were aware that HIV can be transmitted through breast milk. In addition to growing knowledge regarding to HIV/AIDS, changes in behavior have also been noted. Ugandans have fewer sexual partners than Kenyans, Malawians and Zambians. Condom use during sexual intercourse is on the rise. This evidence clearly indicates that Uganda has an effective HIV strategy for increasing knowledge and modifying behaviors to reduce risk of transmission (Albright & Kawooya, 2005).

HIV testing has been a component of ANC since the implementation of the *Prevention of Mother-to-Child Transmission* (PMTCT) *Strategy* by the Ugandan Ministry of Health in 2000. In 2006, the government initiated the current opt-out policy whereby all mothers attending ANC will be tested for HIV unless they specifically decline (Larsson et al, 2009). In cases of a positive diagnosis, women are treated, counseled, and educated regarding precautionary measures at the time of delivery and infant feeding practices (Kizito et al, 2008).

Women are also asked to disclose their status to partners and bring them in for testing (AVERT, 2010).

It is hypothesized that women in Kabarole district are now more knowledgeable about the risk of transmitting HIV to their children and the present findings indicate a change in behavior. Although stigma related to HIV is an ongoing issue in Western Uganda, mothers are not willing to risk passing the virus onto their children. Parents expressed a desire to have healthy children that can assist them with household chores and farming. Thus, it is desirable to avoid the risk of infecting a child with HIV. Unhealthy children may also be seen as a burden since they will require more care and support. A positive correlation between the knowledge of HIV testing and the willingness to be tested was identified in maternal research from Zimbabwe (Perez, Zvandaziva, Englesmann & Dabis, 2006). In previous studies related to malaria during pregnancy, perception of the illness was identified as a motivating factor for health seeking behaviors (Kiwuwa & Mufubenga, 2008; Nydomugyenyi, Neema & Magnussen, 1998). Similarly, it is believed that perceiving transmission of HIV as a risk during pregnancy may motivate women to seek ANC so that they will be tested. Furthermore, women may be more willing to undergo HIV testing as part of routine ANC rather than seek voluntary counseling and testing on its own due to known deterrents for testing such as stigma and fear of positive diagnosis (Dahl, Mellhammar, Bajunirwe & Bjorkman, 2008; Larsson et al, 2009; Karamagi, Tumwine, Tylleskar & Heggenhougen, 2006).

Results of studies assessing the acceptability and uptake of HIV testing as part of ANC have been equivocal. The majority of existing literature on suggests that HIV testing is a deterring factor to seeking ANC (Perez, Zvandaziva, Englesmann & Dabis, 2006; Dahl, Mellhammar, Bajunirwe & Bjorkman, 2008; Larsson et al, 2009; Karamagi, Tumwine, Tylleskar & Heggenhougen, 2006). A population-based study in rural eastern Ugandan showed that only 60 percent of participants consented to be tested for HIV (Larsson et al, 2009). Larrson et al (2009) conducted interviewer-mediated questionnaires with 403 women with a live baby between 1 and 4 months of age during the period of March to August 2007. These authors alluded to a situation in which women select their source of ANC so that they can avoid testing; this finding is to be explored in a forthcoming publication (Larsson et al, 2009). This view is echoed in a comment made by an HIV/AIDS Focal Person, Chris Rwabwogo: "Pregnant women avoid hospitals having noted that HIV testing is now imposed as mandatory to them." (Lilian, 2010).

Our research however, suggests that women seek ANC in order to be tested for HIV. We have not identified any previous research documenting such a finding. However, a countrywide report found that, during the twelve-month period between July 2008 and June 2009, 92 percent of pregnant women attending ANC were tested and counseled on the result (Government of Uganda, 2010). Prior literature has shown that the more contact a woman has with health care providers the more likely she is to accept HIV testing (Perez, Zvandaziva, Englesmann & Dabis, 2006). Studies from Zimbabwe, Botswana, and Kenya

also highlighted the availability of free testing services at ANC, same day results and adequate education and counseling to promote acceptability of HIV testing during pregnancy (Chandisarewa et al, 2007; Kaire et al, 2000; CDC, 2004; Perez, Zvandaviza, Englesmann & Dabbis, 2006).

We believe that the strong HIV education campaigns in Uganda have resulted in more awareness of the disease, lower stigma associated with having the disease, and higher levels knowledge regarding prevention strategies. The availability of safe, convenient testing services at health facilities has also influenced women to seek antenatal services. Recently, Uganda has moved away from focusing on HIV programming to address other health issues (Uganda Districts Information Handbook, 2005) but it is important to shed light on this unintended, positive outcome of the HIV campaigns on ANC in Uganda. Further research is needed to better understand the relationship between HIV testing and ANC. Moreover, it is important to identify *why* there are inconsistent findings on this issue.

5.2 Services accessed during pregnancy and childbirth

Women access a mix of both traditional and biomedical services during pregnancy so that they receive a combination of biomedical and traditional services from midwives and traditional health workers. Our findings indicated that women hold explanatory models, which are modified, based on their experiences and exposure to advice from various 'experts'. It was clear that belief systems surrounding pregnancy and childbirth were not solely biomedical nor

were they solely traditional, rather there was an overlap leading to a continuum of services women choose to seek. There were some circumstances such as being a victim of witchcraft and having "tied" pregnancies that warranted purely traditional services from traditional healers. HIV testing, for example, was an instance where women required only biomedical services, as traditional health workers could not provide HIV testing.

The mixture of traditional and biomedical services during pregnancy is a common finding in other literature (Amooti-Kaguna & Nuwaha, 2000; Rutakumwa & Krogman, 2007). Numerous studies have found similar belief systems in Uganda, which affect the services women, seek. The importance of the position of the baby, for example, has been noted previously. Mothers ensure that the baby is in a good position for vaginal delivery because cesarean sections are feared (Amooti-Kaguna & Nuwaha, 2000). Mal or abnormal presentation of the fetus is an indication for health facility delivery. When women face complications or abnormalities during pregnancy, they believe childbirth is more likely to be complicated; but when pregnancy is normal there is a greater inclination to expect normal childbirth (Amooti-Kaguna & Nuwaha, 2000).

We found a preference to seek care in health facilities at the time of delivery, but there are also many qualities about TBAs that women found useful during pregnancy. TBAs are flexible with timing, payment is negotiable and they are close by (Amooti-Kaguna & Nuwaha, 2000). Husbands also identified TBAs as kinder women who are easily accessed during the night. TBAs are believed to have the ability to cleanse the womb, provide herbal remedies, and protect

pregnancies from bad omens (Amooti-Kaguna & Nuwaha, 2000). Health workers in developing countries are part of the literate elite while many community members are poor and illiterate (Kamal, 1998). The TBA is part of the community; she is socially acceptable and does not judge women who lack education or clean clothing. Moreover, in this study support is offered for previous findings that TBAs provide more "motherly" care than do midwives (Kamal, 1998). TBAs will prepare food, help with cleaning and washing and provide emotional support after childbirth. These services are not part of the midwifery package (Kamal, 1998). Our study also found that women desire support during pregnancy and childbirth. Pregnancy and childbirth are vulnerable times in a woman's lives so they need extra care and assistance. It is really not surprising that poor women without family or a husband would much rather avoid embarrassment or shame of their social situation and deliver with a TBA who will take care of her. This may even occur if she is aware that the care provided by a midwife would be safer.

Rutukumwa & Krogman (2007) found that modern medicine is preferred but when it is ineffective or inaccessible women seek traditional remedies such as herbal teas and rubs. Our findings actually showed a belief in using both traditional and biomedical remedies so that where one is unsuccessful the other may be effective, resulting in care for all aspects of pregnancy. For example, using herbal mixtures to reduce the risk of needing a cesarean section or vaginal tears and to cleanse the womb is a common belief because, biomedically, there is no medication one can take to avoid cesarean sections. There is little available

evidence to assess the effectiveness of such herbal mixtures. Our findings support previous literature in that the majority of the population believes in the efficacy of herbal remedies (Rutakumwa & Krogman, 2007).

A preference for a skilled attendant at the time of birth was also noted in previous studies (Amooti-Kaguna & Nuwaha, 2000) because TBAs were said to lack knowledge, cause problems and delay referral. The notion of stalled pregnancies and *obuzaire* was not found in other studies. This concept may be specific to the Tooro people and thus, specific to our study participants. However, it is a situation in which traditional practitioners are preferred. Biomedical health workers cannot remedy a tied pregnancy; traditional healers must provide the remedy. An important aspect of *obuzaire* was not so much the concept itself, but more the fact that women were seeking support after childbirth. Women indicated the importance of care and someone to cook for them and assist them in regaining their strength after labor.

5.3 The real cause of maternal mortality

One of the main objectives of this research was to understand the decision-making process women undergo when determining the services that they choose to access during pregnancy and childbirth. It is known that the majority of maternal deaths are a result of direct obstetric complications; of these complications, almost all are preventable if timely emergency obstetric care is available (WHO, 2010(a)). In this research, we wanted to understand how women determined the course of action to take at the time of childbirth. Findings related

to decisions at the time of childbirth indicated that women were aware of the benefits of hospital or institutional delivery and actually preferred this course of action. A multitude of barriers sometimes prevented this. It is these barriers that delay receiving appropriate services, thus contributing to increased maternal mortality. These findings verify previous east African research indicating that despite high levels of ANC there is less access to SBAs due to similar barriers (Waiswa et al, 2008).

The barriers identified in this study were the ability to get to health facilities, poverty, attitudes of health care workers, quality of health services and availability of support. Thaddeus and Maine (1994) designed a universal model identifying delay as the root cause of maternal mortality due to the preventable nature maternal deaths. The three delays model (see appendix N) based on evidence from low income countries can be a tool to better understand our findings within the context of known literature (Thaddeus & Maine, 1994). The barriers identified through the research findings can be applied to Thaddeus and Maine's model (1994) (See figure 1).

Our version of the three delays model (figure 1) illustrates how barriers to accessing skilled attendants determine if a woman is able to receive appropriate care.

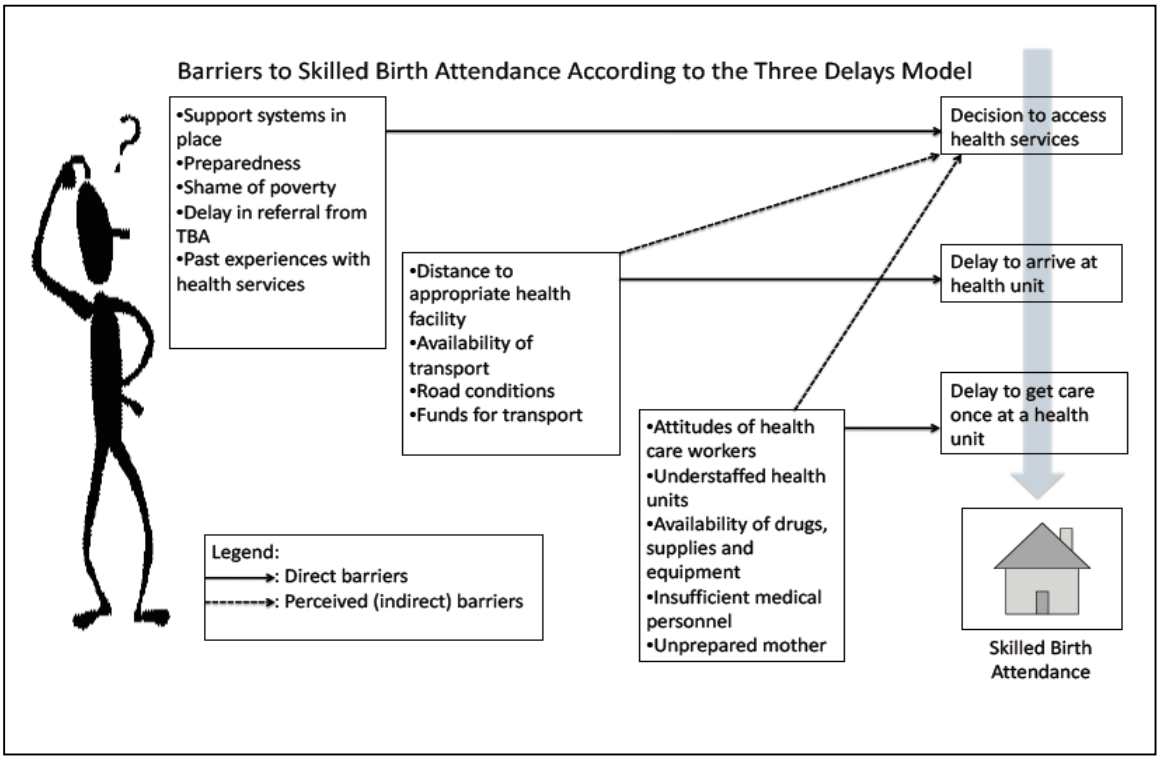


Figure 1. Application of the three delays model.

The discussions in Kabarole district showed that the majority of participants were aware of the benefit of delivery in the presence of a skilled worker. Mothers and their partners both knew that complications could occur during childbirth that TBAs or non skilled attendants would not be able to manage due to lack of necessary equipment and lack of knowledge and training. Furthermore, in some cases, the desire to have a safe delivery with optimal outcomes outweighed the care provided by TBAs although they were reported to be kinder and more accessible. For example, some women said that TBAs had caused damage to their body parts. Although TBAs were perceived as helpful to the community in emergency situations where women were unable to access health facilities, they were not always preferred.

This finding supports previous research where satisfaction with TBAs in neighboring Tanzania was assessed. The satisfaction rankings were health facilities, TBAs, alone at home, with health facilities being the best experience and delivering alone being the least preferred (Mbaruku et al, 2009). Moreover, research in Zambia has shown that while only 42 percent of women deliver in a health facility, 75 percent prefer it to home deliveries (Van den Boogaard et al, 2008). Both of these studies indicated that it is important to consider the barriers to facility delivery rather than assuming women deliver with TBAs or alone because it is their preference (Mbaruku et al, 2009; Van den Boogaard et al, 2008). A similar finding is evident in Kabarole district leading to the following analysis of barriers to seeking SBAs. Many women that delivered with TBAs reported that if possible, they would prefer subsequent deliveries to be with formal health care providers such as midwives practicing in health facilities because they were unhappy with their experiences with TBAs.

Our findings do not support those of a previous study from Uganda that found that women only went to health facilities as a last resort and preferred TBAs despite their lower levels of knowledge and skill when compared to formal health workers (Kyomuhendo, 2003). Kyomuhendo (2003) conducted a cross-sectional, descriptive study using both qualitative and quantitative methods in Hoima district in mid-western Uganda. In this study, women preferred TBAs because they are familiar and part of the community. Moreover, there were beliefs identified where women perceived pregnancy as a test of their own endurance (Kyomuhendo, 2003). These findings were not found in the current

study. It is important to note that the reasons for a difference may be related to the new policy in Uganda which has banned the use of TBAs, increased education related to the importance of SBAs at every delivery, and the fact that this study was conducted in a different district (Kyomuhendo, 2003).

A preference for institutional delivery does not always mean that women *decide* to deliver in health facilities. The first delay, the decision to seek health services, is directly impacted by the support systems women have in place, preparedness for delivery, shame of living in poverty, and past experiences with health services. There are also some cases in which a woman is experiencing complications with a TBA; the TBA often tries to handle the situation herself instead of immediately recognizing the signs of danger and referring to biomedical health facilities. Moreover, perceived or indirect barriers impact the decision to seek health care at the time of delivery; the perception that one cannot reach health services due to transport barriers and even if one reaches the health center, perceiving abusive or indifferent care may deter women from seeking health services.

The women who deliver in villages without assistance of a skilled birth attendant can be those that do not have the support of a husband or family member. Males that do not prioritize formal health services during childbirth may not support their wives or partners in accessing them. Single women and those that are in polygamous relationships are more vulnerable during pregnancy because they do not have a man to care for them. Our findings showed that men provide women with financial assistance and those men, as the head of the

household, make the decision about the level of care that the women can seek. Single women or those in polygamous relationships lack this critical support system. Those who are single and/or poor are often unable to acquire the needed required supplies for delivery, they may not be clean and may feel ashamed due to their circumstances. These mothers do not want to be judged or show their poverty in front of the health care workers who almost always dress in clean, white uniforms. Moreover, if, in the past, women have experienced any of the direct or indirect barriers, they are less likely to seek health care for subsequent deliveries. Thus, the experiences women have with health services actually determine future use. Direct and perceived barriers are interrelated and, if substantial, they result in the maternal or family decision *not* to seek formal health services at the time of delivery.

Similar barriers were found in research from central Uganda. Lack of support and husbands perceiving pregnancy and reproduction as women's issues is a common finding (Rutakumwa & Krogman, 2007; Mbonye, 2001). The Ugandan culture places men as the decision maker in most situations including family planning, site of delivery and distribution of money (Amooti-Kaguna & Nuwaha, 2000). Women often need permission from their husbands to access health care, thus men must believe in the importance formal health care and be accountable for associated fees (Kyomuhendo, 2003). Women are usually responsible for taking care of the farm and caring for children and are unable to work outside their homes and generate personal income (Rutakumwa & Krogman, 2007). Moreover, many women refuse to seek health services because they are

not prepared, don't have clean clothing, or financial resources for transport and/or treatment, if needed. An appropriate support system can facilitate preparedness and therefore, increase access of health services (Kyomuhendo, 2003; Mbaruku et al, 2009; Mbonye, 2001). A final reason that women do not seek health facilities at the time of delivery is past experience. If women faced a barrier to accessing health services including abusive, inadequate or indifferent services, they are less likely to seek similar services in the future (Rutakumwa & Krogman, 2007).

The second delay in receiving health services is reaching the health facility. The majority of the population resides in rural communities and have numerous geographic barriers in reaching health centers. Most families do not own vehicles and thus, are required to pay for either public or private means of transport (buses run during the day and take longer while taxis are expensive). Unpaved roads and an absence of ambulances and other suitable modes of transportation contribute to a delay in reaching health facilities. In Kabarole district, 49 percent of the population lives within 5km of health facility, but this does not equal access to required services. Not all health facilities offer skilled care at the time of birth; therefore, women may still have to travel further to reach a major hospital to deal with emergency complications (Ssengooba et al, 2003; Kamal, 1998; UBOS & Macro International, 2007).

These findings are consistent with Thaddeus and Maine's analysis on maternal mortality. Distance to skilled attendants, for example, has been identified as both a direct and indirect barrier because sometimes the actual distance to health facilities is too difficult to travel, moreover the perception of

distance can deter women from deciding to seek professional or skilled care (Thaddeus & Maine, 1994; Rutakumwa & Krogman, 2007; Amooti-Kaguna & Nuwaha, 2000; Kamal, 1998). Distance, in this case, combines physical distance between the home and health facility as well as the means required to travel – vehicle, adequate road conditions and funds for transport (Thaddeus & Maine, 1994; Rutakumwa & Krogman, 2007; Mbonye, 2001).

The third and final delay in the presence of skilled attendants at the time of birth is receiving care upon arrival at a health facility. Our findings indicated several barriers to receiving care, which have deep rooted causes within the health system. These barriers are: attitudes of health workers, inadequate numbers of health professionals at health units, insufficient medical supplies, drugs and equipment, and an unprepared mother. All of these barriers are interrelated and can be explained through an example of an unprepared mother. A mother who goes to a health unit without necessary supplies, such as gloves, the midwives may scold her, which can be perceived by a laboring woman as abusive. The midwife may not have sufficient rest, leisure time or remuneration. Midwives, knowing the risk of HIV transmission have been trained to avoid assisting with deliveries unless they have protective gloves. Health facilities often lack the funds to maintain continuous supplies of necessities such as gloves, thus the midwife, facing a combination of exhaustion, burnout, and stress at the situation will scold the mother for not coming prepared. Midwives are required to be on call 24 hours a day, 7 days a week, often with little support staff. When a woman is in labor at night, husbands or family members will obviously ask midwives to

wake up and assist their wives. The midwife however, may be tired and stressed and express this through inappropriate anger.

Inadequate working conditions for health care workers are evident in other studies. Low pay combined with a stressful work environment and understaffed health units lead to a situation where women may be neglected and/or given a low quality of care (Kyomuhendo, 2003; Rutakumwa & Krogman, 2007; Amooti-Kaguna & Nuwaha, 2000). Health facilities have been known to lack essential supplies for emergency obstetric intervention such as antibiotics, intravenous fluids, blood for transfusion and supplies for universal precautions (Mbonye, 2001; Amooti-Kaguna & Nuwaha, 2000). Moreover, health facilities often lack skilled professionals such as well-trained midwives, doctors and clinical officers. Although midwives, nurses and nurses' aides are very competent, emergencies and complications may require access to higher levels of intervention (Mbonye, 2001). Nurses and midwives are trained to manage complicated cases and having at least one nurse and midwife in health units along with assistants such as nurses' aides and medical assistants can significantly reduce risk of adverse outcomes (Mbonye, 2001). Uganda has made efforts to increase access to ambulances, medical equipment and supplies (Mbonye, 2001). However, the sites visited were not equipped to provide the level of care needed to cope with obstetrical emergencies.

Ugandan women reported that health care workers, especially in government facilities, are rude, proud, negligent and vulgar. Moreover, women presented at health facilities without an ANC card were abused and told that they

were negligent mothers. Similar results were evident in a study from Zimbabwe; health workers lack a welcoming attitude, patience, friendliness, listening, and did not provide general and specific information about pregnancy and childbirth (Mugweni, Ehlers & Roos, 2008). Other studies in Uganda have reported a fear of being abused by midwives as a deterring factor to seeking health services (Amooti-Kaguna & Nuwaha, 2000). It was clear, through interviews that most midwives were kind women but exhibiting inappropriate behaviors in a high stress job. Practicing in an environment lacking essential supplies and facing staff shortages combined with low income women who are unable to purchase supplies that may be needed when they give birth creates a scenario that can be described as abusive. Although I can understand the situation midwives face, this behavior is not excusable. Stories of midwives refusing to wake up or opting to have lunch or tea instead of performing an assessment or assisting a woman with labor is unacceptable and certainly provides rationale for why women might choose to remain in a more supportive environment in their own villages and communities. The blame however, cannot be placed solely on one factor. It is important to address all of the contributing factors in order to rectify the situation.

5.4 Recommendations for change

The findings from this and other research on similar issues indicate that it is not appropriate to assume that women prefer to deliver with TBAs or in their homes, rather it is more important to identify and address the factors that play a role in decision making at the time of childbirth (Mbaruku et al, 2009; Mugweni, Ehlers & Roos, 2008). Understanding the health needs of women from their own

perceptive is important in identifying and addressing the challenges women face (Rosenfield & Min, 2007). This research is a clear example of how women may not always prefer the services they receive during childbirth but, in fact, they access them because they are unable to receive the care they desire.

The issue of TBAs poses a difficult topic in global health. Women appreciate the care that TBAs provide but are also aware of their shortcomings. Similarly, women trust in the medical knowledge and skills health workers have but are aware of the barriers they will face in receiving these services. In an effort to reduce the harm that can be caused by untrained non-medical personnel during childbirth, the Ugandan government enlisted a law banning TBAs from practicing. They are still practicing however, and women are still utilizing them. The work they do during childbirth is a source of income for TBAs, moreoever, they will not refuse to care for a women that is need of it (Shaikh, 2010). Many other countries that have undertaken similar actions have found that a law will not cause TBAs to disappear. The community requires their services and without offering a replacement service and ensuring that women can access midwives and other skilled attendants, they will continue to exist (Kamal, 1998; Shaikh, 2010; Fleming, 1994; Yousuf et al, 2010). This study showed that many women use TBAs when they have too many obstacles to overcome in receiving biomedical care. Even if they are aware that TBAs are banned, without additional support from the Ministry of Health, what choice do women have?

From the findings of this study, I believe it is important for Uganda to accept the value of TBAs and integrate them into the health system whilst

upgrading services so that they are more accessible. For example, if ambulances were functioning in the district, women may be able to access transport to reach health centers. Furthermore, literature has shown that TBAs delay referral because they will not be paid their fees if women end up delivering in health facilities (Ssengooba, 2007). It is important to recognize that these services are TBAs' source of income. It may be feasible to recommend a payment system for advising women to deliver in health facilities while still allowing TBAs to provide traditional care during pregnancy and supportive care during the post-natal period could be an effective way to integrate TBAs. Sierra Leone, a country with an extremely high maternal mortality rate, has found that incorporating TBAs in the hospital system and offering stipends for referral of cases is an effective way to encourage the use of health facilities (Fofanah, 2010). TBAs are known to be respected community members and if they suggest delivery in health facilities and are able to acquire support to facilitate transport, perhaps some of the barriers women face will be eliminated (Fofanah, 2010). It is clear that TBAs have good intentions and want to help mothers deliver healthy babies, but they may lack equipment, understanding and skill. Rather than shunning TBAs, allowing them to be a part of the local health teams in villages could help them feel like they are still respected members of the community (Kamal, 1998; Mbaruku et al, 2009).

It is also important to fund further research into the traditional practices in Kabarole district. Some investigators such as Ssengooba et al (2007) found that traditional herbs may be toxic or harmful to the mother and baby. The majority of women accessed some type of herbal remedy during pregnancy and it is

important, therefore, to critically evaluate these herbs with respect to their efficacy, safety, purpose and effectiveness as they are clearly an important part of the pregnancy and childbirth experience. Health care workers in the district must also be made aware of the importance of traditional practices and, rather than judging women and TBAs, they should be trained to acknowledge these beliefs. If health workers are aware of women's beliefs, they may be able to better negotiate treatment strategies that take beliefs and biomedicine into account leading to improved adherence.

The attitudes of health care workers as deterrents for seeking health services is also important to address. There are many structural problems that must be addressed in order to tackle this issue. Ensuring that health care workers are not over worked and receive adequate wages for their work is one factor, which must be modified. In Kenya, the attitudes of health care workers were also identified as deterrents to obstetric services (Essendi, Mills & Fotso, 2010). It is important to take a closer look at the situation in Uganda to better understand how to modify the attitudes of doctors, nurses and midwives. Fear of being abused is a phenomenon that affects maternal/community decisions regarding health services. Therefore, during their training, health workers should be informed of this ongoing issue and given strategies for 'public relations' (Essendi, Mills & Fotso, 2010). Moreover, health care workers should also be given an opportunity to their perspectives on this issue instead of placing blame so that the Ministry of Health can work towards addressing underlying issues. It is hypothesized that midwives and nurses were overworked in the health centers included in this study.

Strategies to decrease workload and employee satisfaction must be further explored. Adding in more nurses' aides and assistants might also provide additional support.

Barriers such as distance to health facilities, lack of transport and quality of health services require a deeper understanding of the Ugandan health financing system. It would be very easy to say 'provide more ambulances' and 'provide more medications', but in developing countries, there are often financial barriers to incorporating such strategies. Informing policy makers of these issues is important so that they are made aware of the fact that many women *want* to access biomedical services but they are unable to. The demand for services is there so it is important to invest in health infrastructure. It is essential for the Ministry of Health to strategize and place emphasis on acquiring essential medications, improving communication between health services, improving transport services between health facilities and ensuring that the required supplies for delivery are available in health facilities. This requires an analysis of the policy and structure of the health system so that the most cost-effective improvements can be made.

Further research is required in western Uganda. An assessment of acceptability of HIV testing in ANC is essential to confirm if it has become a reason for which women seek ANC. Moreover, if this is the case, similar strategies of education and changes to health practices can be incorporated to ensure that the women that are HIV positive deliver in health facilities. Further research can address stresses faced by health care workers that lead to negative attitudes. As previously mentioned, rather than placing blame, it is important to

identify the underlying structural issues that lead to this negative behavior. More investigation is needed regarding the efficacy and safety of traditional herbs that are used during pregnancy and childbirth. It is important to identify whether these herbs are helpful, harmful or have no known affect.

5.5 Study limitations

This research was conducted in two sub-counties of one district in Uganda. It cannot be assumed that the findings can be generalized to the entire country or even to the district as a whole. The study was also conducted by a foreign researcher in a population where English was not the primary language. The majority of the participants spoke limited English, thus all the interviews were conducted in the local language by research assistants; the researcher only conducted interviews with health care workers in English. The primary researcher had to rely on transcripts and cultural explanations by research assistants. Although the primary researcher was aware of this limitation and made attempts to minimize it through ensuring accurate transcriptions and discussions of understandings and findings with the research team, it cannot be guaranteed that she possessed the same understanding as someone that was fluent in Rutooro. Moreover, the researcher only lived in Kabarole district for four months; this cannot ensure an adequate understanding of cultural practices and non-verbal cues.

There was a noted hierarchy between the research team and study participants. A team of educated, well-dressed, upper class Ugandans and one

Canadian outsider may have been led to participants providing responses that they thought we were looking for. For example, it is widely known that women should deliver in health facilities so perhaps participants shaped their responses so that they would not be judged by the research team as being bad parents or uneducated. Moreover, seeing a person from a developed country may have led to the conclusion that financial assistance could be provided as many participants pointed to poverty as a root cause of all their problems. Although poverty is a very real issue in developing countries, the extent to which it impacts decision making during pregnancy and childbirth was difficult to ascertain and thus should be the subject of another research project.

Chapter 6

Conclusion

Sub-Saharan Africa, accounting for just 11% of the world's population, carries the burden of half of the maternal, newborn and child deaths (Friberg et al, 2010). The recent focus of global public health research has been on reducing the number of maternal deaths, as it is the one health indicator that illustrates the widest gap between low and middle to high income countries (Carroli, Rooney & Villar, 2001). Although Uganda has made significant progress on reducing the burden of HIV/AIDS, the same cannot be said for maternal health (AVERT, 2010). With 435 maternal deaths per 100,000 live births and only 42% of births taking place in a health facility despite a 92% ANC rate, Uganda must take action to save the lives of mothers (UBOS & Macro International, 2007). This research project aimed to identify the biomedical and traditional health services that Ugandan women in Kabarole district seek and receive through the generation of local explanatory models.

A focused ethnography approach using interviews, focus groups and observation was utilized to gather data. The findings indicated that women have an assortment of beliefs that emerge from both the biomedical and traditional realms. These beliefs are shaped by the advice given to them from various sectors including the biomedical and traditional; and through their families and communities. Importantly, findings indicated that women believe ANC to be an important service to seek during pregnancy because it allows them to be tested for HIV and to ensure the baby is okay in the womb. Similarly, from the traditional

realm, the majority of women accessed herbal remedies during pregnancy to ease labor, cleanse the womb, prevent cesarean sections and prevent miscarriages. Many mothers believed that choosing TBAs as their birth attendant was a risky choice because they lack the training of health workers, appropriate supplies and may practice unhygienically. Despite the preference many women showed for SBAs and a law banning TBAs from practicing, women continue to deliver in villages with the assistance of TBAs, family members or alone. This is due to a plethora of barriers including distance to health facilities, transport to health facilities, poverty, shame of poverty, attitude of health workers, quality of health services and inadequate support systems. By using Thaddeus and Maine's Three Delays Model (1994), it was possible to place the barriers to utilizing SBAs into a framework. It was clear that interaction of these barriers lead to delays in seeking and accessing health services at the time of delivery leading to maternal mortality. In order to reduce maternal mortality in Uganda to meet Millennium Development Goal 5, action must be taken at the level of researchers, health care workers and policy makers.

This research pointed to the complexity of factors that affect women's access to safe maternity services. Women, at a vulnerable time in their lives, face barriers, which prevent them from receiving the health care they need and desire. If a woman wants to be attended to by a skilled worker, it should be her right to be able to access such services (Costello, Azad & Barnett, 2006). Reducing these disparities requires political will and sustainable evidence based changes to 'the system' (Schmidt et al, 2010). It is crucial at this time, to not only recognize the

existence of these disparities but also to advocate for the women that are the victims of these health inequities.

6.1 Dissemination of findings

One of the most important aspects of research is to disseminate knowledge to other venues so that it can be utilized for policy, future research and health program planning. As part of her master's degree, the researcher will aim to publish at least one academic publication in a peer-reviewed journal. The researcher will also share research findings through posters and presentations at academic conferences within the fields of maternal health, global health and qualitative research. Furthermore, as the University of Alberta Department of Public Health Sciences has established connections with Kabarole District, this project will inform further research undertaken on maternal health in this district. The completed manuscript as well as a summary of findings will be shared with the Ugandan Ministry of Health, Kabarole District Health Services and Makerere University 's School of Public Health in Kampala. Recommendations for change based on research findings will be provided through each of these venues in the hopes that the research can lead to change in policy and planning and thus improve the health of women in Uganda.

References

Albrecht, GL, Fitzpatrick, R, & Scrimshaw, S. (2003). *Handbook of social studies in health and medicine.* USA: Sage publications.

Albright KS & Kawooya D. (2005). The role of information in Uganda's reduction of HIV/AIDS: individual perceptions of HIV/AIDS information. *Information Development*: 21: 106.

Amooti-Kaguna B & Nuwaha F. (2000). Factors influencing choice of delivery sites in Rakai district of Uganda. *Social Science & Medicine* 50: 203-213.

Atkinson, SJ. & Farias, MF. (1995). Perceptions of risk during pregnancy amongst urban women in northeast Brazil. *Social Science & Medicine*: 41(11), p 1577-1586.

AVERT. (2010). *HIV and AIDS in Uganda.* AVERTing HIV and AIDS. Retrieved August 16, 2010 from http://www.avert.org/aids-uganda.htm.

Government of Uganda. (2010). UNGASS country progress report Uganda: January 2008-December 2009.

Belizan JM, Farnot U, Carroli G & Al-Mazrou Y. (1998). Antental care in developing countries. *Pediatric and Perinatal Epidemiology* 12 (Suppl. 2): 1-3.

Berer M. (2007). Maternal mortality and morbidity: is pregnancy getting safer for women? (editorial). *Reproductive Health Matters* 15(30): 6-16.

Birks M, Chapman T & Francis K. (2008). Memoing in qualitative research: probing data and processes. *Journal of Research in Nursing* 13(1): 68-75.

Bhutta ZA, Chopra M, Axelson H, Berman P, Boerma T, Bustreo F, Cavagnero E, Cometto G, Daelmns B, de Francisco A, Fogstad H, Gupta N, Laski L, Maliqi B, Mason E, Pitt C, Requejo J, Victoria CG & Wardlaw T. (2010). Countdown to 2015 decade report (2000-10): taking stock of maternal, newborn, and child survival. *Lancet* 375: 2032-2044.

Braveman P. (2006). Health disparities and health equity: concepts and measurement. *Annual Review of Public Health* 27: 167-194.

Bryce J, Daelmans B, Fauveau V, Lawn JE, Mason E, Newby H, Requejo J, Salama P, Shankar A, Starrs A, Wardlaw T. (2008). Countdown to 2015 for maternal, newborn and child survival: the 2008 report on tracking coverage of interventions. *Lancet* 371: 1247 – 1257.

Campbell OMR & Graham WJ. (2006). Strategies for reducing maternal mortality: getting on with what works. *Lancet* 368: 1284-1299.

Carroli G, Rooney C & Villar K. (2001). How effective is antenatal care in preventing maternal mortality and serious morbidity? An overview of the evidence. *Pediatric and Perinatal Epidemiology* 15 (Suppl. 1): 1-42.

Chadisarewa W, Stranix-Chibanda L, Chirapa E, Miller A, Simoyi M, Mahomva A, Maldonado Y, Shetty AK. (2007). Routine offer of antenatal HIV testing ("opt-out" approach) to prevent mother-to-child transmission of HIV in urban Zimbabwe. *Bulletin of the World Health Organization* 85(11): 821-900. http://www.who.int/bulletin/volumes/85/11/06-035188/en/

Chapman, RR. (2003). Endangering safe motherhood in Mozambique: prenatal care as pregnancy risk. *Social Science & Medicine*: 57, p 355-374.

Chapman, RR. (2006). Chikotsa – secrets, silence, and hiding: social risk and reproductive vulnerability in central Mozambique. *Medical Anthropology Quarterly* 20(4), p 487-515.

Centers for Disease Control and Prevention (CDC). (2004). Introduction of routine HIV testing in prenatal care – Botswana, 2004. *MMWR Weekly* 53(46): 1083-1086.

Dahl V, Mellhammar L, Bajunirwe F & Bjorkmann P. (2008). Acceptance of HIV testing among women attending antenatal care in south-western Uganda: risk factors and reasons for test refusal. *AIDS Care* 20(6): 746-752.

Donalek JG & Soldwisch S. (2004). An introduction to qualitative research methods. *Urologic Nursing* 24(4): 354-356.

Ells C & Gutfreund S. (2006). Myths about qualitative research and the tri-council policy statement. *The Canadian Journal of Sociology* 31(3): 361-373.

Essendi H, Mills S & Fotso J. (2010). Barriers to formal emergency obstetric care services' utilization. *Journal of Urban Health: Bulletin of the New York Academy of Medicine* August 2010.

Fleming JR. (1994). What in the world is being done about TBAs? An overview of international and national attitudes to traditional birth attendants. *Midwifery* 10: 142-147.

Fofanah M. (2010). *SIERRA LEONE: Defining new role for traditional birth attendants*. IPS: Communicating MDG 3. Retrieved August 16, 2010 from http://www.ips.org/mdg3/sierra-leone-defining-new-role-for-traditional-birth-attendants/.

Friberg IK, Kinney MV, Lawn JE, Kerber KJ, Odubanjo MO, Bergh A, Walker N, Weissman E, Chopra M & Black RE. Sub-Saharan Africa's mothers, newborns and children: how many lives could be saved with targeted health interventions? *PLoS Medicine* 7(6).

Genzuk M. (2003). *A synthesis of ethnographic research* [electronic version]. Center for Multilingual, multicultural Research, University of Southern California: Los Angeles.

Global Health Council. (2010). Maternal, newborn, child and reproductive health. *A global health council position paper, January 2010.* Washington, DC, USA.

Grant RW & Sugarman J. (2004). Ethics in human subjects research: Do incentives matter? *Journal of Medicine and Philosophy* 29(6): 717-738.

Groleau D, Young A & Kirmayer LJ. (2006). The McGill illness narrative interview (MINI): an interview schedule to elicit meanings and modes of reasoning related to illness experience. *Transcultural Psychiatry* 43: 671 – 691.

Hammersley M & Aktinson P. (2007). *Ethnography: Principles in Practice* (3rd ed). NY: Taylor & Francis Group.

Hogan MC, Foreman KJ, Naghavi M, Ahn SY, Wang M, Makela SM, Lopez AD, Lozano R & Murray CJL. (2010). Maternal mortality for 181 countries, 1980-2008: a systematic analysis of progress towards Millennium Development Goal 5. *Lancet* 375: 1609-1623.

Holloway I. (1997). Basic concepts for qualitative research. USA: Wiley-Blackwell.

Horton R. (2008). Countdown to 2015: a report card on maternal, newborn, and child survival. *Lancet* 371: 1217-1219.

Jokhio AH, Winter HR & Cheng KK. (2005). An intervention involving traditional birth attendants and perinatal and maternal mortality in Pakistan. *The New England Journal of Medicine* 352: 2091-2099.

Kamal IT. (1998). The traditional birth attendant: a reality and a challenge. *International Journal of Gynecology & Obstetrics* 63 (suppl. 1): S43-S52.

Karamagi CAS, Tumwine JK, Tylleskar T & Heggenhougen K. (2006). Antenatal HIV testing in rural eastern Uganda in 2003: incomplete rollout of the prevention of mother-to-child transmission of HIV programme? *BMC International Health and Human Rights* 6(6). http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1533856/

Key JP. (1997). *Module R14: Qualitative research.* Research Design in Occupational Education: Oklahoma University.

Kiarie J, Nduati R, Koigi K, Musia J & John G. (2000). HIV-1 testing in pregnancy: acceptability and correlates of return for test results. *AIDS* 14(10): 1468-1470.

Kizito D, Woodburn PW, Kesande B, Ameke C, Nabulime J, Muwanga M, Grosskurth H, & Elliot AM. (2008). Uptake of HIV and syphilis testing of pregnant women and their male partners in a programme for prevention of mother-to-child HIV transmission in Uganda. *Tropical Medicine and International Health*: 13 (5) P 680-682.

Kleinman A. (1978) Concepts and a model for the comparison of the medical systems as cultural systems. *Social Science & Medicine*: 12 (2), p 85-95.

Kleinman A & Mendelsohn E. (1978). Systems of medical knowledge: a comparative approach. *Journal of Medical Philosophy*: 3, p 314–330.

Knoblauch H. (2005). Focused ethnography. *Forum: Qualitative Social Research* 6(3). Retrieved May 1, 2009 from http://www.qualitative-research.net/index.php/fqs/article/view/20.

Kyomuhendo GB. (2003). Low use of rural maternity services in Uganda: Impact of women's status, traditional beliefs and limited resources. *Reproductive Health Matters* 11(21): 16-26.

Larsson EC, Waiswa P, Thorson A, Tomson G, Peterson S, Pariyo G & Ekstrom AM. (2009). Low uptake of HIV testing during antenatal care: a population-based study from eastern Uganda. *AIDS* 23(14): 1924-1926.

Lilian L. (2010). Ugandan women shun antenatal care due to HIV testing. HealthDev.net. Retrieved August 16, 2010 from http://healthdev.net/site/post.php?s=6417.

Malinga J. (June 2010). *Traditional birth attendants show no sign of abandoning their work in Katine*. The Guardian online: Wednesday June 30, 2010. Retrieived August 16, 2010 from http://www.guardian.co.uk/katine/2010/jun/30/traditional-birth-attendants-work.

Matsuyama A & Moji K. (2008). Perception of bleeding as a danger sign during pregnancy, delivery and the postpartum period in rural Nepal. *Qualitative Health Research* 18: 196-208.

Mayan M. (2009). *Rigour in qualitative research.* Lecture: May 2009. Qualitative Research Methods, University of Alberta, Edmonton, Alberta.

Mbaruku G, Msambichaka B, Galea S, Rockers PC & Kruk ME. (2009). Dissatisfaction with traditional birth attendants in rural Tanzania. *International Journal of Gynecology and Obstetrics* 107: 8-11.

Mbonye AK. (2001). Risk factors associated with maternal deaths in health units in Uganda. *African Journal of Reproductive Health* 5(3): 47-53.

Mbonye AK, Mutabazi MG, Asimwe JB, Sentumbwe O, Kabarangira J, Nanda G & Orinda V. (2007). Declining maternal mortality ratio in Uganda: priority

interventions to achieve the Millennium Development Goal. *International Journal of Gynecology and Obstetrics* 98: 285 – 290.

Medley AM & Kennedy CE. (2010). Provider challenges in implementing antenatal provider-initiated HIV testing and counseling programs in Uganda. *AIDS Education and Prevention* 22(2): 87-99.

Mugweni E, Ehlers VJ & Roos JH. (2008). Factors contributing to low institutional deliveries in the Marondera district of Zimbabwe. *Curationis* June 2008: 5-13.

Mumtaz, Z. (2008). *Qualitative data analysis*. Lecture: May, 2008. Foundations in Qualitative Research Methods, Health Services Academy, Pakistan.

Pearson, M. (2000). Uganda: country health briefing paper. *Department for International Development by IHSD*: London.

Perez F, Zvandaziva C, Engelsmann B & Dabis F. (2006). Acceptability of routine HIV testing ("opt-out) in antenatal services in two rural districts of Zimbabwe. *Journal of Acquired Immune Deficiency Syndrome* 41(4): 514-520.

Orb A, Eisenhauer L & Wynaden D. (2000). Ethics in qualitative research. *Journal of Nursing Scholarship* 33(1): 93-96.

Riemer FJ. (2008). Chapter 11: Ethnography research. P 203-221. Retrieved online June 1, 2009 from http://media.wiley.com/product_data/excerpt/95/04701810/0470181095-2.pdf.

Rosenfield A & Bardfield J. (2009). Women's global health. *Journal of Pharmaceutical Sciences* 98(1): 43-45.

Rosenfield, A. & Min, CJ. (2007). Women's health in perspective: framing problems, framing solutions. *International Journal of Gynecology and Obstetrics*: 98, p 200-202.

Rothe JP. (2000). Undertaking qualitative research: concepts and cases in injury, health and social life. Edmonton: University of Alberta Press.

Rutakumwa W & Krogman N. (2007). Women's health in rural Uganda: problems, coping strategies and recommendations for change. *Canadian Journal of Nursing Research* 39(3): 104-125.

Ryan-Nicholls K & Will C. Rigour in qualitative research: mechanisms for control. *Nurse Researcher* 16(3): 70-85.

Schmidtt M, Joosen I, Kunst AE, Klazinga NS & Stronks K. (2010). Generating political priority to tackle health disparities: a case study in the Dutch city of the Hauge. *American Journal of Public Health* 100(Supplement 1): S210-S215.

Shaikh A. (2010). *Traditional birth attendants persist in Uganda.* UN Dispatch: Global News and Views. Retrieved August 16, 2010 from http://www.undispatch.com/traditional-birth-attendants-persist-uganda.

Squires A. (2009). Methodological challenges in cross-language qualitative research: a research review. *International Journal of Nursing Studies* 46: 277-287.

Ssengooba F, et al. (2003). Maternal Health Review Uganda. *Makerere University Institute of Public Health:* UK Department of International Development.

Starrs AM. (2006). Safe motherhood initiative: 20 years and counting. *The Lancet* 368: 1130-1132.

Tann CJ, Kizza M, Morison L, Mabey D, Muwanga M, Grosskurth H, Elliot AM. (2007). Use of antenatal services and delivery care in Entebbe, Uganda: a community survey. *BMC Pregnancy and Childbirth* 7(23).

Taylor C, Gibbs GR & Lewins A. (2005). Quality of qualitative analysis. *Learning Qualitative Data Analysis on the Web*. Retrieved August 4, 2010 from University of Huddersfield: http://onlineqda.hud.ac.uk/Intro_QDA/qualitative_analysis.php

Thaddeus S & Maine D. (1994). Too far to walk: maternal mortality in context. *Social Science & Medicine*: 38(8)), p 1091- 1110.

The World Bank. (2010). *Data: Uganda*. Retrieved August 11, 2010 from *http://data.worldbank.org/country/uganda*

Trochim WM. (2006). Research methods knowledge base: nonprobability sampling. Retrieved June 1, 2009 from http://www.socialresearchmethods.net/kb/sampnon.php

Tuckett AG. (2005). Part II: Rigour in qualitative research: complexities and solutions. *Nurse Researcher* 13(1): 29-42.

Uganda Bureau of Statistics (UBOS) & Macro International Inc. (2007). Uganda Demographic and Health Survey 2006. Maryland, USA: UBOS & Macro International Inc.

Uganda District Information Handbook. (2005). Kampala: Foundation Publishers.

Ulin PR, Robinson ET & Tolley EE. (2005). *Qualitative methods in public health: A field guide for applied research.* San Francisco: Jossey-Bass.

UNICEF. (2009). *Goal: improve maternal health*. Millennium Development Goals. 5. Improve maternal health. Retrieved August 11, 2010 from http://www.unicef.org/mdg/maternal.html

United Nations. (2008). The Millennium Development Goals Report 2008. New York: United Nations.

United Nations Development Programme (UNDP). (2010). *What are the millennium development goals?* Millennium Development Goals: Basic Facts. Retrieved August 11, 2010 from http://www.undp.org/mdg/basics.shtml.

Van den Boogaard J, Arntzen B, Chilwana J, Liyungu M, Mantingh A & Stekelenburg J. (2008). Skilled or traditional birth attendant? Choices of communities in Lukulu district, rural Zambia. *World Health & Population* 10(1): 34-43.

Waiswa P, Kemigisa M, Kiguli J, Naikoba S, Pariyo GW & Peterson S. (2008). Acceptability of evidence-based neonatal care practices in rural Uganda – implications for programming. *BMC Pregnancy and Childbirth* 8(21).

Weiss MG, Doongaji DR, Siddhartha S, Wypij D, Pathare S, Bhatawdekar M, Bhave A, Sheth A & Fernandes R. (1992). The explanatory model interview catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. *British Journal of Psychiatry* 160: 819-830.

Whitehead, M. (1992). The concepts and principles of equity in health. *International Journal of Health Services* 22 (3): 429-445.

World Bank. (2006). Maternal mortality at a glance. World Bank Publication.

World Health Organization (WHO). (2003). Antenatal care in developing countries: Promises, achievements and missed opportunities: an analysis of trends, levels and differentials, 1990-2001. World Health Organization: Geneva.

World Health Organization (WHO). (2000). World Health Report 2000. Geneva.

World Health Organization (WHO (a)). (2010). *Why do so many women still die in pregnancy or childbirth?* Ask the expert: on-line Q&A. Retrieved August 11, 2010 from http://www.who.int/features/qa/12/en/index.html.

World Health Organization (WHO (b)). (2010). *Maternal mortality ratio falling too slowly to meet goal*. Joint News research WHO/UNICEF/UNFPA/World Bank. Retrieved August 11, 2010 from http://www.who.int/mediacentre/news/releases/2007/pr56/en/index.html.

World Health Organization (WHO (c)). (2010). *Millennium Development Goals: Progress Towards the Health Related Millennium Development Goals*. Media Centre: fact sheet n.290. Retrieved August 11, 2010 from http://www.who.int/mediacentre/factsheets/fs290/en/index.html.

World Health Organization (WHO). (2004). *Making pregnancy safer: the critical role of the skilled attendant. A joint statement by WHO, ICM and FIGO*.

Making Pregnancy Safer. Department of Reproductive Health and Research. World Health Organization: Geneva.

World Health Organization (WHO). (2009). *WHO recommended interventions for improving maternal and newborn health* (2nd ed). Integrated Management of Pregnancy and Childbirth. WHO Department of making Pregnancy Safer. WHO Press: Geneva.

Worldmapper. (2006). Maternal Mortality. Retrieved August 16, 2010 from http://www.worldmapper.org/display.php?selected=258.

Yoder PS. (2001). Conducting qualitative research on demographic issues. Maryland, USA: Macro International Inc.

Yousuf J, Mulatu T, Nigatu T & Seyum D. (2010). *Revisiting the exclusion of traditional birth attendants from formal health systems in Ethiopia.* Discussion paper no 003: AMREF Discussion Paper Series. The African Medical and Research Foundation: Nairobi, Kenya.

Appendix A. Map of Uganda

Uganda Bureau of Statistics (UBOS) & Macro International Inc. (2007). Uganda Demographic and Health Survey 2006. Maryland, USA: UBOS & Macro International Inc. P. xxxi.

Appendix B. Study Approval by District Health Officer

KABAROLE DISTRICT LOCAL GOVERNMENT

Tel: +256 483 22575 - District Health Officer (DHO)
Tele-Fax: +256 483 23043 – Secretariat
E-mail: ddhskabarole@yahoo.com

Department of Health Services
Kabarole District
P.O. BOX 38,
FORT PORTAL

Date: 25th August 2009

TO WHOM IT MAY CONCERN

This is to confirm that the Research Proposal entitled "Risk Perception and Decision-Making Related to Childbirth in Kabarole District, Western Uganda" by Neelam Merchant, a Masters of Science Candidate of the University of Alberta, School of Public Health Sciences Canada, has been reviewed by our team and found to be useful. The results will contribute to a pool of knowledge which will be beneficial not only to Kabarole District but to Uganda as a whole.

I highly recommend and approve that when ready she may go ahead with the study.

Thank you.

Mr. Fulgensio Ntegyereize
For: DISTRICT HEALTH OFFICER
KABAROLE DISTRICT

Appendix C. Interview guides for participants

(To be modified after the initial interviews)

Interview guide (For women that have recently (last 12 months) given birth) – Age 18-49	
Questions	**Prompts, notes**
Section 1: Experiences with Pregnancy	
1.1 Tell us about your pregnancy 1.2 Tell us about any care you sought during pregnancy 1.3 What services are available to you during pregnancy	* Elicit ideas about the proper care and management of pregnancy according participant * Try to probe as much as possible * Probe regarding care sought during pregnancy
2.1 What happens inside the body that explains problems during pregnancy	
3.1 Are problems during pregnancy linked to, or related to, or caused by specific life events?	
4.1 What other help, treatment, therapy or care have you sought out related to pregnancy? 4.2 What would you like to receive?	*Not specific to the most recent pregnancy or childbirth, can be any
Section 2: Experiences with Childbirth	
1.1 Tell us about your experiences with childbirth 1.2 Where did you give birth? In hindsight, would you change anything?	*If participant uses other terms in place of childbirth, use that term in all subsequent questions *Include previous births, not just the most recent, get as much information as possible *probe* * let this narrative go on for as long as possible, with only simple prompting such as "what happened then? And then?"
2.1 We would like to know more about your childbirth experience. Could you tell us more about what happened? 2.2 Did anything else happen?	* Continue asking 2.2 as needed to draw out all information and all events
3.1 Did you have any helpers or a traditional birth attendant, or a midwife with you? Tell us about your experiences. What happened? What made you seek help? What happened afterwards 3.2 What services were available to you during childbirth?	*inquire about the environment in which childbirth occurred * Probe for opinions regarding available services
4.1 If you went to see a doctor, tell us about your visit to the doctor, any hospitalization, and what happened afterwards.	* Seek opinions regarding formal health care providers from this question *If informal services used, ask questions about those services
5.1 Did you have any tests or treatments?	* Clarify if they felt any tests or treatments were necessary * Include any non-biomedical tests/treatments
6.1 Has anyone in your family, or someone close to you experienced a childbirth experience similar to yours?	* Aim to find out if their experience was "typical"

7.1 In what ways do you consider your childbirth experience to be similar or different from that of others	*Clarify what is normal and abnormal, what is typical, atypical, what is expected, unexpected
8.1 Where did you learn what you know about childbirth	*Probe regarding sources of information, try to find out if learned through experience, through community, through surroundings, through helping others through childbirth, etc…
9.1 Do you have any other terms or expressions that you use when discussing childbirth?	Define all new terms
10.1 According to you, what should happen during childbirth? 10.2 What usually happens during childbirth? 10.3 What are some problems that can occur during childbirth? 10.4 How common are these problems? 10.5 Why do these problems occur? 10.6 Do these problems start at a certain time? Why?	* When discussing problems, use the problems cited by participants in subsequent questions. Ie. If in 10.3, bleeding is mentioned, ask why bleeding occurs in 10.5
11.1 What happens inside the body that explains problems during childbirth?	*use problems that were mentioned in question 10 as guides for this question
12.1 Are problems during childbirth linked to, or related to, or caused by specific life events?	*use problems that were mentioned in question 10 as guides for this question
13.1 During your visit with the doctor, midwife, traditional birth attendant, what did they tell you your health problem was? 13.2 Did you receive any treatment, medicine or recommendations for interventions? 13.3 Tell us more about the treatments. Did you use them? Did they work? Why or why not? Was the treatment easy to follow? Difficult? 13.4 Did you go to the doctor, midwife, traditional birth attendant etc… expecting certain treatments? Did you receive what you expected? What did you not receive? Why did this happen?	*Only ask if participant utilized a service * Obtain detailed information for all treatments *As extra questions as probes, try to elicit as much as information as possible about *all* the treatments/recommendations/interventions * Get all the "whys" here
14.1 What other help, treatment, therapy or care have you sought out related to pregnancy and childbirth? 14.2 What would you like to receive?	*Not specific to the most recent pregnancy or childbirth, can be any
15.1 Has childbirth changed the way you live your life?	*Aside from the obvious answer of having children to care for
16.1 What has helped you through your childbirth experience(s)	
17.1 Is there anything else you would like to add?	Inquire about other potential participants

Interview Guide (For older women living in the community 50+)	
Questions	**Prompts, notes**
Section 1: Experiences with Pregnancy	
1.1 Tell us about your experiences with pregnancy in your community 1.2 What services are available to women during pregnancy	* Elicit ideas about the proper care and management of pregnancy according participant * Try to probe as much as possible * Probe regarding care sought during pregnancy
2.1 What happens inside the body that explains problems during pregnancy	
3.1 Are problems during pregnancy linked to, or related to, or caused by specific life events?	
Section 2: Experiences with Childbirth	
1.1 We would like to know more about how women living in this community experience childbirth. Could you share some experiences that you know of?	* Ask this question if women have been present at any childbirths in the community or have personal stories to share
2.1 What services were available in this community during childbirth?	* Probe for opinions regarding available services *Ask about formal and informal health services, tests treatments, services offered, what should be offered and what women actually receive
3.1 Is it necessary for services to be used during childbirth? Such as TBAs, doctors, nurses, midwives, etc… 3.2 Should any treatment, medicine or interventions be used?	*Only ask if participant utilized a service * Obtain detailed information for all treatments *As extra questions as probes, try to elicit as much as information as possible about *all* the treatments/recommendations/interventions
4.1 Where did you learn what you know about childbirth	*Probe regarding sources of information, try to find out if learned through experience, through community, through surroundings, through helping others through childbirth, etc…
5.1 Do you have any other terms or expressions that you use when discussing childbirth?	Define all new terms
6.1 According to you, what should happen during childbirth? 6.2 What usually happens during childbirth? 6.3 What are some problems that can occur during childbirth? 6.4 How common are these problems? 6.5 Why do these problems occur? 6.6 Do these problems start at a certain time? Why?	* When discussing problems, use the problems cited by participants in subsequent questions. Ie. If in 6.3, bleeding is mentioned, ask why bleeding occurs in 6.5
7.1 What happens inside the body that explains problems during childbirth	*use problems that were mentioned in question 6 as guides for this question
8.1 Are problems during childbirth linked to, or related to, or caused by specific life events?	*use problems that were mentioned in question 6 as guides for this question
9.1 Does childbirth change the lives of women in your community?	*Aside from the obvious answer of having children to care for
10.1 What can help women through their childbirth experience(s)	

11.1 Is there anything else you would like to add?	Inquire about other potential participants

Interview Guide (for formal and informal health care workers)	
Questions	**Prompts, notes**
Section 1: Experiences with Pregnancy	
1.1 Tell us about your experiences with pregnancy in this community and within your health practice 1.2 Tell us about any care that can be used during pregnancy?	* Elicit ideas about the proper care and management of pregnancy according participant * Try to probe as much as possible * Probe regarding care sought during pregnancy
2.1 What happens inside the body that explains problems during pregnancy as you/your patients understand it.	* try to avoid asking for biomedical terms; use lay terms whenever possible
Section 2: Experiences with Childbirth	
1.1 We would like to know more about how women experience childbirth. Could you tell us some of your experiences? 1.2 What was your role?	* Ask this question to understand the hcw's role in childbirth
2.1 What services were available and utilized in this community during childbirth?	* Probe for opinions regarding available services *Ask about formal and informal health services, tests treatments, services offered, what should be offered and what women actually receive
3.1 Is it necessary for services to be used during childbirth? Such as TBAs, doctors, nurses, midwives, etc… 3.2 Should any treatment, medicine or interventions be used?	*Only ask if participant utilized a service * Obtain detailed information for all treatments *As extra questions as probes, try to elicit as much as information as possible about *all* the treatments/recommendations/interventions
4.1 Where did you learn what you know about childbirth	*Probe to understand backgrounds, opinions, community knowledge *This question is especially important for informal health care providers
5.1 Do you have any other terms or expressions that you use when discussing childbirth?	Define all new terms
6.1 According to you, what should happen during childbirth? 6.2 What usually happens during childbirth? 6.3 What are some problems that can occur during childbirth? 6.4 How common are these problems? 6.5 Why do these problems occur?	* When discussing problems, use the problems cited by participants in subsequent questions. Ie. If in 6.3, bleeding is mentioned, ask why bleeding occurs in 6.5
6.6 What happens inside the body that explains problems during childbirth	*use problems that were mentioned in question 10 as guides for this question
7.1 Are problems during childbirth linked to, or related to, or caused by specific life events?	*use problems that were mentioned in question 6 as guides for this question
8.1 What can help women through their childbirth experience(s)	
9.1 Is there anything else you would like to add?	Inquire about other potential participants (both more hcw and women that can be participants)

Appendix D.

Focus Group Guide for Males (with children under 2 years)

(To be modified after the initial focus group)

1. What is pregnancy like for women in this community?
2. What are some problems that women can experience during pregnancy and childbirth?
3. What health services do women use in this community during pregnancy and childbirth?
4. What do you think of these services?
    a. Are they good?
    b. Bad?
    c. What changes need to be made?
5. What is your role during pregnancy and childbirth? (Role of the father)
6. Where do women deliver in this community? /in your family?
7. Are there risks during pregnancy and childbirth in this community?
    a. How can we minimize the risks?
8. Do women die during pregnancy and childbirth?
    a. How can we help them?
9. Have we missed anything? Is there anything anyone would like to add?

Appendix E. Information Letter for Local Council

UNIVERSITY OF ALBERTA

Hello,

My name is Neelam Merchant and I am a graduate student within the School of Public Health at the University of Alberta. I am working in Fort Portal over the next several months to learn more about the experiences of pregnancy and childbirth in your community. I am working towards understanding the related risks factors that contribute to maternal deaths (deaths during pregnancy and childbirth) in this particular culture and environment.

I am currently working towards recruiting participants in your particular community. I would greatly appreciate any assistance you can provide my research team.

If you have any questions or concerns at any point in the research, you may contact either myself (Neelam Merchant) at nmerchan@ualberta.ca and 0775141776, my supervisor, Dr. Zubia Mumtaz at zubiamumtaz@phs.med.ualberta.ca or Mr Tom Rubaale at the Health Department in Fort Portal at 0777912866.

Thank you very much for your assistance,

Neelam Merchant

Masters of Science Candidate

University of Alberta, School of Public Health

0775 141 776

Appendix F. Study Information Sheets for Participants

Title: Risk Perception and Decision-Making Related to Childbirth in Fort Portal, Western Uganda

Principle Investigator: Neelam Merchant, School of Public Health, University of Alberta, Canada. nmerchan@ualberta.ca Mobile: 0775141776
Supervisor: Dr. Zubia Mumtaz, School of Public health, University of Alberta, Canada. zubiamumtaz@phs.med.ualberta.ca

Information Letter for Women of Reproductive (age 18-49) and Older Women (age 50+)

UNIVERSITY OF ALBERTA

Hello,

My name is Neelam Merchant and I am a graduate student within the School of Public Health at the University of Alberta. I am working in Fort Portal to over the next several months to learn more about the process of pregnancy and childbirth in your community. By being involved in this project, you can share your experiences related to pregnancy and childbirth in your community and provide valuable information on the related risks factors that contribute to maternal deaths (deaths during pregnancy and childbirth) in this particular culture and environment.

Procedure: After being given some information, you will be asked if you are interested in participating in this study. You may choose to not participate and no questions regarding this decision will be asked. If you agree to participate, you will be involved in the following:

1. Talking with me and other research assistants about your recent experiences with pregnancy and childbirth. We will conduct an interview in whichever language you are most comfortable in (English or Rutooro) and can meet at a time and location that is convenient for you. The interview will require 1-2 hours of your time.
2. We may ask you if we can conduct further interviews to gather more information after analyzing the interview notes. This may require an additional 1-2 hours of your time.
3. We will ask you if you have any friends or contacts that you think would be interested in participating in this study. We will also ask you if you think your husband/partner would be interested in participating in a focus group discussion (a group discussion with other husbands/partners) on their thoughts on pregnancy and childbirth.
4. We would like to tape record and transcribe all interviews, however, if you are uncomfortable with this, we will only take written notes.

Benefits: By being involved in this study, you can help us better understand the experiences of pregnancy and childbirth as well as the associated risks in your community.

Risks: Sharing personal information about pregnancy and childbirth may make some people uncomfortable. During interviews, you may choose not to answer questions. Furthermore, you can choose to withdraw from the study at any time. We will keep all information confidential (private) and no personal information about you (names, contact information, etc…) will be released.

Confidentiality: We will keep your answers and information private through the following procedures:

1. Your name will be changed into a code that only myself, my research team and my supervisor in Canada will have access to.
2. You have the right to not answer any questions that you do not feel comfortable answering. Moreover, if you say something that you would like to be kept out of the study, you may tell us at any point and we will exclude it.

3. You can withdraw from the study at any point in time without any consequences and no explanation is needed.
4. The only people with access to the information that you provide will be my research team, my supervisor in Canada and myself.
5. We are required to keep all information for at least five years after the study is completed, therefore, we will keep everything in a locked cabinet in the office of Dr. Zubia Mumtaz, my supervisor, in the Department of Public Health Sciences at the University of Alberta in Canada.

The information gathered for this study may be looked at again for further questions and research projects. The research ethics board will review the use of this information to ensure that it is done ethically.

If you have any questions or concerns at any point in the research, you may contact either myself (Neelam Merchant) at nmerchan@ualberta.ca and 0775141776, my supervisor, Dr. Zubia Mumtaz at zubiamumtaz@phs.med.ualberta.ca or Mr Tom Rubaale at the Health Department in Fort Portal at 0777912866.

Title: Risk Perception and Decision-Making Related to Childbirth in Fort Portal, Western Uganda

Principle Investigator: Neelam Merchant, School of Public Health, University of Alberta, Canada. nmerchan@ualberta.ca Mobile: 0775141776
Supervisor: Dr. Zubia Mumtaz, School of Public health, University of Alberta, Canada. zubiamumtaz@phs.med.ualberta.ca

Information Letter for Husbands (focus group participants)

UNIVERSITY OF ALBERTA

Hello,

My name is Neelam Merchant and I am a graduate student within the School of Public Health at the University of Alberta. I am working in Fort Portal to over the next several months to learn more about the experiences of pregnancy and childbirth in your community. By being involved in this project, you can share your experiences related to pregnancy and childbirth within your family as well as in your community. The information provided will be valuable in understanding the related risks factors that contribute to maternal deaths (deaths during pregnancy and childbirth) in this particular culture and environment.

Procedure: After being given some information, you will be asked if you are interested in participating in this study. You may choose to not participate and no questions regarding this decision will be asked. If you agree to participate, you will be involved in the following:

1. Talking with me and other research assistants about your wife/partner's experiences with pregnancy and childbirth in a group setting with other men from your community. We will conduct the session in whichever language the group is most comfortable in (English or Rutooro) and we will meet at a central location.
2. We will ask for approximately 1.5 hours of your time for the focus group session.
3. We will ask you if you have any friends or contacts that you think would be interested in participating in this study as participants for focus groups or as participants for individual interviews.
4. We would like to tape record and transcribe all interviews, however, if you are uncomfortable with this, we will only take written notes.

Benefits: By being involved in this study, you can help us better understand the experiences of pregnancy and childbirth as well as the associated risks in your community from a male perspective.

Risks: Sharing personal information about pregnancy and childbirth may make some people uncomfortable. During discussions you may choose not to answer questions. Furthermore, you can choose to withdraw from the study at any time.

Confidentiality: We will keep your answers and information private through the following procedures:

1. Your name will be changed into a code that only myself, my research team and my supervisor in Canada will have access to.
2. You have the right to not answer any questions that you do not feel comfortable answering. Moreover, if you say something that you would like to be kept out of the study, you may tell us at any point and we will exclude it.
3. I will ask that all information revealed in group discussions remain confidential, however I cannot guarantee that other participants will keep information confidential.
4. You can withdraw from the study at any point in time without any consequences and no explanation is needed.

5. The only people with access to the information that you provide will be my research team, my supervisor in Canada and myself.
6. We are required to keep all information for at least five years after the study is completed, therefore, we will keep everything in a locked cabinet in the office of Dr. Zubia Mumtaz, my supervisor, in the Department of Public Health Sciences at the University of Alberta in Canada.

The information gathered for this study may be looked at again for further questions and research projects. The research ethics board will review the use of this information to ensure that it is done ethically.

If you have any questions or concerns at any point in the research, you may contact either myself (Neelam Merchant) at nmerchan@ualberta.ca and 0775141776, my supervisor, Dr. Zubia Mumtaz at zubiamumtaz@phs.med.ualberta.ca or Mr Tom Rubaale at the Health Department in Fort Portal at 0777912866.

Title: Risk Perception and Decision-Making Related to Childbirth in Fort Portal, Western Uganda

Principle Investigator: Neelam Merchant, School of Public Health, University of Alberta, Canada. nmerchan@ualberta.ca Mobile: 0775141776
Supervisor: Dr. Zubia Mumtaz, School of Public health, University of Alberta, Canada. zubiamumtaz@phs.med.ualberta.ca

Information Letter for Formal and Informal Health Care Providers

UNIVERSITY OF ALBERTA

Hello,

My name is Neelam Merchant and I am a graduate student within the School of Public Health at the University of Alberta. I am working in Fort Portal to over the next several months to learn more about the experiences of pregnancy and childbirth in your community. By being involved in this project, you can share your experiences related to pregnancy and childbirth within the community from a medical and community health perspective. The information provided will be valuable in understanding the related risks factors that contribute to maternal deaths (deaths during pregnancy and childbirth) in this particular culture and environment.

Procedure: After being given some information, you will be asked if you are interested in participating in this study. You may choose to not participate and no questions regarding this decision will be asked. If you agree to participate, you will be involved in the following:

1. Talking with me and other research assistants about your recent experiences with pregnancy and childbirth. We will conduct an interview in whichever language you are most comfortable in (English or Rutooro) and can meet at a time and location that is convenient for you. As a healthcare worker, you may have a very busy schedule; we will try our best to work around your schedule. Interviews will be limited to 20-30 minutes.
2. We may ask you if we can conduct further interviews to gather more information after analyzing the interview notes. This may require an additional 20-30 minutes of your time.
3. We may also ask you if we can observe the maternal health clinics that you may work in or observe your interaction with pregnant women. During observations, we will not acquire any personal information about patients or women /families that you work with.
4. We will ask you if you have any friends or contacts that you think would be interested in participating in this study.
5. We would like to tape record and transcribe all interviews, however, if you are uncomfortable with this, we will only take written notes.

Benefits: By being involved in this study, you can help us better understand the experiences of pregnancy and childbirth as well as the associated risks in your community from a male perspective.

Risks: Sharing personal information about pregnancy and childbirth may make some people uncomfortable. During discussions you may choose not to answer questions. Furthermore, you can choose to withdraw from the study at any time. We will maintain confidentiality with all information that is shared and observed.

Confidentiality: We will keep your answers and information private through the following procedures:

1. Your name will be changed into a code that only myself, my research team and my supervisor in Canada will have access to.

2. You have the right to not answer any questions that you do not feel comfortable answering. Moreover, if you say something that you would like to be kept out of the study, you may tell us at any point and we will exclude it.
3. You can withdraw from the study at any point in time without any consequences and no explanation is needed.
4. The only people with access to the information that you provide will be my research team, my supervisor in Canada and myself.
5. We are required to keep all information for at least five years after the study is completed, therefore, we will keep everything in a locked cabinet in the office of Dr. Zubia Mumtaz, my supervisor, in the Department of Public Health Sciences at the University of Alberta in Canada.

The information gathered for this study may be looked at again for further questions and research projects. The research ethics board will review the use of this information to ensure that it is done ethically.

If you have any questions or concerns at any point in the research, you may contact either myself (Neelam Merchant) at nmerchan@ualberta.ca and 0775141776, my supervisor, Dr. Zubia Mumtaz at zubiamumtaz@phs.med.ualberta.ca or Mr Tom Rubaale at the Health Department in Fort Portal at 0777912866.

Appendix G. Consent Form for Participants

UNIVERSITY OF ALBERTA

Title: Risk Perception and Decision-Making Related to Childbirth in Kabarole District, Western Uganda

Principle Investigator: Neelam Merchant, School of Public Health, University of Alberta, Canada.
nmerchan@ualberta.ca Mobile: 0775141776
Supervisor: Dr. Zubia Mumtaz, School of Public health, University of Alberta, Canada.
zubiamumtaz@phs.med.ualberta.ca

Consent of Participant

Please circle YES or No for the following questions:

Do you understand that you have been asked to participate in a research study involving interviews?	YES	NO
Have you read and received a copy of the attached information sheet?	YES	NO
Do you understand the benefits and risks involved in taking part in this study?	YES	NO
Have you had adequate opportunity to ask questions and discuss the study and your participation?	YES	NO
Do you understand that you are free to withdraw from the study at any time, without having to give a reason and without facing any consequences?	YES	NO
Has the issue of confidentiality been explained to you?	YES	NO
Do you understand who will have access to the information you provide?	YES	NO
Do you agree to participate in this study?	YES	NO

This study was explained to be by: _____

Participant Name (print): _____

Signature or thumbprint of participant: _____

Date/Time: _____

Witness (print name): _____

Witness Signature or thumbprint: _____

Date/Time: _____

I believe that the person signing this form understands what is involved in this study and voluntarily agrees to participate.

Signature of investigator or designee: _____

Date/Time of consent: _____

Appendix H.

Research Assistant/Transcriber Confidentiality Agreement

This study is being undertaken by Neelam Merchant through the School of Public Health, University of Alberta. The purpose of the project is to assess risk perception during pregnancy and the subsequent impact of such understandings on decisions regarding childbirth in Western Uganda. Data from this research may be used to create modifications and improvements to maternal health practices in Uganda. The results may be written up for publication in academic journals, conference presentations and reports to policymakers in Uganda.

Project Title: Risk Perception and Decision-Making Related to Childbirth in Kabarole District, Western Uganda

I, _____ , the *Research Assistant/Transcriber*, agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing research information in any form or format (e.g. disks, tapes, transcripts) with anyone other then the research team.
2. Keep all research information in any form or format (e.g. disks, tapes, transcripts) secure in my possession
3. Return all research information in any form or format (e.g. disks, tapes, transcripts) to the principle investigator when I have completed the research tasks
4. After consulting with the researcher/research team, erase or destroy all research information in any for or format regarding this research project that is not returnable to the researcher/research team (e.g. information stored on computer hard drive).

Research Assistant/Transcriber

_____ _____ _____
(print name) (signature) (date/time)

Principle Researcher/Investigator

_____ _____ _____
(print name) (signature) (date/time)

If you have any questions or concerns about this study, please contact:
Neelam Merchant
School of Public Health, University of Alberta, Canada
nmerchan@ualberta.ca
+256 775 141 776

Appendix I. University of Alberta Ethical Clearance

APPROVAL FORM

Date: July 6, 2009

Principal Investigator:	Zubia Mumtaz
Study ID:	Pro00007579
Study Title:	Risk perceptions and decision-making related to childbirth in Fort Portal, Kabarole district, Uganda: A focused ethnography
Sponsor/Funding Agency:	6/2/09 6/2/09 ID00000448 Department of Public Health Sciences, School of Public Health

Expiration Date: July 5, 2010

Thank you for submitting the above study to the Health Research Ethics Board (Health Panel). Your application, along with revisions submitted July 3, 2009, has been reviewed and approved on behalf of the committee.

The ethics approval is valid until July 5, 2010. A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Capital Health or other local health care institutions for the purposes of the research. Enquiries regarding Capital Health administrative approval, and operational approval for areas impacted by the research, should be directed to the Capital Health Regional Research Administration office, #1800 College Plaza, phone (780) 407-1372.

Sincerely,

Glenn Griener, Ph.D.
Chair, Health Research Ethics Board (Health Panel)

Note: This correspondence includes an electronic signature (validation and approval via an online system).

Appendix J. Ugandan Ethics Approval

Uganda National Council For Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

UNCST

Your Ref:.....

Our Ref:.....SS 2276 *Date:*.....15/01/2010...

Ms. Neelam Merchant
Kabarole District Health Department
P.O Box 38
Fort Portal

Dear Ms. Merchant,

RE: RESEARCH PROJECT, "RISK PERCEPTION AND DECISION-MAKING RELATED TO CHILDBIRTH IN KABAROLE DISTRICT, WESTERN UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **February 09, 2010.** The approval will expire on **July 09, 2010.** If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,

Leah Nawegulo
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Appendix K. Antenatal Care Package

1) Screening for HIV and STIs

2) Health education (prophylaxis and prevention of malaria, HIV and STIs, family planning, danger signs of pregnancy, infant feeding, preparation for delivery*, immunization, signs of labor, birth plan*, hygiene and sanitation, diet and nutrition during pregnancy)

3) Preparation for delivery*

4) Birth plan *

5) Physical exam (palpation)

6) Interventions and prophylaxis (tetanus immunization, malaria prophylaxis, folic acid, ferrous sulfate, fansidar, dewormer; antibiotics and pain killers as needed)

* See appendix M.

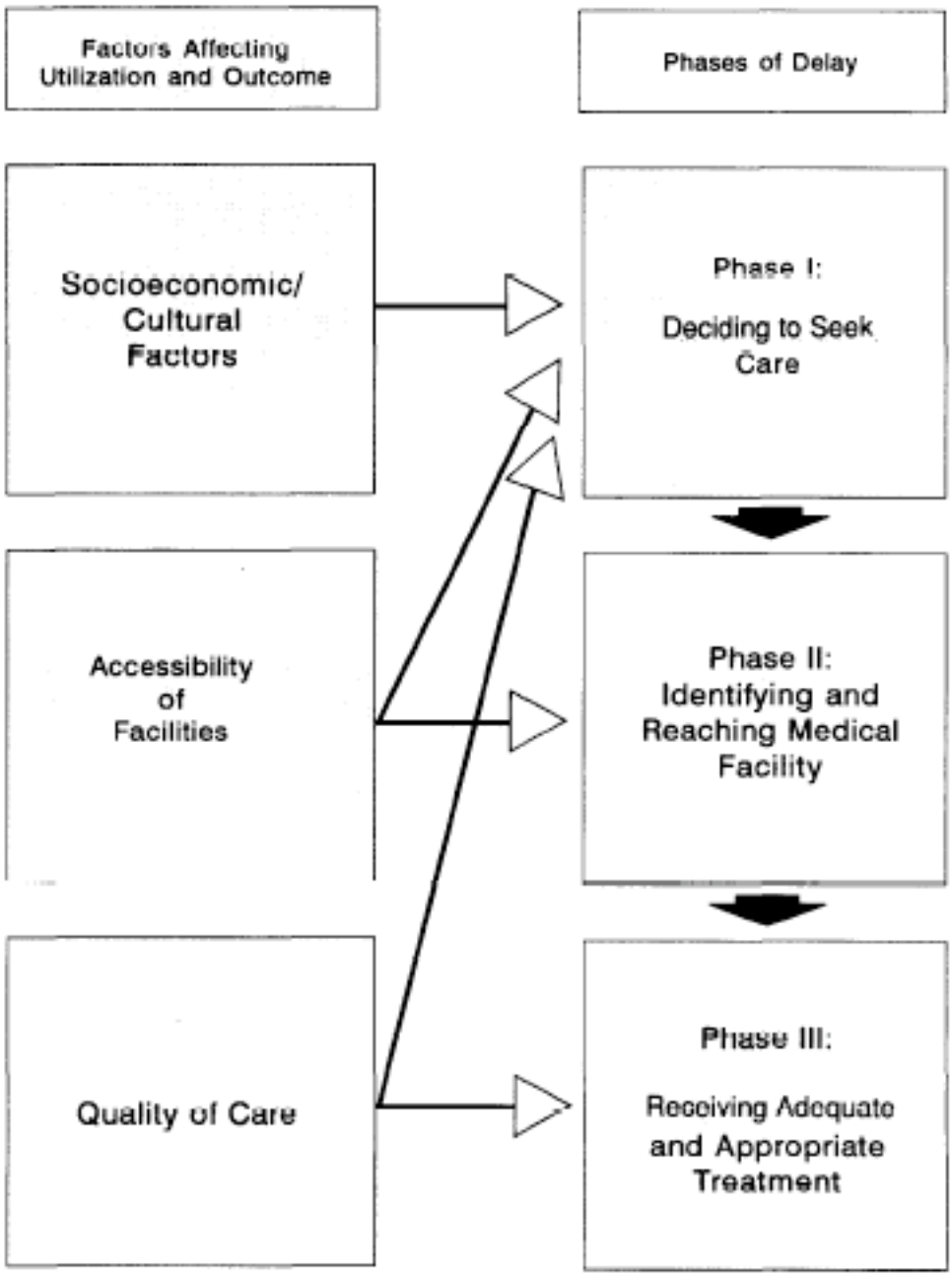
Appendix L. Herbs taken during pregnancy

Cleanses the baby inside the Womb
Rukunya
Wankura
Omweya
Prevents bleeding during pregnancy and after delivery
Omugina
Ekiragi
Enybarasana
Canya
Akejwiso
Facilitates (speeds up) labor
Ekigaragara
Omuhanga
Enculiko
Black Tea
Ekizimyamurro
Softens bones of the uterus/softens walls of the vagina
Kumenya
Wankura
Leaves from sweet potatoes
Cures Headache due to *obuzaire*
Ekitokotoko
Ehohwa

Appendix M. Birth Plan

- Demographics – name, where you live, etc…
- Health facility where you plan to deliver
- Who will accompany you?
- What means of transport will you use to get there?
- Who will be at home to look after your children while you are gone?
- Who will stay with you during labor?
- How do you want to dispose of the placenta?
- How do you plan to delay the next pregnancy?
- Supplies to take:
    - 4 pairs of gloves
    - Plastic sheet
    - Cotton wool
    - Gauze
    - Razor blade
    - Soap
    - Sanitary towels
    - Baby clothing
    - Sugar and tea leaves
    - Money for emergency transport
    - Clean clothes

Appendix N. The three delays model



Thaddeus S & Maine D. (1994). Too far to walk: maternal mortality in context. *Social Science & Medicine*: 38(8) p. 1093.