

AN ABSTRACT OF THE THESIS OF

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Melissa J. Cheyney

In Uganda, there are an estimated 200,000 women suffering from obstetric fistula, with 1,900 new cases expected annually. These figures, combined with a persistently high maternal mortality rate, have led to an international discourse that claims the solution to improving maternal health outcomes is facility-based delivery with a skilled birth attendant. In accord with this discourse, the Ugandan government criminalized traditional birth attendants in 2010. In this study, I examine the lived experience of traditional birth attendants and women who have suffered from an obstetric fistula in eastern Uganda. Using data collected from open-ended, semi-structured interviews, focus groups, and participant-observation, I describe the biocultural determinants of obstetric fistula. Based on findings, I argue that although emergency obstetric care is critical to prevent obstetric fistula in cases of obstructed labor, the criminalization of the locally constructed system of care, TBAs, serves as yet another layer of structural violence in the lives of rural, poor women. Results demonstrate how political-economic and cultural determinants of obstetric fistula are minimized in favor of a Western prescribed, bio-medical solution,

which is heavily resource dependent. This solution is promoted through a political economy of hope fueled by the obstetric imaginary, or the enthusiastic belief in Western-style biomedical obstetric care's ability to deliver positive health outcomes for women and infants regardless of local context and constraints. Recommendations include increased obstetric fistula treatment facilities with improved communication from medical staff, decriminalization of traditional birth attendants and renewed training programs, and engaging local populations in maternal health discourse to ensure culturally competent programs.

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Shattered Lives: Understanding Obstetric Fistula in Uganda

by  
Bonnie J. Ruder

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APPROVED:

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Major Professor, representing Applied Anthropology

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Director of the School of Language, Culture, and Society

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Dean of the Graduate School

I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

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Bonnie J. Ruder, Author

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# Shattered Lives: Understanding Obstetric Fistula in Uganda

## Chapter 1: Introduction

*After our morning rounds, I was invited into the doctor's room to observe antenatal care with Dr. Chipeta<sup>1</sup>, the head obstetrician, and Winnie, a resident currently on the maternity ward. Around mid-day, we took a short break and began discussing medical school and doctor's pay when the conversation turned to traditional birth attendants (TBAs). I told them I'm doing a study with local TBAs and with women who have suffered from obstetric fistula. Dr. Chipeta said he doesn't think TBAs should be trained because then women will keep using them. "We just need to be done with them". If the TBAs aren't there, he explained, then all the women will come to the clinics or hospitals for delivery. I pointed out all the other obstacles women face -- poverty, lack of transportation, and especially the overcrowding at the hospitals. It was just 12:30 in the afternoon and all the maternity ward beds were full. Already women were lying on mats on the floor just outside his door. Dr. Chipeta agreed with my points, yet this didn't seem to change his mind on TBAs.*

*I asked Winnie her opinion. She said she didn't really know about obstetric fistula, but she thinks the TBAs could still be of some use: "I think training might still be helpful in the meantime, until things improve at the hospitals." I asked her if she thought she would go on and train as an obstetrician. She said probably not. It's three more years of school and the pay is so little. In fact, none of the residents I talked to were planning to specialize in obstetrics.*

*(Field notes, hospital maternity ward, Soroti, Uganda, December 2011)*

In Uganda, a persistently high maternal mortality rate, combined with one of the highest obstetric fistula rates in the world (Murk 2009), has led to the adoption of an international discourse that constructs institutional births with skilled birth attendants as imperative to improving maternal health. Dr. Chipeta's comments illustrate how this discourse has permeated local, reproductive health fields despite tangible evidence of the difficulties associated with implementing this heavily resource dependent system. This maternal health discourse around the superiority of institutional deliveries originates in the global north and is based on a biomedical, technocratic model of birth. Adoption of U.S.-style, biomedical models of obstetric care, that are imported and often uncritically embraced by those least able to implement them, has contributed to the rejection of

locally constructed systems of care, that are dependent on community-based traditional birth attendants (TBAs). This rejection culminated in the criminalization TBAs in 2010 by the Ugandan government. The purpose of this project was to conduct ethnographic research among obstetric fistula survivors and traditional birth attendants in Soroti, Uganda in order to identify and describe emic perspectives on the causation, treatment and prevention of this devastating birth injury. Specifically, I aimed to answer three questions: how do obstetric fistula survivors and traditional birth attendants describe and understand the barriers to receiving maternal health care? What do they perceive are the risk factors for developing an obstetric fistula? And third, what barriers do fistula survivors face in attempting to access treatment for their fistula? Using data collected from interviews, focus groups and participant observation, I identify central overlaps and discordances between internationally derived discourses on obstetric fistula and the lived experiences of those most directly affected by them. Keys to improving maternal and infant health in this area of the world, I argue, lie in the mitigation or resolution of these discordances.

Currently, the majority of the literature on obstetric fistula is focused on clinical aspects of the injury -- how they are formed and how they can be repaired, for example. A better understanding of how women and their birth attendants experience obstetric fistula and maternal health care is a vital, yet under-examined, piece of the puzzle needed to reduce rates of related mortality and morbidity, in Uganda and in other low-income nations. Utilizing an integrated biocultural perspective, I draw on ethnographic evidence from open-ended, semi-structured interviews to describe how privileging Western-prescribed, biomedical solutions to improving maternal health outcomes minimizes the

structural barriers women seeking care must endure and does not succeed in meeting immediate, reproductive health care needs. Reliance on imported practices and biotechnologies in the birthplace have failed Ugandan women, while simultaneously criminalizing their culturally embedded system of birth attendants. Furthermore, while U.S-style biomedical strategies have been embraced by governing bodies worldwide, the ability of these models to deliver in resource poor settings is not based on evidence, but rather on an obstetric imaginary (Cheyney 2012) marketed in a political economy of hope (Good 2010).

## ***Background***

### Maternal Mortality and Obstetric Fistula in Uganda

Maternal mortality claims 358,000 lives per year worldwide, and nowhere is the problem more profound than in resource-poor countries (WHO 2010b). The reduction of maternal mortality has been a major international health goal since 1990, and for the first time, global maternal deaths appear to be on the decline -- from 500,000 deaths in 1990 to 358,000 in 2008 (WHO 2010b). However, much of this decline has been in the global north, while little progress has been made in the poorest regions of the world. In sub-Saharan Africa, for example, there has been very little improvement (Hill, et al. 2007), despite the fact that this region accounts for the majority of maternal deaths worldwide (WHO 2010b), as well as the highest rates of obstetric fistula (Lewis and De Bernis 2006).

An obstetric fistula is a traumatic birth injury that leaves a woman incontinent of urine and/or feces. Caused by prolonged, obstructed labor and delayed intervention,

obstetric fistulas are both treatable and preventable, and therefore, rarely seen in high-income nations. The suffering of obstetric fistula survivors is horrific and chronic. Their prevalence is a clear indication that reproductive healthcare systems are failing to meet the needs of childbearing women. In Uganda, approximately 200,000 women currently suffer from an obstetric fistula, with an additional 1,900 new cases annually (UBOS 2007). Yet, to date, there is no dedicated fistula hospital and a severe shortage of trained fistula surgeons in the country (Hancock and Collie 2004).

In 2010, the United Nations Development Program (UNDP) and the Ugandan government convened a special study to assess the nation's progress towards the Millennium Development Goals (MDG). Findings showed insufficient progress towards reaching MDG 5 -- the improvement of maternal health. Though the maternal mortality rate has declined slightly, from 505/100,000 in 2000 to 435/100,000 in 2008, Uganda is unlikely to meet its target goal of 131/100,000 by 2015 (Madsen 2010). These figures prompted the government of Uganda to publicly declare its commitment to maternal health -- a commitment that consisted of a policy to ban traditional birth attendants (TBAs) from attending births and the recommendation that every mother deliver in a health facility with a skilled birth attendant. An unfunded mandate, increasing institutional deliveries is currently promoted as *the* solution to Uganda's maternal health crisis.

Critics have articulated the shortcomings of this solution (Ana 2011; Prata, et al. 2011; Walraven and Weeks 1999). In many resource poor countries, and especially in remote, rural areas of these countries, access to health facilities and skilled birth attendants is limited. TBAs are often their only option for women in these areas and

researchers have argued that it is unethical to exclude TBAs from the struggle to improve maternal mortality (Ana 2011). Similarly, Prata and colleagues (2011) contend that, due to the stark disparities between urban and rural health facilities, focusing on skilled birth attendants and emergency obstetric care is unlikely to have much affect on women living in remote communities. Uganda is not alone in this approach, however. In 2007, the Malawian government banned TBAs, only to reverse its decision in 2010 based on evidence that the felonious TBAs were still being utilized; the ban had only driven them underground (IRIN 2010). Even the World Health Organization (WHO), whose official stance advocates for skilled birth attendants at every delivery, warns against the banning of TBAs outright as potentially dangerous (Ana 2011).

In Uganda, the availability and utilization of both skilled birth attendants (SBAs) and emergency obstetric care is a major concern, and there is generally agreement that these would improve maternal health. However, currently, Uganda has only one doctor and thirteen nurses/midwives per 10,000 people, compared to 24 doctors and 98 nurses/midwives per 10,000 people in the U.S. (WHO 2012). Adding strain to this system, Uganda has one of the highest population growth rates in the world, 3.2 percent, and a total fertility rate of 6.7 births per woman (POPSEC 2011). Like most low-income nations, Uganda's health facilities, skilled health professionals, and emergency obstetric care are most concentrated in urban areas, yet Uganda is one of the least urbanized countries in Africa with approximately 87 percent of its 30 million people living in rural communities (WHO 2010a). The magnitude of human, financial and structural resources needed to implement a nationwide system of skilled attendance at every delivery and emergency obstetric care is currently inconceivable in Uganda.

Though the Ugandan government makes a concerted effort to appear supportive of maternal and infant health reform, concrete evidence of tangible support is lacking. A large discrepancy exists between the government's reported budget for maternal health and actual disbursement, illuminating the discord between rhetoric and reality (Madsen 2010). Weak investment in rural health services has resulted in dire maternity care shortages, with long distances between health facilities that are understaffed and often lack essential drugs, supplies, and basic necessities including gloves and electricity. Although user fees were abolished from Ugandan hospitals in 2001, unofficial demands for remuneration by midwives and nurses are common (McPake, et al. 1999). Overall, the number of women who have skilled attendants with them at the time of delivery is low and has actually declined in recent years, from 40 percent in 2008 to 33 percent in 2010 (POPSEC 2011). The majority of Ugandan women deliver at home, with the help of family members or traditional birth attendants, with very little access to quality emergency obstetric care when needed (UBOS 2007).

### **Historical Overview: Traditional Birth Attendants**

The WHO organization defines a traditional birth attendant as, "a person who assists the mother during childbirth and who initially acquired her skills by delivering babies herself or through apprenticeship to other TBAs" (WHO 1992:4). For decades development agencies like the WHO and other United Nations agencies promoted the training of traditional birth attendants as a global health strategy to reduce maternal mortality (Allen 2002; Maglacas and Simons 1986; Sibley and Sipe 2006). In 1987, major development agencies including WHO, UNFPA, UNICEF, The World Bank, the

International Planned Parenthood Federation, and the Population Council sponsored the Safe Motherhood Conference in Nairobi, Kenya. The result of this conference, the Safe Motherhood Initiative, highlighted training of TBAs as central players in maternity care reform. According to WHO:

Traditional birth attendants are often the first (if not only) health care workers with whom pregnant women in poor countries have contact. Therefore, it is essential that they be made as effective as possible through training, supervision and support. (1986:181)

The Safe Motherhood Initiative set the goal to reduce maternal mortality rates by 50 percent by the year 2000. Thus, the initial, stated aims of TBA training programs were to improve antenatal and intrapartum care -- especially through the reduction in sepsis via instruction in sterile and clean technique -- and to reduce hemorrhage rates with informed third stage (delivery of the placenta) management. TBAs were to be educated about prenatal and intrapartum complications, as well as processes for appropriate referral (Kruske and Barclay 2004).

Nearly ten years later, maternal mortality rates in the poorest regions of the world had not improved. In fact, due to improvements in data measurement, new figures actually showed a rise in maternal deaths (WHO 1999). Development policy makers concluded that traditional birth attendants, due to low literacy rates and traditional beliefs, were part of the problem. The WHO declared:

In many countries, TBAs have received training in order to promote safer birth practices, including clean delivery and avoidance of harmful practices. However, to fulfill all the requirements for management of normal pregnancies and births and for identification and management or referral of complications, the education, training, and skills of TBAs are insufficient. Their background may also mean that their

practices are conditioned by strong cultural and traditional norms, which may also impede the effectiveness of their training. (1999:31)

In 1996, the Safe Motherhood Initiative changed their strategy and called for “skilled birth attendants” to be present at every birth. A skilled birth attendant (SBA) is defined as “people with midwifery skills (for example, doctors, midwives, nurses) who have been trained to proficiency in the skills necessary to manage normal deliveries and refer obstetric complications” (WHO 1999).

The shifting policies of the WHO and development agencies meant traditional birth attendants were left out of maternity care strategies, and donor funds for trainings quickly evaporated (Kruske and Barclay 2004; Walraven and Weeks 1999). Support was realigned towards skilled birth attendants and access to emergency obstetric care. Traditional birth attendants were seen as useful only in terms of referral to skilled birth attendants, rather than as care providers themselves.

Upon closer examination, many issues have been raised that call into question the logic behind criminalizing or prohibiting TBAs from attending deliveries. Sibley and Sipe (2006), reviewed TBA training programs and found discrepancies in length of training, (with some lasting just a few days, while others lasted several weeks), the quality of the training and the training objectives. Denise Allen Roth (2002) found “failed” training programs in Tanzania fraught with inconsistencies, including the training participants who had no previous experience as a TBA. Training programs were also found to lack cultural and local appropriateness (Kruske and Barclay 2004), to privilege biomedical knowledge rather than the mutual accommodation of ‘traditional’

knowledge (Saravanan, et al. 2011), and to utilize didactic training rather than experiential learning methods (Jordan 1993).

In addition to TBA training programs, the effectiveness of TBAs has also been examined. Sibley and Sipe (2004) found TBA training was associated with substantial improvement in knowledge, attitudes, and behavior that resulted in eight percent fewer deaths among women living in areas served by trained TBAs. In another analysis, trained TBAs demonstrated competency in referral of high-risk pregnancy (Jokhio, et al. 2005; Sibley and Sipe 2006) and were associated with increases in antenatal care use (Sibley and Sipe 2006). Specifically in Uganda, two studies found that TBAs were able to identify and refer high-risk women (Chalo, et al. 2005; Keri, et al. 2010), though there was rarely anyone to refer them to. Furthermore, several studies have found that training TBAs resulted in decreased perinatal and maternal mortality rates (Jokhio and Kelly 2006; Jokhio, et al. 2005; Sibley and Ann Sipe 2004; Sibley and Sipe 2006) along with reduced neonatal mortality (Darmstadt, et al. 2009; Gill, et al. 2011; Sibley and Ann Sipe 2004; Sibley and Sipe 2006; Wall 2009).

Extending beyond the debate on TBAs' effectiveness, a number of studies contend that even when SBAs are available, women continue to utilize TBAs (Keri, et al. 2010; Kruske and Barclay 2004; Titaley, et al. 2010). The cultural and social roles that TBAs play in a community, along with explanatory factors such as cost, convenience, familiarity, and kindness, along with the negative perceptions birthing women may hold of health facilities, are credited for women's continual preference for TBAs (Izugbara, et al. 2009; Keri, et al. 2010; Kruske and Barclay 2004).

However, even supporters of TBA inclusion in maternal health programs recognize that skilled birth attendants and access to emergency obstetric care is a desired longer-term goal to improve maternal health outcomes. Nevertheless, they contend that this strategy alone does not address the immediate needs of the world's most vulnerable women (Costello, et al. 2006; Kruske and Barclay 2004; Lawn, et al. 2006). In remote, impoverished settings, a TBA may be a woman's only choice of care provider, and due to scarce resources, this is unlikely to change in the near future (Lawn, et al. 2006; Prata, et al. 2011). Noting TBAs continued cultural value, many are now calling for greater cooperation between TBAs and SBAs, a phased approach of moving towards SBAs, and continued, improved TBA trainings (Ana 2011; Chandy, et al. 2007; Darmstadt, et al. 2009; Falle, et al. 2009; Keri, et al. 2010; Kruske and Barclay 2004; Lawn, et al. 2006; Prata, et al. 2011; Saravanan, et al. 2011; Sibley and Sipe 2006; Thatte, et al. 2009). Despite these calls, the debate over the value and the role of TBAs in improving maternal mortality is ongoing (Ana 2011; Harrison 2011), and the international discourse continues to stress skilled birth attendants and improved emergency obstetric care as the way forward (Filippi, et al. 2006).

### **Research Site: Soroti, Uganda**

In order to conduct this study, I worked with a Uganda-based NGO, The Association for the Re-orientation and Rehabilitation of Women for Development (TERREWODE), which is located in Soroti, the district capital for the Teso region in eastern Uganda. Founded in 2001, TERREWODE's mission is to address the deteriorating state of reproductive health of women and girls, and to find treatment,

prevention, and rehabilitation services for victims of obstetric fistula. TERREWODE is the only Ugandan NGO working on a national level to eliminate obstetric fistula, partnering with local government, women's groups, and community volunteers.

TERREWODE's well-established relationship with fistula survivors and staff at the local hospital created an entry point for this study as did my own training as a midwife in the United States.

Located in eastern Uganda, the town of Soroti serves as the administrative center for the district, which is one of the most impoverished in the country. Fifty three percent of the population survives on less than US\$1 per day (UBOS 2007). While most of Uganda has experienced relative peace since the mid-1980's, Soroti and the surrounding area has been devastated by repeated political insurgencies that have wreaked havoc on infrastructure and development efforts. Today, peace has been restored to the area and Soroti is experiencing a revitalization, though poverty, drought, lack of infrastructure, and poor quality medical services continue to plague the region. Soroti town and district is served by one regional hospital, one private hospital, three health centers, and twelve sub-dispensaries. The regional hospital has 250 beds and serves as the referral hospital for the surrounding six districts, though the peripheral health facilities lack ambulances or telephones necessary for referral (Kaye 2009). The regional referral hospital is the only hospital in eastern Uganda to offer emergency obstetric care and fistula repair, and thus was an ideal site for participant observation for this study.

This study combines qualitative, in-depth interviews with obstetric fistula survivors (Phase I) and TBAs (Phase II), reciprocal ethnography through focus groups with both fistula survivors and TBAs (Phase III), and participant observation with

TERREWODE and in the maternity ward of the local hospital. In the chapter that follows, I discuss relevant literature on obstetric fistula in order to contextualize this study. In Chapter Three, I present the methodological framework and analytical tools I used in this study, and in Chapter Four and Five, I present my key findings, using a case studies approach to illuminate the women behind the numbers. I triangulate fistula survivors' experiences with the narratives shared by traditional birth attendants, as well as my own experiences and participant observation. This approach allows fistula survivors the space to share their stories, and thus, to "give voice" to their lived experiences (Inhorn 2006), while placing survivors within a larger cultural and clinical context. In Chapter Six, I discuss the relevance and significance of these findings, and present recommendations and conclusions in the final chapter.

<sup>1</sup> In order to protect the anonymity and confidentiality of study participants, all names are pseudonyms.

## Chapter 2: Literature Review

In order to provide the necessary background to contextualize this study and to identify the gaps in the literature that this study will help fill, I provide a brief overview of the literature. I utilize an integrated biocultural perspective (Goodman and Leatherman 1998) to explore the complex connections between biological, political-economic and cultural determinants of obstetric fistula. I begin by examining biological and clinical perspectives on obstetric fistula that include the epidemiology, evolutionary predictors, and treatment options. Next I synthesize the literature on the political-economic determinants of obstetric fistula, including the structural barriers to obtaining maternity care, malnutrition, and early marriage and childbearing. Finally, I review the body of research on the cultural/ideological determinants of this birth injury along with the lived experiences of fistula survivors. Several of the determinants overlap considerably and cannot be neatly divided between the biological, political-economic, and cultural categories -- a fact that, in itself, reinforces obstetric fistula as a profoundly biocultural phenomenon resulting from a complexity of intersecting determinants. I argue that the current literature has privileged biological and clinical perspectives on obstetric fistula over women's embodied experiences, and has thus, missed the opportunity to identify sustainable, holistic, and integrated solutions.

### **Obstetric Fistula: Epidemiology, Evolutionary Predictors, and Treatment**

Obstetric fistulas are most often caused by a long, obstructed labor, due to either cephalo-pelvic disproportion or fetal malpresentation. The continuous pressure of the fetal head on the bladder or rectum tissues against the pelvic rim causes ischemia, or

diminished blood supply. Eventually the tissue becomes necrotic and sloughs off, leaving a small hole, or fistula, between the woman's vaginal walls and the bladder and/or the rectum. The result is a near constant leakage of urine or feces. Fistulas between the vagina and bladder (vesico-vaginal fistula, VVF) are the most common. Fistulas can also develop between the vagina and rectum (recto-vaginal fistula, RVF), which results in fecal incontinence. In the majority of the cases, the fetus dies of asphyxia (Ahmed and Holtz 2007; Creanga, et al. 2007).

Incontinence is not the only consequence of an obstetric fistula. The pressure exerted by the fetal head can result in a massive field of damaged tissue. The related multisystem injuries are described by Arrowsmith et al. as the "obstructed labor injury complex" (1996:568), and include stress incontinence, renal failure, amenorrhea, infertility, foot-drop from lumbosacral or common peroneal nerve injury, and chronic excoriation of the skin from maceration by urine or feces.

Numerous studies have examined the risk factors that are associated with obstetric fistula (Lewis Wall, et al. 2004; Tebeu, et al. 2011; Wall 2006). Specifically, nulliparity, early childbearing and adolescent motherhood, short stature, and prolonged labor have all demonstrated an increased risk for obstetric fistula (Muleta, et al. 2007; Tebeu, et al. 2011). Other studies complicate these results by concluding that obstetric fistula can also occur in older, multiparous women (Bangser 2007; Bangser, et al. 2011; Kalilani-Phiri, et al. 2010; Tsui, et al. 2007). As Wall (2012) argues, it is extremely difficult to predict the risk of obstructed labor for any individual pregnancy: despite years of research, there is no consensus on how to identify which women will experience cephalo-pelvic disproportion during labor.

It is estimated that three million women worldwide suffer from an unrepaired obstetric fistula (Wall 2006) and almost all of them live in low-income nations in Africa and South Asia (Bangser 2007). The exact prevalence is hard to estimate due to poorly developed or nonexistent tracking systems in rural communities, as well as to associated social stigma (Bangser 2006; Browning 2004; Velez, et al. 2007). This staggering number of sufferers is compounded by the approximately 50,000 to 100,000 new fistula cases that develop each year (Lewis and De Bernis 2006).

Obstructed labor is a result of what Washburn (1960) described as the human “obstetrical dilemma”. This dilemma refers to the difficulty humans experience in childbirth due to two competing selective pressures that make birth uniquely challenging for human females -- upright walking, or bipedal locomotion, and encephalization, or progressively larger brain size. The fossil record indicates that bipedalism predates encephalization for human ancestors, and likely began 4.4 million years ago during the time of the *Ardipithecus ramidus* (Lovejoy 2009). Bipedalism required major skeletal changes to support the body weight and to maintain balance in an upright position. These changes resulted in a complex pelvic structure with a narrow front-to-back inlet, a twisted midpelvis, and a narrow side-to-side outlet (Trevathan 1997). While our closest primate relatives have ample pelvic room to accommodate the infant at birth, the human fetus must navigate a complex sequence of rotations, called the “mechanisms of labor”, through the changing diameters of the pelvis (Cheyney 2010). These mechanisms allow the largest diameter of the fetal head to align with the largest diameter of the maternal pelvis (Cheyney 2010).

Increasing brain size began about 1.8 million years ago with the *Homo erectus* creating an even tighter fit between the fetal head and the maternal pelvis. To compensate for this increasingly tight fit, secondary altriciality developed. This adaptation results in infants born with relatively small brains compared to their adult size, requiring that infant brains continue to grow at a rapid pace after delivery. The trade-off for this altriciality, or the tendency towards immaturity at birth relative to adult status, means that human infants are born helpless and require continuous and more intensive parental support as compared to their mammal relatives (Trevathan 1997). Without this adaptive feature of extra-uterine development, human infants could not pass through the maternal pelvis. However, while human birth may accurately be described as difficult, the effectiveness of our evolutionary adaptive features is evidenced by the demographic success of humans around the world.

### Treatment

The majority of obstetric fistulas can be successfully treated with surgical closure. In their literature review, Ahmed and Holtz (2007) found successful rates of repair, defined as closure of the fistula at two weeks post surgery, in 85 to 90 percent of women. Treatment is most successful when women receive immediate medical attention; small fistulas (<2 cm in diameter) may even heal spontaneously following decompression of an overextended bladder and the prompt insertion of an indwelling catheter, which gives the bladder time to heal (Waldijk 1994; Wall 2012). Most women who have undergone a successful surgical repair will remain continent, however some will experience ongoing stress incontinence, urge incontinence, and urinary urgency and frequency (Ahmed and

Holtz 2007; Wall, et al. 2008). A minority of obstetric fistula survivors will have such extensive tissue damage that the fistulas are irreparable or require complicated urinary diversions that transplant the ureters into the colon (Wall, et al. 2008).

These studies make important contributions to our understanding of clinical success rates; however it is important to contextualize biomedical understandings of obstetric fistulas repair and prevention against an ethnographic backdrop that integrates political-economy and socio-cultural determinants. For as Wall elucidated in the “Obstetric Fistula Pathway” (2006), this devastating morbidity is caused by a complex combination of the socio-economic and biological factors. In the following section, I review the body of literature that examines to the role of political-economic processes in obstetric fistula susceptibility.

### **Political-Economic Determinants of Obstetric Fistula**

Poverty and low socio-economic status are now widely recognized as the most important determinants of poor health outcomes, especially for women (Bangser 2007). In the case of obstetric fistulas, the lack of accessible and affordable obstetric care is at the heart of the issue; true cases of obstructed labor need immediate medical attention to obtain a positive outcome. Today, when cases of cephalo-pelvic disproportion exist in high-income nations, they are mitigated by timely access to caesarean section delivery (Browning 2004). Conversely, in low-income nations, many women do not receive quality prenatal care, are not attended by a trained birth attendant during labor, and emergency obstetric care and caesarean section are unavailable when needed (Bangser 2007; Browning 2004).

In their ovarian article, Thaddeus and Maine (1994) identified the “three-delay model”<sup>1</sup> in their examination of obstacles to accessing timely obstetric care. This explanatory framework proposes that the delay in receiving high quality obstetric care is an important factor driving high maternal mortality and morbidity rates and can be divided into three categories: 1) the delay in seeking care, 2) the delay in accessing care, and 3) the delay in the provision of care (Thaddeus and Maine 1994). While Thaddeus and Maine were specifically addressing maternal mortality, these same three delays are causative factors for obstetric fistula and neonatal mortality. In cases of obstructed labor, high quality and timely obstetric care are crucial; the longer a woman experiences obstructed labor, the more extreme the tissue damage and the more likely she will have to deal with the death of her baby (Bangser, et al. 2011; Browning 2004; Mselle, et al. 2011a; Wall 2012).

The first delay, the delay in seeking care, can be attributed to several factors including the lack of money for health services, failure to recognize danger signs in labor, women’s lack of autonomy and authority in decision making, distrust of medical providers, and conversely, trust in local, traditional birth attendants (Keri, et al. 2010; Thaddeus and Maine 1994).

Once the decision to get help is made, securing money and transportation to the health facility, the distance of health facilities, and the time involved in the transport all contribute to the second delay, the delay in accessing care (Thaddeus and Maine 1994). Here the underlying relationship between poverty and the delay in accessing care is easily discerned -- limited financial investment in health facilities for rural areas has resulted in

large distances between hospitals, often over treacherous roads that are impassable during the rainy season.

The third delay, the delay in the provision of care, occurs when women finally access a health clinic. There a number of circumstances may cause further delay: the facility may be understaffed or the staff may have inadequate training, the facility may lack essential supplies, additional financial resources may be demanded of the family, and/or the facility may be ill-equipped to handle obstetric emergencies such as an obstructed labor (Thaddeus and Maine 1994). Again, lack of expenditures on rural facilities and maternal health care have resulted in health inequities that constrain the type of care that is available. In Uganda, this weak investment is primarily the result of poverty, however this poverty is historically structured and inextricably tied to larger macro-economic, neoliberal forces that conspire to create global wealth inequities.

Several studies expose how poverty and its consequences are instrumental in inscribing risk factors on women's bodies, thereby making them vulnerable to obstetric fistula (Muleta 2004; Wall 2006). Malnutrition and early marriage are two examples and both are risk factors for obstetric fistula (Cook, et al. 2004; Konje and Ladipo 2000; Tsui, et al. 2007). Malnourished women are more likely to experience ineffective contractions in labor, leading to unusually long labors and a risk of obstructed labor (Ahmed and Holtz 2007). In addition, poor women often grow up undernourished, resulting in an even smaller than normal skeletal structure and pelvis (Ahmed and Holtz 2007). Small stature and stunting are highly predictive of obstetric fistula (Muleta 2004). Early marriage and childbearing are additional risk factors for obstetric fistula (Tsui, et al. 2007; Wall 2006). Early, arranged marriage is the cultural norm in many low-income nations, including

Uganda and is often considered a means of transferring the financial responsibility of the child to a different household (Nour 2006; UNICEF 2001). In countries like Uganda that engage in the practice of dowry exchange, early marriage also represents a means to achieve financial gain for the parent's of the bride (Nour 2006; UNICEF 2001).

While political-economic processes largely drive both malnutrition and early marriage and childbearing, their affects overlap biologically in the bodies of adolescent girls when they become pregnant. According to Moerman (1982), when girls reach menarche, their growth in height is completed or slows; however their pelvis continues to grow continuously throughout adolescence. DeSilva (1998) points out that in areas with high rates of malnutrition, adolescent girls' growth in height continues past menarche as well. Comparing studies from Bangladesh and Japan, DeSilva (1998) found that nutritionally compromised girls grew an additional 20% after menarche, compared to well-nourished girls who had reached 90% adult height by menarche. Similarly, Scholl et al. (1994) have demonstrated that in countries with early childhood malnutrition, post-menarche growth is extended to ages 19 – 24, into what is classically considered childbearing years. However, for malnourished adolescent girls who are not finished growing, early childbearing results in competing demands for nutrients within the young mother; her need for post-menarche growth may be at odds with the growth of her developing fetus (Konje and Ladipo 2000; Moerman 1982; Scholl, et al. 1994).

Political-economic processes also negatively affect treatment possibilities for women with obstetric fistula. Despite high rates of success with treatment, the possibility of repair is unavailable to the women most likely to suffer from an obstetric fistula (Roush 2009). Access to treatment is severely limited due to financial constraints for both

transportation and the surgery itself, the lack of awareness of the availability of treatment, and the lack of health facilities and qualified medical personnel (Ahmed and Holtz 2007; Browning 2004; Kalilani-Phiri, et al. 2010; Muleta, et al. 2007). Though the cost of surgical repair is only around US\$350, this amount of money is completely out of reach for the majority of the women who suffer this complication (Cook, et al. 2004; Wall 2006). For many, the cost of transportation alone makes treatment an impossibility (Kalilani-Phiri, et al. 2010). Additionally, many more trained surgeons are needed to deal with the millions of current cases worldwide (Browning 2004; EngenderHealth 2003; Kalilani-Phiri, et al. 2010; Yeakey, et al. 2009). Internationally, the capacity to treat fistula is estimated to be 6,500 cases per year (Husain, et al. 2005), while the number of women suffering from fistula is estimated to be 3 million (Wall 2006). According to Browning and Patel (2004:321): “At the world’s current capacity to repair fistulas, it would take at least 400 years to clear the backlog of patients, provided there are no new cases”. The reality is that there are approximately 50,000 to 100,000 new fistula cases each year (Lewis and De Bernis 2006). Collectively, the biology of obstructed labor, combined with political and economic determinants of fistula susceptibility, contribute to immeasurable human suffering in resource poor nations. In the final section, I address the third dimension of the biocultural approach, socio-cultural processes. An understanding of these processes further elucidates the intersectionalities of cultural, political-economic and biological determinants and the resulting complexity of the human experience of obstetric fistula.

### *Socio-cultural Determinants of Obstetric Fistula*

Socio-cultural processes affect many of the same determinants as the political-economic. For instance, studies show that in many low-income nations, malnutrition is often exacerbated by cultural norms that dictate that women and girls eat last after men and boys (Cook, et al. 2004), and in times of drought or famine, this situation is made even worse. Cultural determinants also prescribe a gender-based division of labor where women and girls carry very strenuous and labor-intensive workload (Mwaka 1996). In Uganda, a rural woman's daily workload is 15 – 18 hours of heavy and tedious labor (Mwaka 1996). This level of work necessitates a high caloric intake for normal growth, development and maintenance. When these calories are not readily available, wasting and stunting (both risk factors for obstetric fistula) result.

Education plays an important role in the occurrence of obstetric fistula, and in maternal mortality and morbidity in general (Harrison 1997; Tebeu, et al. 2009). When girls are allowed to attend school, marriage and childbearing are delayed, thereby providing girls more time for skeletal and physiological development (Wall 2012). Education and literacy provide women with information about maternal health processes (Harrison 1997) and raise their general standard of living (Wall 2012). Conversely, several studies have demonstrated a correlation between low levels of education and obstetric fistula prevalence. In Malawi, Yeakley (2009) found that 60% of women with obstetric fistulas had five or fewer year's education. Similarly, Nisar (2010), working in Pakistan, found that 81.5% of women with fistulas were illiterate and that 63% of their husbands were illiterate. In his research in northern Nigeria, Harrison (1997) demonstrated a clear link between maternal mortality and education. While the maternal

mortality ratio was 1,050 deaths per 100,000 live births, risk of perinatal death was 1,154/100,000 for illiterate women, 400 per 100,000 for women who had some primary education, and there were no instances of maternal mortality for women with post-primary education.

### *Embodied Experience*

Numerous studies have addressed the stigmatization, isolation and abandonment women suffering with obstetric fistula experience (Ahmed and Holtz 2007; Alio, et al. 2011; Mselle, et al. 2011b; Muleta, et al. 2008; Turan, et al. 2007; Yeakey, et al. 2009). According to Yeakey (2009), obstetric fistula survivors in Malawi expressed a constant struggle with sadness, worry and fear. The majority of women who suffer fistulas are divorced or abandoned (Ahmed and Holtz 2007; Bangser 2007; Muleta, et al. 2008), though several studies have shown that this is not always the case (Pope, et al. 2011; Yeakey, et al. 2009). Women suffering from fistula are rarely employable, commonly experience the loss of family support (Muleta, et al. 2008), and are often pushed deeper into poverty as a result of their injury (Bangser 2007). Due to the extreme social and physiological effects of fistula, mental health disorders and suicidal tendencies are prevalent (Muleta, et al. 2008; Yeakey, et al. 2009). One study examined mental health among Ethiopian women with obstetric fistulas and found that all of the women screened positive for depression prior to treatment (Browning 2007). Furthermore, most communities do not understand the true cause of obstetric fistula. It is commonly believed to be a punishment from God, witchcraft, or a sexually transmitted disease, and

thus, women themselves are blamed for their condition (Ahmed and Holtz 2007; Muleta, et al. 2007).

Several studies mention women's difficulty accessing treatment for their fistula, due to lack of knowledge that treatment exists (Bangser, et al. 2011; UNFPA 2012), the cost involved in both transport to a facility or the procedure itself (Bangser, et al. 2011; UNFPA 2012), and the severe shortage of trained fistula surgeons (Bangser, et al. 2011; Rushwan, et al. 2012; Turan, et al. 2007; Yeakey, et al. 2009). According to the WHO, despite the estimates of three million women suffering from obstetric fistula, since 2003, only twelve thousand women have been treated (WHO 2010b). In addition, only one qualitative study (Turan, et al. 2007) has been conducted on the experiences of women seeking treatment. The authors found that women seeking treatment in Eritrea received very little information from medical staff both pre- and post-surgery about the cause of their fistula or what to expect from the surgery (Turan, et al. 2007). They contend that standardized information and counseling should be provided to fistula patients to address this inadequacy in care (Turan, et al. 2007)

Post-treatment, women who have a successful repair are often able to reintegrate back into their community (Bangser 2007; Browning and Member 2008; Muleta, et al. 2008; Pope, et al. 2011), and many women even go on to have another pregnancy (Pope, et al. 2011; Yeakey, et al. 2009). However, due to the stigma and isolation involved with fistula, psychological consequences linger; reintegration, counseling and social services are needed in addition to surgical treatment (Muleta, et al. 2008; Pope, et al. 2011; Turan, et al. 2007; Velez, et al. 2007). Furthermore, despite women expressing satisfaction with their treatment, urinary incontinence post "successful" surgery has been found to be as

high as 50% (Browning 2006; Kelly and Kwast 1993). Both Turan et al. (2007) and Browning and Menber (2008) argue that many women under-report ongoing incontinence and further research and follow-up services are needed to address this aspect of treatment.

The current body of literature on obstetric fistula is predominantly concerned with the epidemiology of the injury and surgical treatment techniques. While the clinical aspects have been studied extensively, and to a lesser extent, the political and economic predictors, qualitative ethnographies from fistula survivors remains an under-explored area (Roush 2009). Though in recent years there have been a handful of studies reporting on the ethnographic experience of women living with obstetric fistula (Alio, et al. 2011; Bangser 2007; Bangser, et al. 2011; Mselle, et al. 2011a; Mselle, et al. 2011b; Muleta, et al. 2008; Pope, et al. 2011; Yeakey, et al. 2009), most studies discuss women's experience with fistula based on what women were said to report, which is far inferior to the rich understanding deep ethnography (Scheper-Hughes 2000) can provide. Furthermore, though the majority of women in low-income nations give birth without skilled birth attendants (Darmstadt, et al. 2009), only one study examines obstetric fistula from the perspective of TBAs (Keri, et al. 2010), and only one study has examined obstetric fistula survivors' and TBAs' experiences with obstetric fistulas (EngenderHealth 2007). Women's reproductive health agenda is currently dictated from a "top-down" position (Inhorn 2006), yet a call for ethnographic research has been made in order to combine "top-down" and "bottom-up" perspectives, and thus, to ensure that policies set in national and international arenas align with women's embodied experiences, beliefs, and desires (Jenkins 2003). As Bangser (2006) has argued, if outsider understandings of the condition are inaccurate, the interventions aimed at

prevention cannot possibly be effective. This study responds to that call, and aims to further our understanding of women's experiences with obstetric fistula and TBAs' experiences with providing care.

<sup>1</sup> Various authors have further divided and differentiated the three delays (Hirose, et al. 2011; Rodríguez Villamizar, et al. 2011), yet the three-delay model proposed by Thaddeus and Maine (1994) remains the most widely accepted model.

### **Chapter 3 Research Methods**

In this study, I integrate in-depth, semi-structured interviews with fistula survivors (Phase I) and traditional birth attendants (Phase II) with focus group data (Phase III) in order to examine the experiences of two groups of women -- those who have survived obstetric fistula as a birth injury and those who face the enormous task of attending women during childbirth with extremely limited resources. The study sample for phases I and II consisted of 17 fistula survivors and 20 traditional birth attendants, respectively. In addition to interviews and focus groups, I relied on participant-observation at the maternity and fistula wards at the local hospital and with TERREWODE, the NGO site of my internship, to provide the ethnographic foundation for this study. I utilized a modified grounded theory approach (Glaser 1978; Glaser and Strauss 1967; Strauss 1987) as proposed by Charmaz (1990; 2000) in analyzing data. As a qualitative methodology, this approach allows themes to emerge organically from participants' narratives (Glaser 2001; Glaser 1978; Glaser and Strauss 1967), and then facilitates theory building based on the connections that develop between key themes (Charmaz 2000; Charmaz 2006). During data analysis, I transcribed the interviews and developed an initial coding system based on the emergent themes in the narratives (Cheyney 2008). I utilized this coding system to build a theoretical model and to guide future interview questions. I received IRB approval from Oregon State University prior to the start of the study.

#### ***Phase I: Qualitative Interviews with Obstetric Fistula Survivors***

Initial contact with obstetric fistula survivors occurred through collaboration with TERREWODE, the NGO site of my internship. At TERREWODE events, when fistula

survivors would drop in seeking services, or during our visits to the fistula ward at the hospital, my translator and I presented a verbal description of the study (Appendix A) and explained the voluntary nature of participation. Potential participants received a detailed verbal explanation of the interview process and how the interviews would be recorded and transcribed. Women were asked to let one of the TERREWODE staff members know if they wanted to participate. They were also asked to inform other fistula survivors of the study. Women who accepted the invitation to share were self-selecting on the basis of a desire to tell their stories. In addition, each interview began with an explanation of informed consent and verbal agreement to participate (Appendix B).

Interviews were conducted at the TERREWODE office or at the participant's home, depending on their preference and typically lasted one hour. All interviews were audio recorded with the participants' permission. I worked with a local, female translator who is a trained counselor for fistula survivors and comfortable with the sensitive nature of the subject matter. The interviews were conducted both in English and the survivor's native language, either *Ateso* or *Kumon*. I supplemented the audio-recordings with handwritten notes that allowed me to record emotions and non-verbal communication that would be lost with audio recording alone.

I began the semi-structured, open-ended interviews by asking each woman to describe the birth experience that led to the obstetric fistula. I asked for details such as the woman's age, location and length of labor, and who attended her birth. I asked women what they believed to be the cause (i.e. their explanatory model per Kleinman 1978) of their fistula and what could have been done to prevent their fistula. After I conducted the first five interviews, I utilized the modified grounded theory approach and transcribed

and coded these initial interviews to identify key, emerging themes that could be explored in more detail as the interviews continued. I also attempted to identify relationships between themes, and thus developed preliminary theoretical codes (Charmaz 2006) to explain participants' explanatory models that were grounded in their experiences and fistula narratives. I continued interviews with fistula survivors until no new information regarding theory construction was supplied and concept saturation (Charmaz 2006; Glaser 2001) was reached. After identifying several key, preliminary themes from my initial interviews, I revised my interview questionnaire and added additional open-ended questions that helped me to explore two key areas that I had not anticipated -- the role of the hospital in the development of the fistula and the information fistula survivors received about their injury from hospital staff.

### *Study Population*

Phase I of the study was limited to women over the age of eighteen who had experienced an obstetric fistula. I conducted a total of seventeen (n=17) interviews with fistula survivors, thirteen of whom had already received successful treatment for their fistulas at the time of the interview. The remaining four women were preparing for surgery. Nine of the seventeen women, 52.9%, developed the fistula during their first pregnancy, while 41% received the fistula during their fourth or greater pregnancy. The mean age at which the fistula occurred was twenty years, with ten years of age as the youngest and thirty-five as the oldest. Five women suffered from their fistula for less than one year before successful treatment, while the remaining women had the fistula for a

mean of nine years before treatment, with a high of twenty-one years before successful treatment.

***Phase Two: Qualitative Interviews with Traditional Birth Attendants***

Traditional birth attendants were recruited through snowball sampling -- a common strategy for recruiting hidden populations that can be very effective for developing an exhaustive sample in relatively small populations that are likely familiar with one another (Bernard 2006). Fistula survivors and TERREWODE staff members told TBAs in their community about the study. TBAs interested in participating contacted the translator to set up an interview and also informed other TBAs in their community. Using this approach to recruitment, I was able to recruit both TBAs who lived near Soroti town (and thus close to the hospital), as well as TBAs who lived and worked in outlying rural areas much further from health facilities.

My translator and I presented potential participants with a detailed verbal description of the study (Appendix A), a verbal explanation of the interview, audio-recording and transcription process and explained the voluntary nature of participation. TBAs were asked to let one of the TERREWODE staff members know if they wanted to participate. TBAs who accepted the invitation to share were self-selecting on the basis of a desire to tell their stories. At the start of each interview, my translator began with an explanation of informed consent, and verbal agreement to participate was documented (Appendix B).

Interviews were conducted at the TERREWODE office, at a community center, or the participant's home, based on their travel restrictions and the participant's preference.

As with Phase I, all interviews in Phase II were audio recorded with the participants' permission. I worked with a local, female translator and the interviews were conducted both in English and the survivor's native language, either *Ateso* or *Kumon*. During the interviews, I took hand-written notes allowing me to capture the non-verbal nuances of our discussions, as well as emerging themes that helped to guide future interviews.

I began interviews with TBAs by asking details about their experiences providing maternity care in their communities, such as how long they had been a TBA and where they received their training. I then asked them to describe obstetric fistulas, how they are caused, and what the danger signs are in labor that might cause them to refer a woman to a health clinic or hospital. I asked what they thought could be done to prevent fistulas and whether they thought fistulas could be treated. After the initial five interviews were transcribed and coded, I revised the questionnaire to reflect key themes and continued interviews with TBAs until concept saturation (Charmaz 2006; Glaser 2001) was reached. Guided by findings from initial discussions with TBAs, I revised my interview guide to include questions designed to examine the tension between home and health facility care and the duplication of care that was commonly reported.

### *Study Population*

In Phase II, I defined study eligibility as a traditional birth attendant who is eighteen years or older and has worked as a TBA for at least one year. I conducted a total of twenty (n=20) interviews with traditional birth attendants, all female, with the mean age of 50 years. The mean number of years practicing as a TBA was sixteen years, with thirty years as the high and five years as the low and one undetermined number of years.

All participants reported receiving some form of training: eight participants (40%) received informal training from a family member; fifteen participants (75%) received formal TBA training with an NGO, government agency, or doctor; and four participants (20%) received both family and formal training. The formal trainings ranged in length from one day to eighteen months.

### ***Phase III: Reciprocal Ethnography***

In order to assess reliability and validity of my findings, I utilized a reflexive technique called reciprocal ethnography (Lawless 1992), during which the research findings were returned to focus groups of participants (Phase II). During these gatherings, I invited TBAs and fistula survivors to make corrections and additions to my interpretations. Reciprocal ethnography can help control for researcher bias by adding additional voices and perspectives to the analysis phase of qualitative inquiry, while also providing an opportunity for theoretical modeling to be corroborated, added to, or in some cases, corrected, before the researcher leaves the field (Barbour and Kitzinger 1999).

In this phase, I conducted four different focus groups -- two with obstetric fistula survivors and two with traditional birth attendants. Focus groups were conducted in the participants' native language with the help of the translator and were audio recorded. This process of evaluation provided informants with the opportunity to comment on whether research interpretations accurately represented their experiences, and allowed for elaboration, correction and clarification of the themes analyzed. All of the women who participated in the first and second phases of interviews were invited to participate in the

focus group discussions. Twelve of the seventeen fistula survivors participated and all twenty of the TBAs participated. The focus groups lasted on average two hours. Three of the focus groups were held at TERREWODE's office, and one was held at a community center. Prior to the start of each focus group session, my translator and I explained the voluntary nature of participation, how the focus group would work, and that the focus group would be audio recorded. I began each focus group by reading a summary of my findings from the individual interviews in Phase I and II, and asked participants if my descriptions/interpretations of their experiences were correct, if there was anything they would like to add, and what they might like to change or clarify. I continued until I had presented summaries of all of the key themes and observations that emerged from individual interviews. I concluded each focus group by asking participants if there was any information they would like to add or that they felt was missing from the study, allowing time for anyone who wished to share to do so. This phase greatly enhanced my ability to make sense of participants' experiences and added to theory building as both TBAs and fistula survivors elaborated on answers given during individual interviews. For fistula survivors, their mutual understanding of the oppression of living with an obstetric fistula allowed participants the opportunity to speak fully and comfort one another as they recounted their shared experience. Similarly, TBAs benefited from the synergistic interaction a focus group affords as they recounted the blame and marginalization they experience.

## **Participant Observation**

As an intern with TERREWODE, I was able to rely on participant-observation to build an ethnographic foundation for this research. I assisted program staff in supportive care of fistula survivors as they sought treatment. We checked daily on patients in the fistula ward at the hospital to ensure they had the food and medical supplies necessary. We also advocated for survivors and communicated their needs to hospital staff, making sure they were receiving adequate treatment.

At TERREWODE, I also helped facilitate organizational events to raise community awareness of obstetric fistula. I met with local medical staff and diplomats to discuss barriers to treatment and prevention faced by fistula survivors, the role of traditional birth attendants, and the current state of maternity care in Uganda. My daily work in the TERREWODE office facilitated many informal conversations, which provided me a deeper ethnographic understanding. I observed fistula survivors as they attempted to reintegrate into their community post-treatment, and heard first-hand about their struggles and challenges. In addition, two of my colleagues at TERREWODE were pregnant at the time of my internship, both university educated Ugandan women who were paying for private obstetric care. Their daily stories and experiences with maternity care both highlighted and contradicted the ethnographic data I collected, and facilitated a familiarity with the local customs and choices in maternity care. I was able to use these experiences and observations to familiarize myself with obstetric fistula survivors' experiences and to build rapport with study participants (Bernard 2006).

In addition to my internship with TERREWODE, I was also able to use my background and skills as a midwife to volunteer in the maternity ward at local hospital.

This experience granted me the opportunity to work alongside doctors and midwives in providing maternity care to local women. I was able to witness and contextualize many of the situations that were reported during the qualitative interviews with both fistula survivors and traditional birth attendants. I drew from this experience and my background as a homebirth midwife in the United States in order to build rapport during interviews with TBAs in particular. This experience allowed for the triangulation of results of obstetric fistula survivors' responses, traditional birth attendants' responses, and my own observations.

### **Limitations**

This study took place over a relatively short period of time and was concentrated in the geographical area near Soroti, Uganda. Thus results may not be representative of the total population of obstetric fistula survivors and traditional birth attendants in Uganda, nor of women's experiences in other resource poor nations for that matter. I conducted interviews with women up to 200 km from Soroti, yet due to time constraints, women in very distant, rural areas were not included in this study. In addition, the majority of fistula survivor informants had already received treatment or were in the process of seeking treatment. The voices of the women still suffering from obstetric fistula who have not yet sought medical treatment (or may not even know it exists) are absent in this study. However, the results do shed some light on why women often find themselves unable to seek treatment.

An additional area of concern is my position as a non-native anthropologist and the relations of power between myself as the researcher and participants as subjects. I

attempted to mitigate these dynamics by choosing a study in which I have a high level of expertise (maternal health) from my background in midwifery. This expertise meant I was familiar with common labor and delivery scenarios, language and terms. I was able to use personal experiences to share stories, and thus, to build rapport and trust with my participants. This background knowledge, in addition to my daily work with TERREWODE -- an organization the women in my study respected and trusted implicitly, provided me an “insider” status that allowed me the latitude to ask the in-depth, sensitive questions necessary to understand the participants’ birth trauma narratives.

I also chose to engage feminist methodologies in the study to further allay my non-native status. As a feminist methodology, women interviewing women replicates the common, “everyday” experience women have speaking to other women (DeVault 1990; Spender 1998). Women-to-women interviewing is comfortable, interactive, and places value on the act of listening. By listening, and sharing or dialoguing about personal events, both women (researcher and subject) cooperate in the project of constructing meanings together (DeVault 1990). In addition, focus groups “mirror everyday social interchange in a fairly naturalistic way”, thus allowing participants to communicate in a setting and style that feels safe and comfortable (Wilkinson 1999:224). Focus groups are also recognized for their ability to shift the power balance away from the researcher in favor of the participants. This shift-in-power dynamics is beneficial in its ability to facilitate conversation and the “free-flow and interactive exchange” of viewpoints (Wilkinson 1999). Finally, as a methodology, reciprocal ethnography allows women an

active, participatory role in analyzing research findings (Green and Thorogood 2004; Lawless 1992).

In the following chapters, I present key findings on the lived experience and the explanatory model of obstetric fistula as interpreted from the stories of the women who participated in this study. I discuss the theoretical and pragmatic relevance of these findings to the larger work of preventing obstetric fistula and improving maternal health.

## Chapter 4: The Four Delays

A great deal about women's health can be learned by letting women talk -- by effectively and compassionately listening to them narrate their own subjective experiences of sickness and health, pain and suffering, oppression and resistance, good health and occasional joy that are part and parcel of women's health experiences around the globe. (Inhorn 2006:367)

Women's illness narratives have a long history of offering women an opportunity to share their painful experiences, to find their own voices, and to become empowered in their lives (DasGupta and Hurst 2007; DeVault 1990; Inhorn 1994; Inhorn 2006; Kleinman 1988). Carolan (2006) discusses the value of narratives and stories as the fundamental way individuals attach meaning to their experiences. By offering women an opportunity to share their stories, this project gives voice to their individual experiences. In the chapter that follows, I use a case study approach to illustrate the ways the delays identified in the three-delay model, the delay in seeking care, the delay in accessing care, and the delay in the provision of care, play a role in obstetric fistula development (Thaddeus and Maine 1994). An emic understanding of the three delays is important to contextualize the health inequities women in poverty are forced to face. In addition, I propose and illustrate a fourth delay -- the delay in accessing and receiving treatment for obstetric fistulas. The fourth delay calls our attention to the violence that is being perpetrated against women in ignoring this devastating injury and not allocating the necessary resources to treat women and assist them in regaining their health and dignity.

## **Delay One: Delay in Seeking Care**

### **Acha Josephine's Story**

I met Josephine in the TERREWODE office. She is petite with delicate features and has a high, almost child-like voice despite being forty years old. She never had the opportunity to attend school and was fifteen when she first married. Shortly afterwards she conceived and gave birth in the hospital to a baby girl. She went on to have two more children who delivered successfully in the hospital.

During her fourth pregnancy, she started labor early, in her eighth month. Because the baby was early, Josephine and her husband had not yet saved the money needed for the delivery. Though she had attended two antenatal care appointments and was planning to deliver in the hospital, her mother-in-law made the decision that this time she should give birth at home. "When I started labor, the old women (the mother-in-laws) said, 'Ah, this one is mature enough. She can deliver at home. Since we don't have money for the hospital, let her deliver at home'."

Though she lived only seven miles from the hospital, Josephine labored at home for four days. She was attended by her three mother-in-laws, her husband's mother and two co-wives. At some point during the labor, her husband suggested that she be taken to the hospital, but the mother-in-laws refused and said they could deliver at home. On the fifth day, she gave birth to a dead infant and was never taken to the hospital. Immediately after the baby was born however, Josephine knew something was wrong: "That same day when they pulled out the baby, I felt there was something that was flowing in me contrary to my experience with the hospital delivery. In the hospital I normally leaked blood, but

now this smell was the smell of urine. That's when I sensed that they (the mothers-in-law) must have tampered with my bladder."

Josephine wanted to go to the hospital then, yet again the mothers-in-law wanted her to wait. They told her: "Hold on because that is the water that people who give birth discharge." She waited two more days before telling her husband that she needed to go to the hospital, that "the old women must have caused me some trouble". Her husband also refused to take Josephine to the hospital. He repeated what the mothers-in-law had said, that the fluid could be the normal discharge after birth.

It was one month before Josephine was able to get to the hospital. When she finally saw the doctor, he chastised her for giving birth at home:

When I explained my condition to the doctor, first he was so hard on me. He said, 'I told you to come and deliver in the hospital. How come you accepted to deliver at home?' I explained to him that it was the transport difficulties that made me deliver at home. And since it was not time, we were not ready for it at that moment. And also the encouragement of the mothers-in-laws, who were sure that I would give birth at home. So the doctor informed me that they had tampered with my bladder and that was the problem.

Unfortunately, the hospital did not have a fistula surgeon. Josephine was referred to a private hospital approximately 40 km from Soroti. Although this hospital does not have a fistula surgeon on staff, several times a year, they sponsor visiting surgeons for three to five days of intensive fistula repair. When Josephine explained the referral to her husband, he accepted her diagnosis and took her to the hospital, only to find the doctor was not yet there. They were to return home and wait for the announcement that the doctor was coming. Josephine explained: "I went back home so frustrated. I knew that

these were just tricks, and the condition perhaps is not curable. And so I was just imaging my children becoming orphans over time. I was forever crying over my children.”

After the failed attempt to seek treatment at the hospital, Josephine’s experience took a turn for the worse: “On reaching home, a few days later my husband chased me away. He told me he could not stay with a person who urinates all the time. So I had to leave, but he even denied my own children to come and see me....My brother came for me, so I went back [to my father’s] home. But my husband would not even allow my children to come and see me.”

Abandoned by her husband, Josephine described her experience: “Life was so miserable. I kept on crying, and I knew that I was going to die. And worst of all, without even seeing my children.”

Josephine lived with her mother, silently suffering from the fistula for the next eight years. She was never allowed to see her children, though when they became old enough they would sneak off to visit her on their way home from school. But, Josephine’s brother was committed to finding treatment for her. After years of dead ends, he was finally referred to TERREWODE. After meeting with the staff himself, he took Josephine to town to the TERREWODE office. “We were welcomed warmly. They counseled me and told me, ‘truly, you will get cured. And even those children you are crying for, they will come back to you’.”

Josephine’s surgery was successful, and she returned to her father’s home dry. At first, she had trouble believing that she was actually cured: “Though I still had doubts that

perhaps the thing would reoccur, my mother and brother kept consoling me. They told me that the doctors cannot deceive you and since you are dry, it means you are cured.”

When neighbors began to bring her food and “come and freely sit” with her, she realized she was truly cured. Yet she was still separated from her children, and unable to put her life completely back together. Four years after her repair, her husband came to her father’s home to beg forgiveness from Josephine and her parents. He arrived with gifts and pleaded with Josephine to return with him to their home. I asked her if she had trouble forgiving him and she replied: “If not for the children, I wouldn’t have forgiven him, and I wouldn’t have gone back. But I felt sorry for the children. And the worst part of it is my children suffered a lot. The father of my kids had taken another wife, so he could not mind so much about the children. They had to struggle on their own at home.”

Josephine went on to have two more children; both delivered at the hospital. Her oldest is now twenty-five and her youngest is seven. When I questioned Josephine about her future, she replied: “My hope is educating my children until they reach such a level that they become independent.”

### **Commentary**

Josephine’s story exemplifies the first delay in the three-delay model (Thaddeus and Maine 1994), the delay in the decision to seek care. However, for Josephine, and many other survivors of obstetric fistula, the decision makers -- those who hold the power in the family -- never decided to seek care. Instead Josephine, and thousands of women like her, labor for days at home. In my study, participants reported labors lasting as long as seven days. The danger signs were missed, with disastrous results for both mother and

baby: “The TBAs kept saying it is not yet time. On the third day, the baby’s hand came out. Then my uncle rode me to the hospital on a bicycle.” (Liana, fistula survivor)

Women reported several reasons for delays in seeking care including confidence of the family and TBA that the baby could be born at home, husbands not present during labor so there is no one who can make the decision/give permission to transport, and war and political instability that prevented travel. For some, labor began earlier than expected and the family had not yet saved the money needed for the delivery and transport. One fistula survivor reported that her husband had died during the pregnancy, and his family refused to provide her money to deliver at the hospital. She endured four days of labor at home, during which time her baby died and she was left with an obstetric fistula.

Traditional birth attendant participants also spoke about delays in seeking care, and we were able to talk in depth about the reasons they refer women to the health center or hospital. All of the TBAs reported a varied list of risk factors that they refer for, though most also reported resistance to referral. The reasons for the resistance are important to consider when examining the delay in seeking care. First, women tend to fear the harsh and hostile treatment from the midwives at the facilities: “I try to refer them, but they tend to plead with me to attend and try to deliver. Most of them (the laboring women) complain that the midwives, the nurses, neglect them. They see you and just pass by. They neglect you when you are in labor” (Leticia, TBA, 28 years experience). Another TBA named Grace Anne who had been practicing for 20 years said: “The midwives are normally rude to these mothers and accuse them of delaying, delaying to go to the hospital.” And Adele, a TBA with five years experience, explained: “The mothers are normally not happy with the care they are given in the hospital, especially

first time mothers, in that giving birth is not an easy thing, it's very difficult, and yet when they go to the hospital they beat them, they slap them, they bark at them, and in most cases the midwives say "we are not your husbands, we did not make you pregnant."

Poverty is another reason women and their families resist referral. Despite the fact that maternity care is supposed to be free in Uganda, women are expected to bring all of their own supplies and to provide a cash tip for the midwives. In contrast, women are expected to have just two pairs of gloves when they birth at home with a TBA. The culturally appropriate payment is a gift of appreciation, brought to the TBA sometime after the baby is born. The family decides what they can afford in terms of appreciation, though it is common to give sugar, soap, and perhaps a chicken. The higher cost of the health center birth, combined with the high cost of transportation, leads families to resist referrals: "Some people, as soon as I refer them, they go. But for those who can't manage, they delay. ...In the hospitals there are a lot of requirements, you have to buy gloves, you have to buy drugs, you have to buy toilet paper, there are a lot of requirements. So for those who have hope and courage in me, ... and they don't have the necessities, the requirements for the hospital- for such, they tend to take some time" (Mimi, TBA, 25 years experience). May, a TBA with 28 years experience, described: "Some of the family members resist. It's normally the financial constraints, given the cost of getting to the hospital and being demanded some bit of money. With me- it's for free."

Despite this resistance, it is often the TBAs themselves who are blamed for delaying the woman and not recognizing the danger signs. The TBAs I interviewed confirmed this and spoke about their experiences with hostile treatment from midwives when they accompany a laboring women whom they have referred: "In most cases they

are not nice to these mothers and also go ahead to accuse the TBAs for delaying the mothers at home. The midwives are a little hostile to the TBAs” (Eleanor, TBA, 8 years experience). Another TBA said: “The nurses are ever so rude to me. But I explain to them it was not me who wanted to deliver the woman at home, but I was just called in to help and I was also trained to deliver” (May, TBA, 28 years experience). Finally, Adele, a TBA with five years experience, explained: “Normally whenever I escort a mother to give birth and I introduce myself as a TBA, the nurses are not happy with me. They are so rude. They keep on saying that it is us, the TBAs that who have diverted the minds of the women, saying that we can also deliver them.”

The narratives of both obstetric fistula survivors and TBAs shed light on the structural barriers that contribute to the delay in seeking care. These narratives challenge the dominant discourse that blames TBAs for causing the delay in seeking care by illuminating the ways in which TBAs experience resistance to referral from pregnant women and their families.

### **Delay Two: Delay in Accessing Care** **Andira Nadine’s Story**

Nadine is not what I had come to think of as your “typical” fistula survivor, that is – thin and short in stature. Nadine is at least 5’6”, robust, and muscular. At the time of our interview, she was thirty years old. She never had the opportunity to attend school. She was orphaned at fourteen, and her clan forced her to marry at fifteen. During the next eight years, she was pregnant four times. With the first three pregnancies, she had uncomplicated births in the hospital. During her fourth pregnancy, she had attended

antenatal care and was planning on delivering in the hospital. However, when she started labor, her husband was away. On her own, she did not have any means to find transport to the hospital:

Nadine: I was planning to deliver at the hospital but my husband, who was supposed to take me to the hospital, was far. I had no choice. I had to wait, and I was praying that I could deliver at home... There was no money to bring me to the hospital.

B: How far do you live from the hospital?

Nadine: Five miles.

B: And how much does that cost?

Nadine: Like 30,000 to 40,000 Uganda schillings. (30,000 to 40,000 Uganda schillings converts to six to eight U.S. dollars.)

Nadine labored at home for two days with the help of a TBA. At the end of the second day, the TBA realized she could not help Nadine and referred her to the hospital. Her husband had still not arrived, so Nadine was put on a bicycle and pushed to the hospital: "I was taken to the hospital around 10 pm and upon check-in the doctor informed me that the uterus had already ruptured, the baby was dead, but I was operated around 11 am the next day."

In my experience, waiting overnight to operate for a uterine rupture is incredibly risky. I asked Nadine why they waited so long to operate. She explained: "The problem was that I needed blood, and yet the blood was not available here, but was in transport from Jinga, so I had to wait. But even the next day, I was operated on without the blood, and I received the blood transfusion two days later."

Nadine was discharged one week later before she realized she was leaking urine. She immediately came back to the hospital and explained her condition to the nurse: “When I explained my condition, I wanted to know why I was leaking and the nurse explained that it was too much drip (IV) water. The nurse just told me that it was the drip water that was leaking, and she told me to go back home and be patient. With time it will dry... So I went back home with my urine, frustrated, and stayed with it for five months.” Eventually, Nadine’s father-in-law was referred to TERREWODE and brought Nadine there for treatment. Thankfully, her first surgery was successful, and she is still dry.

### **Commentary**

I choose Nadine’s story to discuss the delay in accessing care because Nadine only lived five miles from the hospital. The typical scenario described in the literature is of a pregnant woman residing a great distance from the nearest health facility. Without doubt, that scenario is also present in Uganda, and several of my informants experienced delays due to the great distance involved in their journey to a health facility. However, the fact that a distance of just five miles also causes a delay is significant. For one, if women who live nearby the hospital cannot access transportation, certainly women at greater distance are experiencing even more difficulty. In addition, if women are attempting to follow the international and national recommendation to deliver in a health facility, but affordable and accessible transportation to the facilities do not exist, how effective are these recommendations? Who is to blame when they fail?

My third day working at the hospital, I saw more evidence of the second delay -- evidence that continues to haunt me. When I arrived in the morning, in the labor room was a mom lying on her side, all alone. At her feet lay a deceased newborn girl. She was clearly full term, and appeared perfectly healthy. According to the resident obstetrician, the mom was laboring at a health center II, just one designation down from a hospital, when the midwives realized there was meconium present, an indication of fetal distress. The midwives called for the ambulance to transport her to the hospital. It took a “long time” for the ambulance to arrive, and at some point, the umbilical cord prolapsed. A cord prolapse is a highly time sensitive obstetric emergency wherever it occurs, as an immediate cesarean section provides the only possible chance for neonatal survival. Upon arrival at the hospital, the fetus was already deceased, and the mother delivered vaginally. With faster, dependable transport, this baby could have survived.

The traditional birth attendants also spoke about delays associated with transport:

Some of the women refuse (the referral) because they cannot even afford transport. (Leticia, TBA, 28 years experience)

(It is) a long distance to the hospital and the health center. If we move from here, there is another center about 6 km away. That distance is too long and somebody in labor cannot manage to walk. Sometimes there is not even a bicycle at home.

(TBA focus group participant)

Additionally, when I asked the focus groups to discuss what would need to be changed in order to improve maternal health in Uganda, transportation was a prominent theme: “The establishment of more health facilities- to shorten the distance to the health

centers; buy an ambulance for all the health centers, with fuel provided by the government; good roads for easy transport.”

In extreme situations, the TBAs reported taking the responsibility for finding transportation:

Once I attended a mother in the health center who started bleeding, but the child was in the wrong position. The legs were down. So when I realized it, I said ‘let’s take the mother to the hospital’. But it was in the night, so the midwife there said at this time of the night there is no car that can take this mother. But the mother was in danger. So what I decided to do- I was still in my gloves and the health center is just next to the road. I ran to the road, there was a vehicle that was coming. I held up my hands, the vehicle stopped. They asked me what is the problem. I said we have an emergency in the delivery. Immediately the vehicle came and the mother was rushed to hospital. That baby is my namesake. (TBA focus group participant)

Though it has been discussed for decades, the narratives provided here illustrate how transportation constraints continue to create huge barriers for pregnant women seeking maternity care at health facilities. This emic understanding must be included when designing reproductive health care strategies.

### **Third Delay: Delay in Receiving Care at the Health Facility**

#### **Aria Mary’s Story**

The TERREWODE staff cheerfully greeted Aria on the morning she arrived for her interview. She is 5’4” tall with short, cropped hair and an infectious smile. She had only recently received treatment for her fistula, and was due for her final review three months later. Aria is young -- just eighteen, and the staff at TERREWODE seemed particularly protective of her.

When we started the interview a wave of shyness came over her. She began by telling me she never went to school and was not married. She was working at a restaurant in town when she got pregnant. It is very uncommon to hear of young women on their own in Uganda, so I asked Aria about her family. She told me her father had died shortly after she was born. Her mother remarried, and for the first ten years of her life, Aria lived with her mother and stepfather, helping to care for her younger stepsiblings and working in the fields. She is from a pastoral tribe, and according to custom, the women and children eat only once a day: “For us, growing food is not our main activity. So we have a culture that we eat once a day. The Karamoja men can get the food when they go to graze the cattle. They get the wild animals and food and they eat from there. But women, its expected that you are supposed to have only one meal a day.”

At ten, Aria went to work as a maid in a woman’s home in Soroti. There she had breakfast, lunch, and dinner. She also saw other children going to school. Aria said: “Whenever my mother would come and check on me, I would tell her, ‘Mommy, I want to go to school.’ And my mother would tell me, ‘You have to work for money to help me make the family survive. I don’t have money to take you to school.’ So I had to miss school just like that.”

Aria continued working for the woman until she was sixteen. Then she left and started working as a waitress at a restaurant in town. That is also when she started dating. When she was seventeen, she became pregnant and moved in with the man responsible for the pregnancy. Aria started antenatal care at two months and went a total of five times. She was not told about danger signs in labor or the risk of obstetric fistula, only that her baby was big and she should deliver in the hospital.

Aria started labor sometime in the night and in the morning she went to the hospital. She stayed in the maternity ward for three days. On the fourth day, they took her to the theater. Confused by this chain of events, I asked her what happened during those three days and whether the midwives were checking on her. She replied: “They kept on checking on me, but they told me the baby was not yet due. The time was not yet due for the baby to come out.” After three days in the maternity ward, she finally started to push, but not for long. The nurses told her that her pelvic bones were immature, and that she could not push the baby out. So, on her fourth day of labor after a brief period of pushing, Aria was taken to the surgical theater for a cesarean. She explained: “By the fourth day, I was not in my normal senses. So I cannot even know. I do not even know the time they took me to theater, and I do not know the reason they took me there.”

When she awoke post-surgery, she was informed that the baby had died. Unfortunately, her difficulties at the hospital were far from over. Two days after the cesarean, Aria was told that her incision had reopened. They needed to take her back to the theater. The following day, the doctor again took her back to the theater. This time her uterus was removed.

Aria did not want to talk much about losing her uterus. She went straight on to the next part of her ordeal: “After some days, I realized that I was wetting my bed and as each day passed it increased. The rate of wetting the bed increased. And so when I asked the nurse, the nurse told me that ‘maybe the surgical instruments touched the bladder and that’s why you are leaking’.”

She stayed in the hospital for a total of two months, yet she was discharged without any attempt to repair the fistula. Back at home, the man responsible for the

pregnancy “realized the urine and he refused me”. He abandoned her and moved to a town 100 km away. To this day, Aria still has not seen him or received any support. She was able to stay in his house, but she had to depend on handouts. Her nearest neighbor, a nurse, was her main helper. She brought Aria soap and sugar and made her meals. When I asked about this time, she replied:

It was too bad. I found life very difficult. I wanted to socialize with people, but whenever I went near a group of people some of them openly laughed at me, others just marched away as soon as I reached the group. It was really a hard time for me. Especially some of them were saying, ‘that’s the very reason your man left you’. Though I would try to explain to them that I didn’t intend to get this condition, but they would not accept. ... They said, ‘You are also young, but you wanted men, so you are reaping what you sowed’.

Seven months later, Aria was advised to go to the Family and Child Protection Unit of the police. From there she was referred to TERREWODE. With TERREWODE’s assistance, she returned to the hospital, to the fistula ward. After two weeks, she underwent surgery to repair the fistula. She stayed in the hospital for five weeks with a catheter and was sent home with the catheter still in place. She was told to return in three weeks to remove the catheter.

Unfortunately, the surgery wasn’t successful. While she was still at home, Aria realized the “urine was just bypassing the catheter”. After the catheter was removed, she was advised to come back after six months for another surgery. She returned for the second surgery, even though she told me she “had no hope” she would be cured. To make matters worse, she still had no support from the ‘husband’ or ‘mother-in-law’. Throughout both surgeries, they never appeared in the hospital. Instead, TERREWODE

staff cared her for. When staff members could not be present, TERREWODE asked other patients and their family members to attend to Aria. She credits the success of the second surgery to this assistance. At the time I interviewed her, she was still dry and approaching her final review with Dr. Kitria. In Aria's words: "I have regained my dignity. People now know that I've also been healed. That I'm now dry."

Aria has been advised to stay "six months without meeting a man".

TERREWODE staff checks in with her frequently. They are worried she might take up with a man before the six months. This is a common worry they have for young, abandoned fistula survivors struggling to make enough money to survive. For now, Aria continues to work at various restaurants in town washing dishes, earning about \$.60/day. She also works with TERREWODE as a mentor, attending primary schools, secondary schools and girl's conferences to share her story and to encourage girls to stay in school and avoid "meeting up with men".

### **Commentary**

Aria's story is important because despite having followed medical advice, and the national and international recommendations for safe childbirth, her birth ended in a fetal demise, an obstetric fistula, and a hysterectomy, after waiting four days in the hospital. In a pronatalist society, where a woman's value rests in her ability to produce children, Aria -- eighteen years old, single, and unable to bear children, has a bleak future.

TERREWODE's staff has every reason to worry about her.

Aria's story complicates the international and national recommendation that advises all women to deliver at a health facility. If women are being neglected at health

facilities, especially at referral hospitals -- the best equipped hospitals in the country -- to the point of such dire consequences, how can encouraging more women to deliver there be *the* solution?

In my own experience working at the regional hospital, I witnessed several cases that exemplify the third delay or the delay in the provision of care once arriving at the hospital. The most extreme example happened my first day at the hospital. When I arrived in the morning to start my shift, the midwife introduced me to Dr. Chipeta, the obstetrician on duty. I was to follow the doctor on his morning rounds. First we checked on the women in the labor and delivery ward, which consists of six beds -- three delivery beds in the front room and three additional beds in the back room where the emergency equipment, such as vacuum extractor and forceps, are stored. In this back room was a woman, Rudi, who was "almost term" and had been having lots of bleeding. The doctor informed Rudi that she had placenta previa and needed a c-section to deliver. She started crying and the doctor petted her head and told her it would be okay. It was the most nurturing action I witnessed from him during my entire time at the hospital. He later told me that she was afraid of the c-section, afraid she would die. He also told me Rudi was a young, unmarried, HIV positive mother from a rural village. The father of the baby had deserted her after she became pregnant. Her mother was at the hospital with her, but they did not have money or supplies for the c-section. They would wait for the c-section until the family came up with the supplies.

Rudi rested in the back labor room all day. I saw her mother coming and going several times. At one point in the late afternoon, the midwife in charge asked if I would like to observe during the surgery. I agreed, yet by evening when I had to leave, they

were still not ready to do the surgery. To my surprise, when I arrived the next morning, Rudi was in the exact same spot as when I had left the evening before. Her mother was still trying to gather enough money to purchase the supplies. The midwives could sense my worry over the young mother, and reassured me that her bleeding was now under control. Again, Rudi spent the whole day lying in the labor ward. Her mother spent the day waiting by her daughter's side or rushing off to meet a family member to collect money for the supplies. When I left that evening, there was still no change in the family's predicament.

Thankfully, when I arrived the next morning, Rudi was in the postpartum section of the ward, nursing a very small baby girl. At some point during the evening, the family accumulated all the supplies necessary for the cesarean. Very early in the morning, the obstetrician performed the cesarean -- two days after he first made the diagnosis.

Often the delay in the provision of care is due to the lack of qualified staff and equipment in the health centers, especially the rural health centers. I visited one such health center, a health center III, in late January. It was located about 45 km from the referral hospital and was supposed to have two midwives on staff. However, the midwife speaking with us said she alone had been attending the center since early December when the other midwife went to visit family for Christmas. She was unclear about when the midwife would return, and she was forced to close the maternity ward at the health center when she needed rest.

The traditional birth attendants I spoke with also shared many stories of delay at the health centers and hospitals: "Most of them complain that the midwives, the nurses, neglect them. They see you and just pass by. They neglect you when you are in labor"

(Grace Anne, TBA, 28 years experience). Another TBA said: “The hardest part of my job as a TBA is when I escort a mother to the hospital and the blame is shifted to me, and yet I’ve also tried to help the mother. For instance, in most cases, the nurses always have a shortage and have delayed the mother, and that’s why the complications came about” (Adele, TBA, five years experience). Mimi, a TBA with 15 years experience, added: “The first thing is most of the majority of the midwives don’t pay any attention to the women. Like in labor - the baby’s coming out and the mother’s pushing and the midwife tells her, ‘you are not supposed to deliver yet’. She (the midwife) has more work to do. So that is why most women prefer giving birth at home.”

My last day at the hospital, I witnessed this exact scenario. The morning had been busy, and the only midwife on duty in labor and delivery room was mopping the floor, which was covered with blood and amniotic fluid, and trying to get instruments cleaned and sterilized. One of the laboring women was very near to complete and starting to push with contractions. The midwife checked the woman’s dilation, explained to me she was not quite ready to push, and proceeded to yell at her for pushing. She then went back to mopping the adjacent room. I stayed with the woman and tried, despite our language barrier, to help her breath through the next few contractions. Less than four minutes later, her water broke and immediately the head was visible with her pushing intently. I called for the midwife, but helped the mother deliver her baby girl before the midwife made it back to the room.

**The Fourth Delay: The Delay in Receiving Treatment for Fistulas**  
**Anna Margaret's Story**

I had already met Anna several times before the day we conducted our interview. She is twenty-three years old, single, and lives in Soroti. She drops by the TERREWODE office frequently and attends every function. Though she is known for her laughter and outgoing personality, she became unusually serious and thoughtful when we started the interview.

Anna began by telling me she was an orphan. Her parents and four siblings had all died. She thinks her parents died when she was about three. From there, she lived with her paternal aunt until the age ten. Unfortunately, at that time her aunt also died. Orphaned yet again, Anna was forced into marriage at ten years of age: “When auntie died, I remained staying at her home. Then some man came, he stays in (nearby town) but he’s an in-law in that village of ours. He told me that he wanted me to go and stay with him. Since I had no one to stay with, I accepted, knowing that he was going to take me as a child. When we reached his place, after a few days, he told me that he wanted to marry me. At this time I was only ten years old. I told him I’m too young to marry. Then he said ‘its fine, I will teach you what to do’. After some time I conceived.”

Anna did not attend antenatal care during her pregnancy. It is common for in-laws to fear taking young pregnant girls to health facilities. To complicate matters, though young girls are often the most in need of antenatal care, there is also some resistance from health care workers to provide antenatal care to girls who are too young.

Without showing any signs of emotion, Anna recalled when her labor started. She told me she labored at home for one week. She was never transferred to the hospital. For

most of the week, she was attended only by family members. On the seventh day, a TBA was called in to help. She arrived in the afternoon and delivered the baby who had already died. Soon after the birth, Anna realized her “urine was flowing continuously”. At this point, she was taken to the local hospital, only to find the doctors were out. She was brought back home without receiving treatment. In fact, Anna was told by the nurses that they could not help her condition: “They just told me to go back home, there is no treatment in that hospital for such cases. As soon as the medical personnel told me there was no treatment, I broke down into tears- because I knew if I went there, they would help save my life. But now they were telling me there’s no treatment, then the next was death. So I went back home very frustrated and hopeless.”

Unfortunately, life became even more difficult for Anna after she returned home. She explained: “When I came back from the hospital the relatives of my husband denied me, they could not stay with me. Even my husband left. It was so terrible for me. I just stayed there for one month and decided to go back home.”

Anna moved back to her auntie’s home. After three months, her auntie’s son “surrendered” and sold a bull in order to take Anna to the hospital for treatment. At the hospital, the doctors examined her, but ended by advising her to go back home because there were too many fistula patients at that time. I could not tell if fistula or the treatment had been explained to Anna, so I asked if the doctors had told her about treatment. She replied: “I saw there was treatment because even the flying doctors<sup>2</sup> were there. But due to the overwhelming number of patients, I was advised to come the next time, which I failed to do.”

Anna explained that returning to the hospital for treatment was no longer an option for her: “My uncle who had sold the bull, used all the money, and therefore, when the time came for me to go back to the hospital, there was no money.” The money was necessary for the transport back to the hospital, for medical supplies and her upkeep. Having spent money on the first trip to the hospital, Anna had no personal means to return later, when she was told the doctor would have time to see her. On top of this, the uncle who had seemed so kind to sell the bull, went on to spend the rest of the money instead of setting some aside for Anna. Thus, she remained home for the next ten years with the fistula. Like others in her situation, she survived on handouts from the community for survival. When I asked her what was the hardest part of living with a fistula, Anna replied: “The discrimination. The fistula brought me a lot of discrimination. I couldn’t make friends. It was only the well-wishers. All my friends went away except the new friends, the good Samaritans who could come by my side. I had no house even to enter. No one would allow me to dig in his or her garden just to get money. I could do nothing for myself.”

Finally, when Anna was twenty, she came to the referral hospital seeking treatment after encouragement from a neighbor. The nurses directed her across the street to “the organization that helps such women”. From TERREWODE, Anna learned there was treatment for obstetric fistula. She also learned for the first time the true cause of fistulas and, most importantly, that it was not her fault.

In the end, Anna’s fistula turned out to be extremely complex. With TERREWODE’s assistance, she received a total of six surgeries -- four at a private hospital and two at the regional referral hospital. Unfortunately, the lack of

communication continued to cause frustration for Anna: “I was operated on five times. I was not told why it was not successful. Afterwards, they would just tell me to take four of six months and come back. But the reason why it was unsuccessful, I was not told.”

The final surgery was successful. In Anna’s words: “I’m completely dry. I no longer feel ashamed of myself. I freely stay with people.”

At the end of the interview, I asked Anna, “When you were in labor for the week, how far did you live from the hospital?” I was shocked by her answer, “About three miles”.

### **Commentary**

In addition to the three delays identified by (Thaddeus and Maine 1994), victims of obstetric fistula reported experiencing a fourth delay, the delay in accessing treatment for their fistula. Fistula survivors spoke of this delay as one of the most difficult and painful parts of their fistula ordeals. Obstetric fistula survivors are in one sense lucky; women who suffer from fistula have narrowly escaped maternal death. However, for them, the delays and suffering are far from over. Fistula survivors reported waiting from several months to 20 years to access treatment. Many made multiple trips to hospitals and health facilities in search of treatment, at great financial cost. For Anna and others like her, their money ran out after the initial trip in search of treatment, before they were successfully treated. They were advised to return or referred elsewhere, but they had no additional resources to return for treatment. While this referral process may work well for those with financial resources, and is common practice in wealthier countries, for fistula survivors, it was often the end of their search. They were forced to return home, uncured

and without hope of a cure. Lorelee, a fistula survivor, shared her experience this way:

“They (the nurses) told me to come back and look for the money for the operation, but I didn’t have the money. I don’t know how much they wanted but they just said to go sell a bull. And since I was in this condition, how would I even have a bull?”

When Lorelee returned home uncured, her family and community believed the condition must have been caused by witchcraft. She was forced to live alone, isolated in a hut at the edge of her mother’s compound, for the next twenty years. Only after her brother received community training did her family realize the true cause of her suffering and help her seek treatment.

Another survivor explained: “I stayed in the hospital for two months. The urine kept on flowing. So I was asking “what is wrong with me?” They told me that there’s a mistake somewhere but you’ll be fine. So you have to go back home. When you go back home we shall organize to treat you and you’ll be fine. So I went back home and stayed for two years without any treatment. There was no one to help me, not even to bring me back to the hospital. (Liana, fistula survivor)

During the delay in receiving treatment, fistula survivors discussed feeling depressed, hopeless, ashamed, and even suicidal. Here Liana explains: “That was the worst experience of my life, where I felt like even dying. Nobody was staying with me. I was alone and the urine would flow too much. The urine actually tore my body parts- the skin around my private parts was worn out and there was nothing I could do.” Another fistula survivor, Helen, described: “Anyone who would come and see me would just tell me, ‘You’re just about to die, you’ll not survive.’ I had a lot of bad thoughts.”

For some, the shame prevented them from seeking treatment: “We felt so ashamed of ourselves - and that feeling would not let us go beyond our houses. Because even when you reach the hospital you find the nurses say, ‘Who’s that one? Who’s smelling? Who are you? You’re so dirty!’ So, you feel so ashamed. And so we took time to go and seek treatment” (fistula survivor focus group participant).

For others, the experience of seeking treatment only to return home without a cure was unbearable: “I was so frustrated and disappointed. By the time I came back from there, my legs would not even carry me. My legs were so weak. I became so weak and disappointed because they had arranged for this surgeon to see fourteen of us, fourteen women and I was among them. But unfortunately he only worked on nine women, leaving five of us. I was so disappointed. My legs became so weak that I could not walk again” (Helen, fistula survivor).

The narratives in this chapter articulate the continuous presence of the three delays and the revelation of a fourth delay unique to fistula survivors. These delays highlight the importance in recognizing the wider political-economic and cultural forces that create vulnerabilities and gendered health inequities that negatively impact women as they attempt to seek obstetric care. In the next chapter I present case studies that draw our attention to role patriarchy, power, and global discourse plays in shaping maternal health care in Uganda.

## **Chapter 5: Gendered Inequality & the Obstetric Imaginary**

The interplay of power and knowledge produces difference in just such a way that the bodies of women are the ground on which male hegemony and, at least in part, the power of the state in the service of capitalism are elaborated. (Shildrick and Price 1999:436)

The findings in this chapter highlight the ways in which colonialism, patriarchal gender ideologies, and capitalism can inscribe their effects on women's bodies -- in this case, the bodies of Ugandan fistula survivors. Numerous critics have described the gendered inequality and blatant sexism that was (is) embedded in colonialism and that has been perpetuated through western-style capitalism and development (Gordon 1996; Mies 1999; Price and Shildrick 1999). This deeply ingrained, gendered inequality is exported through the discursive power of U.S. -style biomedicine, which functions along prescribed patriarchal hierarchies, emphasizing epidemiological trends and individual pathologies, but failing to unmask the structural violence that differentially affects women (Browner and Sargent 2011; Inhorn 2006). In the following chapter, I again use a case study approach to illustrate the ways patriarchy, power hierarchies, and imported biomedical hegemony shape obstetric fistula determinants. The narratives of obstetric fistula survivors are essential to an ethnographic understanding and they are presented first. These narratives are triangulated with results from the TBAs' narratives and participant observation.

### **A Girl-Child Bride** **Apio Helen's Story**

I traveled to Helen's house on the back of a hired motorbike with my translator. From town, it took us forty-five minutes to reach her house, the road transitioning from

tarmac to dirt to a small trail. When we finally arrived, there were children and chickens running around the well-swept compound. A large mango tree was at the center, surrounded by several huts and beyond the huts, a recently plowed garden. After meeting the family, my translator and I sat with Helen under the large mango tree at the center of the compound and asked her about her experience with obstetric fistula.

Helen was extremely welcoming, offering us roasted groundnuts and tea during the interview. She seemed to have endless energy and is unquestionably in charge of her seven children, despite her petite frame and short stature. Helen grew up during the insurgency and did not have the opportunity to attend school. She came from a large family of seven children. She said that they had enough to eat growing up, but since there were only two girls and five boys, she also had too much hard labor -- fetching water, collecting firewood, and household chores. These are all considered women's work in Uganda.

When Helen was fourteen, she was forced to marry a sixteen-year-old boy she had never met. I asked Helen if she wanted to get married: "No. It was the parents of my husband who came to my parents and requested that they needed me to help me in their family. They wanted to take me to join their family, not because I wanted the boy or I had ever seen him, but it was an arrangement of the parents."

Shortly after the marriage, Helen conceived. She did not attend antenatal care because there was an insurgency at the time, and travel by road was unsafe. Likewise, when she started labor, it was not safe to travel to the hospital. She labored at home for three days attended only by her mother-in-law. On the fourth day, her mother-in-law was

finally able to deliver the baby. According to Helen: “My baby was pulled out when it was still breathing, but it didn’t finish an hour. It died.”

Helen was crushed by the death of her baby. But what followed was worse. Once she started leaking urine, her husband’s family pressured him to desert her and send her back to her family. Helen, now incontinent, isolated, and mourning the death of her child, also wanted to return to her family. Yet her young husband refused:

My husband was so helpful, but all his relatives deserted us. They were advising him to get another woman. And they asked, since my husband was still young, why was he wasting time with this stenchy woman – me.

The people of my husband deserted me and they deserted our whole family. My friends from my husband’s village also deserted me. But my family and friends from my home village did not desert me. So I would tell my husband, ‘since your people don’t want me, let me go back to my people who want me’. But he would say, ‘you did not get the problem there, you got it here. Until we solve it, you’re not going back’.

He told me that he could not take me back home because when he brought me I was very beautiful, and now I was leaking urine, meaning that I got the problem in his home. He said if I wanted to go to my mother’s home, then I should wait until he treats me. Then I could go back when I was clean.

Helen had never heard of an obstetric fistula before and did not know there was treatment. For years, Helen thought she was “almost dead.” When she was around eighteen Helen conceived again. She attended antenatal care this time, but again gave birth at home: “I gave birth at home, and I did it intentionally because I didn’t want to go to the hospital because I already thought of myself as dead.” Fortunately, the delivery was uncomplicated, and Helen gave birth to a healthy baby girl. She felt relieved and

happy to be a mother, stating that if she died now she would be content. She was a mother.

Helen had five more children in the coming years, all born at home. Helen described: “There was no problem in giving birth to the rest of the kids. I used to go for antenatal care, but I couldn’t go give birth in the hospital.” I asked her why she “couldn’t” give birth in the hospital and she replied: “The stench that was coming out of me made me fear going to the hospital because also I knew the nurses would abuse me and neglect me since I was smelly.”

Although Helen did not seek out medical care for her births, she and her husband did look for treatment for her fistula. The first time they heard of treatment was at a hospital in northern Uganda. They traveled there, and Helen was examined and taken to the theater several times. Unfortunately, she was not treated: “I was not operated on, so I don’t know what exactly was happening to me in the theater, but it was all in vain.”

Later, her husband heard over the radio that there were doctors coming to a private hospital 50 km away, so again they traveled in search of treatment. When they arrived, they found fifty women suffering from fistula waiting to be seen. Helen felt extreme relief to see that she was not alone with her condition, but there were others “leaking, just like me”. The relief, however, was short lived. As Helen described: “Out of the fifty of us who were there, only nine women were worked on, and then the doctor was called on the phone. And so the white doctor had to leave. The rest of us didn’t get treatment.”

In 2005, TERREWODE staff visited Helen’s village looking for women suffering from obstetric fistula. Helen met with them, and shortly thereafter, with TERREWODE’s

help, she again sought treatment. Helen underwent surgery at the referral hospital, though when the catheter was removed, her urine started leaking again. “I was ... disappointed, based on the fact that there were very many women who were worked on, and I was the only one who repeated the same problem. So when I came back home I thought: ‘I am meant to die. This condition is going to kill me.’ If it was not going to kill me, then how come it is me who has the problem first and the rest of the women are cured?”

Six months later, the surgeon again operated, and this time the surgery was successful. Having suffered with incontinence for ten years, it took some convincing to get Helen to believe she was really cured. And then she was elated! The doctor also advised her to have any future children in the hospital by cesarean section. For the first time in all the years and multiple doctors’ visits and antenatal visits, the doctor explained to Helen what had caused the fistula. Prior to his explanation, Helen thought her mother-in-law had caused the problem:

I felt it was when my mother-in-law was attending and helping to pull out the baby that caused the fistula. She even told me that she pushed her hand inside there when she was trying to deliver the placenta and she pushed on something soft and big inside.

The doctor advised me to finish six months without messing up with a man but ah, when I thought having been told the cause, that it was having a child that caused me this problem, I requested him to do the tubal ligation on me but he told me that he could not.

Helen was unsure why the doctor could not perform a tubal ligation while she was in the hospital. She went on to have one more baby, her seventh. She delivered by

cesarean section at the hospital. Following this delivery, Helen did receive a tubal ligation.

At the end of the interview, I asked Helen what could be done to prevent obstetric fistula. She replied: “To me, I think that the best way to prevent fistula is to avoid early marriages because for me, because I married when I was young, my pelvic bones were immature and I think that’s why I failed to push the baby out in time. So for me, the best way to prevent fistula is to prevent early girl-child marriages.”

### **Commentary**

So many of my informants were married at a very young age, it was difficult to decide which story to share. Of my seventeen participants, nine were married and had their first pregnancy by the time they were fifteen years or younger. Twenty years was the oldest age at first birth reported, and ten years was the youngest. I chose Helen’s story because she so clearly articulates that the choice to marry was not hers. Her life became an economic transaction between families, and this was too much for her young body.

During my time in Uganda, I heard many references to the economic value of women as brides and the dowry, and the problems it brings to women. According to one fistula survivor, when she protested her marriage her father responded, “I want to eat my cake while I can still enjoy it,” meaning he wanted to reap the rewards of his daughter’s dowry before he was too old. Even the fistula survivors, while citing ending early girl-child marriage as one of the main ways to prevent fistula, were not in support of ending the practice of the dowry. Instead, they recommended encouraging parents to refuse the

dowry until the girl is older. Specifically, they recommended waiting until girls finished their education. Then the parents can allow marriage and accept the dowry.

In my participant observation at the hospital I saw many young women giving birth. However, one young girl caught not just my attention, but the head midwife's as well:

*Today during discharge exams, the head midwife got very upset with the mother-in-law of a very young new mom. The young mom looked about twelve years old. She sat next to her mother-in-law holding a swaddled baby in her arms, looking more like a big sister than a mother. She gave birth a day and a half earlier. They were sitting on the long bench in the maternity ward next to dozens of other mothers and babies, waiting to see the midwife and receive discharge papers. When the midwife got to the young mom, she looked at the mother-in-law and started scolding her. I couldn't understand all of what was said, though it was clear she was not happy. The mother-in-law talked back once or twice, but mainly kept her head down and was silent. By now, the midwife had everyone's attention. All the women in the ward were staring at the young mom and her mother-in-law. The midwife even shouted a few sentences in English: "This girl is too young! She should not be a mother. She's just a baby herself and now she has a baby. How can she be a mother? Why did you allow such a marriage?"*

*(Field Notes, Hospital Maternity Ward, December 2011)*

While there is a general consensus in the literature that youth and teen pregnancy is a risk factor for obstetric fistula, I couldn't help thinking that with this level of humiliation, they will most likely never return to the hospital-- for postpartum care, or the next birth. In Helen's story, the effects of patriarchy and extreme poverty, which create structural factors that force young women into marriage and early childbearing, are clearly articulated. The next narrative documents the disempowering and harmful effects of the paternalistic treatment of women, which is commonly embedded in biomedicine.

**Keeping Her in the Dark**  
**Stella Amujo's Story**

Stella lives in Gweri, about an hour outside of Soroti. Since her home is difficult to find, I met her at Apio Helen's house, Stella's friend and fellow fistula survivor. At the time of the interview, Stella was thirty-seven years old. We met under the large mango tree where I had interviewed Helen. Stella arrived a few minutes late in a formal pink dress and seemed very happy to share her story.

Stella married when she was seventeen and had seven healthy pregnancies and non-complicated deliveries. She delivered five of her children in the hospital and two at home. During her third antenatal visit with her eighth pregnancy, the nurse told her that her uterus was too large and could not contain the baby. At her fourth visit, the nurse told her the pregnancy was "a difficult one" and she needed to deliver in the hospital.

She started labor in the evening and went to the health center at 7 pm. The midwife checked her, but told her she could not deliver at the health center, and she needed to go to the hospital. Luckily, Stella and her husband were prepared and had the resources needed for the transport. Stella arrived at the hospital at 9 pm. She was complete and attempted to push the baby, yet she did not make any progress. The midwives administered an IV drip with oxytocin to speed up labor, but still there was no change. The doctor was called in, though it was three hours before he arrived.

When he finally examined Stella, the doctor repeated what she had heard earlier, that her uterus was too large and she could not deliver normally, but he also did not want to take her for a cesarean:

The doctor said that he had spent the whole day in theater, and so he was tired. He could not go to the theater again.

So he opted that he just pulled out the baby rather than go to theater.

The doctor told me, 'I am going to pump air into your stomach as you push so that the baby can come out'. So he set up the machine and they pumped in air until I felt that the stomach was just growing. ... When the air had filled up the stomach he put in another machine because he said that the baby had become very weak, and so could not come out even with the pressure of the air that they had pushed in my stomach. So he pushed in some machine and the machine pulled out the baby. And the baby was really big. ... They later realized that the baby was big but was weak. They had to put the baby on oxygen. I was put on another drip and sent to the ward.

The next day Stella realized that something was leaking, apart from the normal postpartum blood. On her third day postpartum, as the doctor was preparing to discharge her, Stella informed him that she was leaking both blood and urine. He advised her to go home and wait for three days to see if she could "differentiate what is blood and what is urine". If needed, she could always return to the hospital, he assured her.

At home, the condition steadily grew worse. After a week, Stella returned to the hospital. The doctor told Stella her problems were the result of the difficult delivery. Without explaining what she was suffering from or why, the doctor sent Stella home with some medicine and again assured her she could return to see him if her condition did not improve. According to Stella: "I came back home, I swallowed the drugs, but after one week, there was no improvement."

This time, instead of returning to the hospital to see the doctor, Stella was advised by neighbors to go to TERREWODE. She found transport into town and went to the organization's office. There were a group of women inside, talking and sharing their experiences, and they too were suffering from obstetric fistula. Like other fistula

survivors, Stella felt immense relief with the realization that she was not alone with this condition.

TERREWODE's staff accompanied Stella and the other women to the hospital to seek treatment. However, when they arrived, they were informed the doctor was away for a month. All the women needed to go home and return later for treatment. Stella explained:

I stayed at home for 5 months without again seeking treatment because there's no way I could go back to (the hospital) without transport. My husband, who was responsible for the pregnancy, disliked me and went to his other wife. He told me that he could no longer stay with a woman who's so stenchy like me. I lost all hope, and the only thing I could do was cry and cry. My relatives now all hated me, they said they could not even sit in my home.

One day, one of my relatives came here and as he greeted me I told him of my problem. He told me 'don't get a bad head', because I told him that I wanted to commit suicide and die. But he told me don't commit suicide, and consoled me, and asked me why I refused to go back to the hospital. I told him that there was no one who could help me reach there. I'm sick and I have a baby, and there's none who's willing to carry me, not even on a bicycle, up to town.

Fortunately, Stella's relative decided he would take her to town. He bought her soap for her to wash her clothes, and the next day took her to TERREWODE. From there, the TERREWODE staff intervened on her behalf, accompanied Stella to the fistula ward at the hospital, brought her supplies, and encouraged her to have faith, that she would get well. I asked Stella how she thought her life would have been different if she had been treated for the fistula right after the birth. She replied, "I think I wouldn't have gone through all this torture, because then I would have been treated, and perhaps I wouldn't

have reached the extent of smelling.” Towards the end of the interview Stella reflected on her experience:

I feel somehow frustrated, and I felt a lot pain because I told the doctor-- the expert—about my condition and he could have worked on my fistula before it reached the advanced stage. ... Actually I felt like, how shall I put it; perhaps this doctor was not a qualified one.

Yet, I do not blame any medical expert. I’m not saying that they were the ones who perhaps caused my fistula. Partly because I had already been told that my uterus is too large, and therefore I needed a hospital delivery. The worst part was that it coincided with when the doctor was already tired.

### **Commentary**

Fistula survivors commonly reported receiving no information or very little about their injury, and/or misleading or wrong diagnoses. As one fistula survivor reported: “When I explained my problem to the doctor, he said maybe because we used a machine to pull out the baby, that machine must have pricked the bladder. But it will heal over time.” She waited two years, was abandoned by her husband and left without any resources to survive as she waited for her fistula to “heal over time”.

Many others reported similar experiences: “They just told me that I should go back home, but they gave me medicines to swallow, and I’ll be fine. But the problem continued” (Claire, fistula survivor). Margaret, another fistula survivor explained: “After I gave birth, there was no explanation. The nurses were saying maybe there’s something wrong with your stomach, maybe there’s something that has happened to your bladder. But then other women in the hospital were telling me that since the baby died, maybe I’ll also die...I had no direction. I was like a blind person.” And another said: “I felt a little

bit disappointed when the nurse told me there was no treatment, but that it was just drip water that would cure on its own, especially when I went back home and the community members told me it was urine and not drip water. So I ask myself, when I go to the experts they tell me it is water, when I come to the local people, they tell me it is urine, so where should I go” (Nadine, fistula survivor)?

In addition to the emotional distress this caused women, it also resulted in an enormous economic burden as women spent precious resources traveling in search of a cure, only to be given false diagnoses and false hopes. Over time, this inaccurate information eroded survivors’ hope that they would ever be cured. Many felt that they were “all alone with this curse”, and were not informed otherwise. For some, it was not until they finally met other obstetric fistula survivors seeking treatment that they understood they were not alone. This realization alone gave them hope.

The true cause of the fistula was also frequently a mystery to the survivors. Like members of their community, at first they blamed TBAs, doctors, or even witchcraft. Unfortunately, these beliefs were not corrected when the women sought treatment. In fact, of the four women I interviewed at the fistula ward in the hospital, only two correctly identified the cause of their fistula. The nurse herself explained to me that fistulas could sometimes happen from bicycle accidents.

Fistula survivors also discussed enduring unsuccessful surgeries that were not explained, adding to their feelings of hopelessness. Helen’s story (A Girl-Child Bride) discussed this poignantly when she described feeling so weak her legs that her legs could not even carry her after the disappointment of not receiving treatment. Other survivors began to mistrust medical staff. Some survivors talked of being “tricked”. Josephine said:

The tricks from the medical personnel...they keep on telling you, 'if you take this, you are going to well', and yet actually you never get well.

So when I went to the hospital here they told me I would get well, but I needed to go to the other hospital for treatment. Then when I went there, they told me the doctor is what? The doctor is not yet around. So it came to my mind that perhaps this disease is not curable. They are just trying to use tricks on me...I actually felt that perhaps it would have been good if instead of telling me "you go and come back when the doctor comes" they first should have told me the type of treatment so that I knew there truly was treatment, rather than telling me the doctor is not there.

Many of the TBAs were also misinformed about the cause of obstetric fistula. In most cases, they had been told they were the cause: "They ever accuse us in the village, the TBAs, the old women, that have the strong nails and we can pinch it" (TBA Focus Group Respondent). Another TBA explained: "Most people, including the nurses, tell people that it's the TBAs who insert their hands inside there and pinch the bladder. That's what causes fistula" (Leticia, TBA, 28 years experience). At the end of my interview with Leticia, I went back to this issue:

B: I have to ask one more question about the TBAs causing fistula. You said the nurses have told you that TBAs pinch the bladder and cause fistula. Is that what you believe?

Leticia: To me, that is just an assumption that is not true, because based on my experience of the women that I have helped, none of them have gotten a fistula.

The narratives here illustrate that the lack of forthcoming information, whether due to ignorance on the part of the nurses or the effect of patriarchy embedded in authoritative, biomedical doctor-patient relationships, resulted in discouragement and

further disempowerment as fistula survivors distrusted their own embodied experience and the medical system in which they sought treatment. In the final narrative, the obstetric imaginary (Cheyney 2012), the powerful, hegemonic belief that U.S.-style obstetrics can solve maternal health care problems worldwide, is explored.

### **Faith in the Obstetric Imaginary** **Mirembe Rosie's Story**

I met Rosie at TERREWODE's office. She is twenty-five years old, about five feet tall, very muscular and strong. In her outgoing manner, Rosie greeted everyone in the TERREWODE office, where she drops in frequently. She is single and lives near-by in a crowded settlement on the edge of town. She runs a business from her home, selling home-brewed alcohol.

Rosie was eighteen and still in school when she conceived. When her parents discovered she was pregnant, they took her to the man's home and demanded a dowry. He was twenty at the time. After some time and negotiation, his family paid, and Rosie moved in with him. Yet in the end, she stayed with him for only three months before returning home because his family was mistreating her.

Rosie started antenatal care at five months, though she was never taught about danger signs in labor or an obstetric fistula. When she went into labor at nine months, she labored at home for three days. She had planned to give birth at home because it was the norm in her family. As Rosie described: "Other people had managed to give birth at home" so it made sense to her that she would too. She was attended by a TBA, who

ultimately made the decision to refer Rosie, and on the fourth day, she was taken to the hospital.

I asked Rosie if she wanted to be taken to the hospital earlier in her labor. She said she did but her family resisted, saying, “Just try and hold on a bit.” Apparently Rosie’s contraction pattern was not consistent. She would have strong contractions, but then they would weaken and she would even fall asleep. Her family and the TBA thought Rosie was having false labor. I questioned Rosie about her experience after the referral:

B: So then when you transported, what happened? Did you go to the hospital or the clinic?”

Rosie: The hospital. The nurse checked and told me it was not yet time. Even the second day Dr. Langwa also came and checked on me and said it was not yet time.

B: So that’s the second day in the hospital? The fifth day of labor?

Rosie: Yes. Now the third day in the hospital, around 8 pm, the doctor came and informed me that my child had already died, but now they would take me to the theater.

After the cesarean, Rosie realized she was incontinent of both urine and feces. She stayed in the maternity ward for two weeks recovering. Then she was transferred to the fistula ward where she first had surgery to repair the rectal fistula. After her initial recovery, she returned home for one month to wait for the final surgery. Both surgeries were successful, and she was able to stay with her parents during her recovery.

Thankfully, Rosie did not suffer the isolation and abandonment that the majority of fistula survivors experience. She attributes this to the relative speed in which she was repaired: “I didn’t overstay with the fistula”.

When I asked Rosie what could be done to prevent obstetric fistula, she replied: “I feel that when you are pregnant, as soon as you get your labor pains, rush to the hospital.”

Yet, for Rosie, she spent three days in labor in the hospital without receiving adequate care. She was repeatedly ignored, in part, she explained, because the beds were full and she was on the floor. Due to the shortage of both beds and midwives, the women who are forced to labor on the floor are frequently ignored by the midwives. By the time Rosie finally received medical attention, not only had her baby died, but she was incontinent of both urine and feces. When I asked her about this, and how despite the fact that she was in the hospital and still did not receive the maternity care she needed, Rosie replied: “Its better to go. At the hospital, they just told me that the time was not ready, but it’s better a professional who told me.”

### **Commentary**

Unfortunately, Rosie’s story is not unique. In my study, out of seventeen participants, five went to the health center or hospital as soon as labor began. Another three were referred to the hospital, yet still experienced long delays at the hospital before receiving care. However, all of my participants agreed that the way to prevent fistula was to rush to the hospital when labor begins. Certainly, these women were in need of emergency obstetric care in the hospital, and they all had a good understanding of this. However, even when they followed this recommendation and their labor still resulted in a fistula, their belief in the ability of the health facility and the medicine it can offer was undeterred. During a focus group discussion, one fistula survivor even commented:

“What has brought all of these problems actually is because the white doctor left the African hospital. When the white and American doctors were in the African hospitals, we never had this problem of women getting fistulas.” Though the facts here are incorrect, maternal mortality and morbidity were problematic issues during colonialism, the sentiment -- that the health care of the “white doctor” is superior -- is both clear and pervasive.

The Ugandan government, while doing little else to improve reproductive health care, has made the recommendation to deliver at a health facility the centerpiece of their maternal health policy. Since declaring traditional birth attendants illegal in 2010, they have withdrawn all support and discouraged any TBA training programs. While I saw no evidence of any resources being invested to improve outcomes, I did hear radio stations playing government broadcasts, urging women stay away from TBAs and deliver in the health centers or hospitals. The obstetric imaginary has been whole-heartedly imported and adopted by the Ugandan government.

The doctors and midwives I spoke to also believed in the supremacy of U.S.-style obstetrics and felt that having all women deliver in a health facility is the key to solving poor maternal health outcomes. One afternoon at the hospital, I took a break with the midwives in a supply room/office at the maternity ward. As we sat and talked, several of us tore sterile gauze into small strips to use to tie off umbilical cords. We had run out of cord tape that morning and since this was not part of the supplies women were expected to purchase themselves, we needed an alternative. As we worked, I asked them about the struggles they face as midwives. They responded: “Long hours, not enough midwives, not enough pay, no supplies, shortage of gloves and drugs, and not enough beds.” Yet

despite their list of grievances and their dissatisfaction with feeling overworked, the midwives were also against training TBAs. They thought it would be a “waste of money”, which should be spent in the hospital.

Not surprisingly, the TBAs I spoke to felt differently. When I asked one TBA if she agreed that the solution is for all women to give birth at a health facility, she responded:

That would be one of the solutions, but it is not the only solution. Based on the fact that normally they [the pregnant women] come in to facilities that are small and cannot fit all the women. The government facilities are so small. In one district, you can have almost 500 women pregnant and they need to deliver within one week and all of these 500 cannot stay in the government facilities. Also, not all labor is the same, and it doesn't always allow you time to get to the hospital. Some babies can come within one hour and you are already delivering. (Grace Anne, TBA, 20 years experience)

Another TBA recommended hospital birth, but still found herself being called on: “And me personally, I would really love the mothers to deliver in the hospital, but by the time they come for me...and I reach them, and I see that the baby is due, so I have to deliver them at home. But I would really not advise the mothers to deliver at home” (May, TBA, 28 years experience).

One of the problems with the recommendation that all women deliver at a health facility is access to the facility during what TBAs characterized as an “emergency”. While in many industrialized nations, homebirth is a choice for low-risk women who transport if emergency obstetric care is needed, in Uganda the opposite was often true. Homebirth was frequently the safety net when circumstances prevented the mother from

accessing care at a health facility. In addition to the delays in seeking care already discussed, TBAs reported women using them as emergency care in cases such as a precipitous labor in which the mother does not have time to transport to a facility, the labor starts in the middle of the night preventing safe transport, the labor starts early and the family is not prepared, or the family decision makers are not home. As Grace Anne explained: “Most of the people come to me as an emergency, because they get into labor when they didn’t expect it and the labor tends to be at the highest peak, so they cannot rush there to the hospital. They come to me.” Another TBA described: “Mostly these mothers plan to deliver in the hospital, but when labor comes there’s an emergency. That’s when they run for me” (Pearl, TBA, 20 years experience). And Jenna, a TBA with seven years experience, said: “I think TBAs can be part of the solution in that the women love me, but in most cases they come in emergencies. So in case labor comes as an emergency, the first contact is me.”

In addition, several TBAs explained how many women utilize both systems of care- receiving antenatal care at the health facility and coming to the TBA for massage during their pregnancy:

B: Do the women who see you also get antenatal care at the health center?

Gladys: They go for antenatal care at the hospital. Then they come to me for massage and because they want to know the position of the baby.

B: And why do they choose to deliver with you instead of the hospital?

Gladys: Because of an emergency, they didn’t expect to deliver at that time. (TBA, 5 years experience)

In light of this, its not surprising that the TBAs I interviewed were unanimous in their desire for additional training, either from the government or from non-governmental organizations. Many also gave very specific areas they wanted training in, including more information on when to refer women to the health facility: “because delivery doesn’t tell you that it will come tomorrow. I would also still make sure that TBAs are given adequate skills and knowledge and also given equipment for helping mothers deliver” (Grace Anne, TBA, 20 years experience).

Even the fistula survivors, who universally advocated “rushing to the hospital” when labor begins, also recognized the value in training TBAs: “The TBAs should be given more training because they are the first point of contact in the community. So if they are equipped with knowledge and skills, they can easily detect that perhaps you need a hospital delivery, and they refer you in time” (fistula survivors’ focus group respondent).

Today in Uganda, TBAs are forced to navigate the dangerous territory between the obstetric imaginary and the reality of disparities in maternal health. On one hand, they advise women to seek antenatal care at the health center. Some TBAs even encourage women to deliver at the hospitals. However, when the imagined health care is inaccessible at the critical time of birth, TBAs fill the void and deliver women at home with whatever supplies the women and her family has managed to gather: “The challenge that I face most as a TBA is the lack of readiness by the mothers. Most of the mothers are not prepared enough for birth, so in most cases I reach them and find there are no gloves

but to deliver a mother without them, this is risky to me” (Pearl, TBA, 20 years experience).

As Uganda struggles to adopt a Western, biomedical model for all births, TBAs reported that they would continue to assist women who seek their care. In their daily work, traditional birth attendants challenge the international recommendations and national laws. Living and working with birthing women, they have long recognized the flaws of these dictates and have made their own decisions about the value of their work: “For us, we don’t care. We work and keep working because we are saving lives. We cannot wait for the government to first announce that we should start our work” (Hope, TBA, 30 years experience).

The findings in this chapter illustrate how gender oppression, patriarchy, extreme poverty, authoritative biomedical hierarchies, and the obstetric imaginary conspire to create health demoting consequences which disempower and marginalize women to the point of dire outcomes. In the following chapter I discuss the relevance and significance of these findings.

## Chapter 6: Discussion

Before we can present a program for dealing with human misery, we must represent that misery. (Langer 1997:53)

In this study, I have used women's narratives to describe their experiences with obstetric fistulas and to describe TBAs experiences providing maternity care in impoverished, rural settings. I triangulated their accounts with participant observation in the local referral hospital to reveal several dominate themes. Findings indicate that poor women experience many barriers in their attempts to access maternal health care, that some women receive fistulas while waiting to receive care *at* a health facility, and that, in addition to the well known three-delays model, fistula survivors suffered a forth delay -- the delay in accessing treatment for their birth injury. Furthermore, TBAs, regardless of their current criminalized status, often serve as emergency maternity care in their communities for women who simply cannot reach medical care. Overall, I have argued that the clinical determinants of obstetric fistula have been privileged over political-economic and cultural determinants, both in the literature and in the international discourse that proposes a biomedical solution to improving maternal health and ending obstetric fistula. Yet, by focusing on the pathophysiology of this form of birth trauma, and thus minimizing the political-economic and cultural determinants, the role structural violence plays in women's experiences of navigating maternity care remains under-examined. Although emergency obstetric care is critical to prevent obstetric fistula in cases of obstructed labor, the criminalization of the locally constructed system of care, TBAs, serves as yet another layer of structural violence in the lives of rural, poor women.

Furthermore, while the importation of Western-style biomedical obstetrics has been embraced by governing bodies and academics worldwide, its ability to deliver in resource poor settings is based not on evidence, but rather on an obstetric imaginary marketed in a political economy of hope.

### ***Structural Violence and the Four-Delays***

Fistula survivors' stories confirmed their experience with the well-documented three delay model (Thaddeus and Maine 1994): the delay in the decision to seek care, the delay in accessing care, and the delay in the provision of care at the health facility. Without question, women who have suffered from obstetric fistula were at some point during their labor in need of emergency obstetric care. Their inability to reach that care is a result of macro-level economic forces and social inequities, or structural violence, rather than a personal failure, or failure of agency. Structural violence, introduced by Johan Galtung (1969) and elaborated by Paul Farmer (2003), draws attention to the larger political economic forces that constrict a person's agency with disastrous, or violent, results. In writing about structural violence Farmer states, "such suffering is "structured" by historically given (and often economically driven) processes and forces that conspire - - whether through routine, ritual, or as is more commonly the case, the hard surfaces of life -- to constrain agency" (2003:40).

In Uganda, the impact of structural and socioeconomic inequities make the barriers to accessing care insurmountable for many poor, rural, pregnant women. Structural violence is deeply embedded in the fabric of society. In this way, gender inequities, malnutrition, unequal land rights and marginalization of the poor are

“misrecognized” as normal (Bourdieu 2000). Although the three delay model and the contextual challenges it describes has been acknowledged for more than a decade, in Uganda, the national rhetoric surrounding maternity care is still directed at the individual with the imagined belief that the pregnant woman has a great degree of “choice” in her decision about where to give birth. The intimate narratives fistula survivors provided tell a very different story -- a story where agency is constrained by poverty and gendered inequality to the point of tragic results. The Ugandan government’s maternity care policy that consists primarily of criminalizing TBAs and promoting health facility births is exposed as cosmetic and largely beside the point. In keeping their mission narrowly defined, the Ugandan government is able to appear proactive, though the reality is that no real effort to make safe birth more accessible is currently underway. As women’s narratives make explicit, the Ugandan health care system is not designed to serve those most in need. Both the Ugandan government and international development agencies are complicit in ignoring the local level reality and failing to create strategies that offer immediate care to the women most vulnerable in childbirth.

This study adds to the literature on obstetric fistula as it is the first to document that several fistula survivors lived within five to ten miles of the hospital, yet structural barriers still proved too large to overcome even for these relatively small distances. Other fistula survivors reported receiving their fistula while waiting to receive care at the health facility or the referral hospital. Overcrowding, staff shortages, and resource scarcity forced women to wait days to receive care, with dire consequences. Drawing on Foucault’s concept of the medical gaze (1973), in which great value is placed on the doctor’s ability to perceive and to “see” all as a form of control and discipline, these

women experienced what Gibson describes as the “gaps in the gaze” (2004). Too poor to pay for a bed or pay the “tip” expected by midwives, these women became invisible, laboring on a mat in the corridor waiting for days to receive care. Although they were physically present, in falling outside of the gaze, these women were not seen, their medical needs ignored (Gibson 2004).

Unique to fistula survivors however is the experience of a forth delay, the delay in receiving treatment for their fistula. Though the literature recognizes the extreme inadequacy of surgeon-to-caseload ratios, the human experience of seeking treatment is not well examined. For fistula survivors, the forth delay was a central component of their suffering. Survivors often glossed over losing their child in labor or their uterus due to rupture and focused their story on the struggle to access treatment. This is likely a result of the devastating nature and consequences of their injury -- especially the social isolation and ostracism -- and elucidates the extreme difficulty they experienced in accessing treatment. Survivors who sought treatment overcame enormous structural barriers, only to find repeated disappointment and misinformation at great economic and personal cost. Many did not know about treatment and suffered months or years before learning of the possibility of treatment. Others demonstrated considerable agency and repeatedly sought a cure. The tragedy of their stories is not only the long wait they endured, extraordinary resources spent, and distances traveled, but also the lack of respect they were shown by health professionals as they sought care. Survivors described enduring harsh, discriminatory treatment and receiving minimal information from medical personnel. Others received inaccurate information; they were told that it was not urine, but water they were leaking, that the leaking was normal, or that it would heal over

time. Against their better judgment, the women had little choice other than to return home, still leaking.

Foucault's notion of power/knowledge and biopower applies well here as the women's own experiential knowledge (Lupton 2000) was dismissed by the authoritative knowledge (Jordan 1993) of the doctor. Foucault illustrates how mechanisms of power are validated and reinforced through systems of knowledge (1984), and he argues that power and knowledge are intrinsically intertwined. His concept of biopower specifically addresses the control of bodies through the privileging of scientific knowledge (1984). It is through this power that women's own understanding of their illness had less value than the medical professionals who wielded the scientific knowledge. Sadly, several women reported undergoing surgery multiple times without receiving any explanation as to what was happening to their body or why the surgery was unsuccessful. Applying a Foucauldian lens to these interactions elucidates the power structures that allow a medical hierarchy to surgically treat an illiterate, poor woman without explaining the cause of the injury or the nature of the treatment, or to send a woman home after an unsuccessful surgery with no explanation of why the surgery failed.

### ***“Emergency” Maternity Care and Blame***

Fistula survivors and traditional birth attendants' narratives explain the rationale behind the continued perseverance of, and at times preference for, TBAs. TBAs offer affordable, accessible, and respectful care to poor, local women. They are available at all hours and are willing to travel to the laboring women's home. They accept whatever payment, or “appreciation”, the family can afford, when they can afford it. They are from

the same area and speak the language. These attributes have been well documented in the literature, and they proved to be relevant in Uganda as well (Ana 2011).

Traditional birth attendants also offer something seemingly in short supply in the health facilities -- nurturing care. Despite the fact that emotional support and physical touch during labor have been shown to decrease pain and improve outcomes (Cheyney 2011; Davis-Floyd 1994; Kitzinger 1994), studies have repeatedly shown that impoverished women in resource poor countries often experience abusive care rather than supportive care (Kruger and Schoombee 2010; Kyomuhendo 2003; Van Hollen 2003). In this study, both fistula survivors and TBAs reported abusive and neglectful care from midwives and nurses. Furthermore, both groups reported the mistreatment from midwives as a deterrent for women choosing health facility care. During my participant observation at the referral hospital, I did not witness outright abuse, though this could have been due to my presence and the knowledge among the staff that they were being observed. Neglect, however, was commonplace, and perhaps born out of necessity. I never witnessed any demonstrations of either emotional or physical support from nurses or midwives, and many were simply overwhelmed by the magnitude of the work expected of them. In my conversations with the midwives, they complained bitterly about their position at the bottom of the medical hierarchy. The long hours, low pay, staff shortages and relentless demand for their services left little enthusiasm for their job. In health facility settings like the referral hospital where I worked, harsh, disrespectful care was common among midwives and nurses who were themselves struggling within an incredibly strenuous work environment and professional hierarchy in which they rank last.

Narratives from this study illustrate the ways in which TBAs serve as the “emergency” maternity care system. This is particularly true for women who were utilizing both systems of care concurrently -- the biomedical approach propagandized by the government, and TBAs, the local option. These women followed the government recommendation and attended antenatal care at the health center during pregnancy. They simultaneously visited the local TBA for “massage”, or traditional antenatal care. Many of these women planned on delivering at the health center or hospital. Several TBAs, worn out by the long hours, low pay, and high risk their work entails, even encouraged mothers to do so. Ultimately however, many of these women ended up delivering with TBAs. Political-economic and cultural forces, mainly in the form unforeseen circumstances such as an early birth before sufficient money was saved, a precipitous birth, or a nighttime birth, resulted in a change in their plans. When “emergency” circumstances presented themselves, pregnant women turned to TBAs, omnipresent in most rural villages, knowing at least this care was accessible. In contrast, the “emergency obstetric care” found at health facilities proved to be inaccessible during a true emergency.

When structural violence is overlooked, blame is placed on the individual. The blame is shifted in subtle ways; often the victims themselves unwittingly participate. According to Bourdieu, this internalized blame is a form of symbolic violence (2000). Referring to Bourdieu’s work, Philippe Bourgois writes:

Through symbolic violence, inequalities are made to appear commonsensical, and they reproduce themselves preconsciously in the ontological categories shared within classes and within social groups in any given society (Bourgois and Schonberg 2009:17).

Lupton argues that, in “the ‘new morality’ of preventive health, falling ill has become viewed as a sign of moral failure, a source of blame” (2000:58). In their narratives, fistula survivors spoke of finally reaching the hospital only to be yelled at by midwives and doctors for delaying. The women attempted to defend themselves by reciting the barriers they faced in attempting to reach the hospital. Through this blame, they are “victimized a second time” (Whiteford, et al. 2009:225). Indeed, the women were reluctant to seek medical care for future births and for fistula treatment because of their odor and the self-blame they had internalized.

Even more than the survivors themselves, the TBAs were blamed -- blamed for boldly thinking they could help the women deliver, blamed for not recognizing danger signs, blamed for delaying the women, and finally, blamed for pinching the bladder and causing the fistula. As Douglas has argued: “In all places at all times, the universe is moralised and politicised. Disasters are generally turned to political account: someone already unpopular is going to be blamed for it” (1992:5). Uganda’s “disastrous” maternal health record with one of the highest obstetric fistula rates in the world and a persistently high maternal mortality rate, has repeatedly been blamed on the unpopular and disempowered. In the local landscape, both doctors and midwives were complicit in engaging in this blame-the-victim discourse. Yet this blame can be traced to a much larger arena -- discursive international discourses that years ago demoted TBAs from active participants in maternal health strategies. Absent from the discussion is the failure of health facilities to successfully accommodate poor, pregnant women. Nor is there a critical evaluation of how so-called “free” maternity care has become so poorly funded

that, in actuality, the cost is shifted to those it was intended to help -- pregnant women. Also absent from the debate is a discussion of how women in labor are supposed to reach the clinic, without affordable, accessible transportation, especially in the middle of the night. Women are blamed despite (or perhaps because of) the patriarchal system that explicitly prohibits their decision-making and personal agency without the approval of the husband. Structural violence is continuously overlooked, and as a result, abuse and anguish are taken as natural, the “normal” order of things. This destructive normalization of women’s suffering over-emphasizes individual agency (or the lack of it in this case) and steers the discussion away from any macro-level reconfigurations that could create fundamental change for the individual.

Listening to the narratives in this study and engaging a critical medical anthropology (CMA) lens, the power imbalances and how these imbalances result in differential access to reproductive health care are easily identified. CMA is a theoretical perspective within anthropology that stresses the cultural construction of health and the social origins of disease (Singer 1990; 1995). It recognizes that health is inherently political (Navarro 1984) and critically examines power relations and how these relations determine health research, policy, and programs (Singer 1990; 1995). CMA’s stated goal is emancipatory -- first, to understand and call out the root causes of suffering, and ultimately to change these repressive practices (Singer 1995). Turning the focus away from the biomedical causes of obstetric fistula to the more upstream causes shifts the blame from the victim and reorients the discussion towards addressing the foundational sources of suffering. In the case of obstetric fistula, these upstream, or political-economic

and cultural causes, are acknowledged in maternal health discourses, yet the attention and resources are directed almost entirely to the biological cause and its biomedical solution.

### ***Political Economy of Hope and the Obstetric Imaginary***

According to Mary-Jo Delvecchio Good, the medical imaginary, or the allure and the ever-hopeful belief in biomedicine “arises not necessarily from material products with therapeutic efficacy but through the production of ideas with potential but as-yet-unproven therapeutic efficacy” (2010:274). Applied to obstetric care, Cheyney (2012) has described the obstetric imaginary, or the uncritical belief that the application of U.S.-style biomedical obstetric care can cure maternal and infant health care problems worldwide. The narratives of both fistula survivors and traditional birth attendants demonstrate the power and the allure of this obstetric imaginary as it functions in Uganda, for it is even adopted by women who receive their fistula while waiting for care *at* a regional referral hospital. Despite their experience to the contrary, fistula survivors who had endured long delays in accessing care at the hospital still expressed unquestioned enthusiasm for the superiority of health facility care. When asked what could be done to prevent fistula many repeated the national rhetoric, “rush to the hospital at the first sign of labor”.

One of the ironies of the obstetric imaginary is that despite skilled birth attendants and health facility delivery being recommended and promoted for more than a decade, maternal mortality rates in endemically poor regions remain persistently high. The evidence for this biomedical solution is based in the global north, where the resources exist to implement the exorbitantly costly system. Furthermore, this U.S. system

developed over the course of decades, along with greater human rights, property rights for women, increased wealth in general, and with it improved nutrition and standards of living. Importation of the biomedical, obstetric system alone, without the precursors or social determinants upon which its success depends, has not produced the same results. The decision to outlaw TBAs based on their failure to reduce mortality, did not take into account the political-economic realities and, instead blamed ignorance and cultural tradition. Today, rather than question the efficacy of the imported biomedical solution, the blame continues to be placed on those with the least amount of power. International agencies and governing bodies hold tenaciously to their belief in the obstetric imaginary, never questioning its lackluster results or its ability to deliver in a rural, impoverished setting such as eastern Uganda. Curiously remiss is an examination of macrostructures that import a health care system that has been designed and implemented among the wealthiest nations in the world. Exactly how it is supposed to work without the necessary resources is not addressed.

## Chapter 7: Conclusion

In May of 2010, Amnesty International's Demand Dignity campaign highlighted the United States' rising maternal mortality rates. According to new UN data, the U.S. maternal mortality was on the rise and ranked 50<sup>th</sup> worldwide, meaning 49 countries had better maternal health outcomes than the U.S. (WHO 2010b). The significance of Amnesty International including the U.S. in their maternal health campaign cannot be ignored. Though the U.S. maternal mortality rate was still vastly better than in low-income nations such as Uganda, it ranked dead last among the highly industrialized nations despite the fact that the U.S. outspends every country in the world on healthcare (OECD 2010). While preparing for this research project, I was struck by the irony of this juxtaposition. As the Institutes of Medicine made recommendations to the developing world about how to improve birth outcomes (Bale, et al. 2003) -- recommendations that entailed emulating the costly, biomedical system in the U.S. -- our own maternal mortality rate continued to rise. Unfortunately, these facts have had little effect on the international discourse on obstetric fistula, and U.S.-style biomedical obstetrics continues to be posited as the global cure to poor maternal health outcomes. My work calls this assumption into question, leaving us to question: If it does not work in the US where we have \$98 billion per year at our disposal to combat maternal and neonatal mortality, how might we expect it to work in Uganda or any other resource poor nation for that matter?

The qualitative narratives in this study reveal a more intimate understanding of obstetric fistula than the biological data so often reported. The women's narratives add depth and nuance to our understanding of fistula and maternal health care in Uganda in

valuable ways. In particular, women's narratives highlight the political-economic and cultural determinants of obstetric fistula and elucidate why these determinants must be considered along with biological or clinical predictors as we construct multifactorial and poly-etiological models of obstetric fistula treatment and prevention.

TBAs and obstetric fistula survivors explained how many women seek care from both the government endorsed health center and TBAs simultaneously. Many planned to follow recommendations and deliver at the health facility, yet due to unforeseen, "emergency" circumstances, they ended up delivering with TBAs. I have argued that not training and equipping TBAs to handle such emergencies, or providing the means for women to overcome these emergencies and access the health facility, adds to the structural violence women already face.

The Ugandan government, in conjunction with international development agencies, has recommended and promoted health facility delivery with skilled birth attendants, while simultaneously criminalizing the locally constructed model of care, traditional birth attendants. I have argued that these actions create the illusion that the government is doing something to improve maternal health care without actually having to invest any resources or implement fundamental change. Furthermore, these recommendations ignore the local lived reality and the structural barriers pregnant women face to obtain care. Blame for the persistently dismal maternal health outcomes has been conveniently shifted to those with the least power, and those least able to organize against it, the traditional birth attendants or the laboring women themselves. This blame shifting shields the government and international actors from the more

difficult task of taking real action to address the macro-level, socio-economic causes of poor maternal health.

Perhaps most importantly, obstetric fistula survivors shared their common experience in suffering through a forth delay -- a delay in accessing treatment for their birth injury. Their testimonies reveal that women are forced to endure the tragedy of an obstetric fistula for many months or years and that their attempts to seek treatment often result in yet another layer of structural violence being imposed upon them. They experience harassment, misinformation, and discrimination when seeking care. Additionally, they spend irreplaceable resources in this process and consequently, are pushed more deeply into poverty. As international efforts mobilize to prevent obstetric fistula, this delay must be examined.

This study reveals how the obstetric imaginary, which constructs U.S.-style biomedical obstetric care as crucial for improving health outcomes for women and infants, is marketed in a political economy of hope in Uganda. However, despite years of promotion, recommendation, and importation, this system has yet to improve maternal health outcomes in impoverished areas. Biomedical obstetrics requires massive amounts of resources; the cost burden is immense even in wealthy nations. The government's promotion feeds the (overly) optimistic allure of the obstetric imaginary, while in reality, it cannot possibly "deliver" given the local context. I have argued that the reliance on imported foreign policies and technologies has failed local women, while the hegemonic grasp of these policies has led to the criminalization of their traditionally constructed system.

The results reported here counter the trend in biomedicine to reduce complexities in women's health to "evidence" based research. By giving women voice, this study has aimed to (re) "negotiate relevance" (Yoder 1997) between what information is useful for public health programs and the knowledge provided by ethnographic research. As policy makers gather to decide health care policy for mothers and babies worldwide, documenting women's maternity care narratives is an inherently political act with the power to disrupt the silence surrounding obstetric fistula (DasGupta and Hurst 2007).

### ***Future Studies***

More ethnographically grounded work is needed to fully understand the experiences of survivors of obstetric fistula. The voices of fistula survivors, family members, and care providers will add to our understanding of this devastating injury. In particular, research designed to explore medical providers' perspectives, particularly midwives and fistula surgeons, in relation to obstetric fistula are urgently needed as they will invariably add to our understanding of the forth delay women are experiencing. Additionally, in light of the Ugandan government's ruling against TBAs, research is needed to assess the impact of this standing on TBAs themselves and the women they serve. Furthermore, as local health care systems are increasingly affected by policies determined by international health experts, exploration of the policymakers and the framework and discourse they are operating within is necessary to better understand how expert opinions, policies, and recommendations are produced and reproduced. Finally, although anthropologists are hesitant to generalize that what works in one poor country

will easily translate to another (Allen 2002), research documenting inclusion of traditional midwives and TBAs in successful maternal health care programs will further efforts to think creatively about new solutions to improved maternal health care.

### ***Recommendations***

The field of global health research has grown exponentially in recent years, and this has led to a renewed call for action within the field of anthropology. Anthropologists argue that, as applied social scientists, we have a responsibility to use our skills to engage real world problems -- that we in fact “owe it to our informants” to make positive contributions (van der Geest 2006:13). As Bourgois contends:

By informing fieldwork with critical theory, anthropologists can make the connections between macro forces and intimate social relations, emotions, and dispositions so that individuals are no longer misrecognized as having to be worthy victims or blameful agents. (2006:xi)

In response to this call, I would argue that the first step in designing better maternal health care is to elicit community input in the design and delivery of the program. Women in communities often know best the constraints they face when giving birth. This insider, emic information is crucial if we are to develop programs that speak to those for whom it is designed. As Einstein and Shildrick have argued:

One strategy to break free of our own situated ignorance is to ask situated women what they consider is important to understand about them. Surprising knowledges can emerge from such an approach. (2009:297)

In this study, the women's narratives clearly articulated that more attention and resources need to be directed at increasing the world's capacity to treat obstetric fistula. Fistula survivors voiced the strong desire for better communication from health care staff, both immediately following their injury and when seeking treatment. However, unless more is done to prevent fistula from occurring in the first place, women will continue to suffer this horrific injury. In order to prevent fistula and to improve maternal health outcomes, participants recommended increased capacity at health facilities, especially more midwives and supplies, and emergency transportation available to villages at all times. Women also focused on the need to address one of the root-causes of obstetric fistula, early girl-child marriage. Collectively, they voiced concern over changing the political-economic and cultural environment to encourage girls to stay in school and to delay marriage. This means finding ways to help impoverished parents avoid the temptation of the dowry.

Participants, both TBAs and fistula survivors, overwhelmingly responded in favor of training TBAs. The TBAs also expressed a desire for a more fluid system of referral, where both the TBAs and birthing women felt comfortable transporting from home to a health facility. Expanding on these recommendations, I would add that, while without question improved emergency obstetric care is needed to both prevent obstetric fistula and improve maternal health outcomes, the form and characteristics of that care need not be determined by discourse decided in the global north. Engaging the local population in the design and desired outcomes of maternal health programs will ensure the ultimate product fits with the needs and values of communities. Programs and policies that are designed locally are more likely to be achievable given the local context. Finally, moving

away from the hegemony of biomedical obstetric paradigms in the United States opens up a multitude of new possibilities and creative solutions. Already researchers and local communities around the world have engaged in promising research with encouraging results worthy of our attention, such as women's participatory intervention groups in Nepal (Manandhar, et al. 2004), community centered Home Based Life Saving Skills groups (Sibley, et al. 2001), and emergency life-saving training (rather than the normative referral-only training) for TBAs in Cambodia (Chandy, et al. 2007). New innovations that can be utilized by TBAs in home birth settings are also promising, especially the anti-hemorrhagic tablet misoprostol. This low-cost, thermostable, uterotonic has the potential to significantly reduce maternal mortality due to postpartum hemorrhage. These alternative, community-based strategies challenge the *one-size-fits-all* Western-prescribed biomedical model.

Ginsburg and Rapp have argued that, "regardless of its popular associations with notions of continuity, reproduction also provides a terrain for imagining new cultural futures and transformations" (1995:2). The women in this study imagine a future where young girls are not forced to marry, where emergency obstetric care is available, effective and respectful, and where local systems of maternity care are valued and co-exist with facility based care. I imagine a future without shattered lives.

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## **Appendix A: Verbal Description of the Study**

Hello, my name is Bonnie Ruder and I am a student at Oregon State University in the USA. At the university I study anthropology, to understand how people live in different cultures. Before attending this university, I trained as a midwife in the United States. My special interest is studying how women experience obstetric fistula and what can be done to prevent it from happening. I have come to Uganda because I would like to conduct a research project to learn from women here why their fistula occurred and what could be done here to prevent it.

In the US, I help women have their babies at home, as many women do here in Uganda also. For this study, I want to learn what it was like for women who, after their birth, experienced an obstetric fistula. I also want to learn from women who help women have their babies at home or in their village, what they know about obstetric fistula. I would like to interview women who after giving birth found they had an obstetric fistula. In the interviews I would like to hear women tell me the story of their birth, and then I will ask questions about any parts I didn't understand or would like to hear more about. I would also like to hear women tell me what caused the fistula and what they think could be done to prevent this from happening to other women.

I would also like to interview women who help women give birth, or traditional birth attendants. In the interviews I would like to hear traditional birth attendants tell me stories of women who had an obstetric fistula after giving birth, and then I will ask questions about any parts I didn't understand or would like to hear more about. I would also like to hear traditional birth attendants tell me what causes fistulas and what they think could be done to prevent this from happening to other women.

After the interviews, I will host a group session for all the mothers who shared their story with me, so that they can talk together about their experiences, to learn what about their experiences they share in common. In this group session, I will share what I have learned from all the women, and they will have an opportunity to tell me if I have understood them well, or if I should make corrections in my notes.

I will also host a group session for all the traditional birth attendants who shared their story with me, so that they can talk together about their experiences. In this group session, I will share what I have learned from all the traditional birth attendants, and they will have an opportunity to tell me if I have understood them well, or if I should make corrections in my notes.

To complete this study, I am looking for women who are interested to volunteer in this research. I will not ask women individually, because I want women to feel free of any obligation to participate. Instead, I am announcing the opportunity here, so that women can learn about the opportunity to share their stories with me. Then, anyone who wants to participate in the study and talk with me can contact TERREWODE, who will let me know. A woman's participation in this study is independent from her involvement with TERREWODE, and will in no way impact her relationship with TERREWODE.

## **Appendix B: Oral Consent Guide**

### **What is the Purpose of this study?**

My name is Bonnie Ruder and I am a graduate student at Oregon State University. You are being invited to take part in a research study in which I am seeking to understand how women's experience of obstetric fistula. I encourage you to ask any questions you have about the research project, so that its purpose and methods are clear. When all of your questions have been answered, you can decide if you want to be in this study or not.

### **What will happen in this study, and how long will it take?**

If you agree to take part in this study, you will be interviewed about your experience with obstetric fistula. It usually takes between 1 to 2 hours to complete the interview. Your story will be recorded so that I can listen to it later and put it in writing. If you do not want your story recorded, I will take notes instead. I will use a translator's assistance in the interview and in the typing of the story. When your story is written, I will not use your real name, but will substitute a different one, so others won't know whose story it is.

### **What are the risks of this study?**

The only possible risks anticipated with this study may be if you feel upset when you share your experience. If you feel upset and don't want to continue, you may stop telling your story at any time.

### **What are the benefits of this study?**

We do not know if you will benefit from being in this study, except that you may feel satisfied to tell someone what happened to you and your experience of having a fistula. Hopefully, women in the future will benefit from this study.

### **Who will see or hear the information I share?**

The information you share during this research study will be kept confidential to the extent permitted by law. To help protect your confidentiality, we will use coded numbers and/or different names to refer to all participants. Any materials that could be used to connect real names with numbers or given names will be stored in a locked and secure file box and/or using password protected computer files.

If the results of this project are published, your identity will not be made public.

### **Do I have a choice to be in the study?**

You are free to choose if you want to take part in this study or not. If you decide to take part in the study, it should be because you really want to volunteer. Nothing will change if you choose not to volunteer. Your comfort and safety are the most important thing to me, so always remember that you can stop at any time during the study and we will remain friends.

You will not be treated differently if you decide to stop taking part in the study. You are also free not to answer any questions during the interview that you would prefer not to answer. You may withdraw your interview text from the study at any time prior to publication with no penalty by contacting me or TERREWODE by phone or email.

**What if I have questions during the study?**

If you have any questions about this research project, please contact me: Bonnie Ruder at 0001-541-579-0439 or by email at [bonnieruder@gmail.com](mailto:bonnieruder@gmail.com). Or you may contact the Alice Emasu of TERREWODE at 256-454-461-359.

If you have questions about your rights as a participant, please contact the Oregon State University Institutional Review Board (IRB) Human Protections Administrator, at (541) 737-4933 or by email at [IRB@oregonstate.edu](mailto:IRB@oregonstate.edu)