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Too Long to Wait: Obstetric Fistula and the Sociopolitical Dynamics of the Fourth Delay in Soroti, Uganda

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Abstract

Uganda has one of the highest obstetric fistula rates in the world with approximately 200,000 women currently suffering. Surgical closure successfully treats fistula in the majority of cases, yet there is a severe shortage of facilities and trained surgeons in low-resource countries. The purpose of this study was to examine Ugandan women's experiences of obstetric fistula with the aim of adding narrative depth to the clinical literature on this devastating birth injury. Data were collected through semistructured interviews, focus groups, and participant observation. Resulting narratives were consensus coded, and key themes were member-checked using reciprocal ethnography. Women who suffered from fistula described barriers in accessing essential obstetric care during labor—barriers that are consistent with the three delays framework developed by Thaddeus and Maine. In this article, we extend this scholarship to discuss a fourth, critical delay experienced by fistula survivors—the delay in the diagnosis and treatment of their birth injury.

Keywords

women's health; gender, lived experience; health, reproduction; Sub-Saharan Africa; Africans; qualitative methods; research design, ethnography; research strategies, interviews; qualitative

Introduction

Every day approximately 830 women die from pregnancy or childbirth-related complications around the world. 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 303,000 in 2015 (World Health Organization [WHO], 2015). However, much of this decline has been in the global north, while little progress has been made in the poorest regions of the world where 99% of maternal deaths occur. Sub-Saharan Africa accounts for a disproportionate amount of this burden with 66% of maternal deaths worldwide.

In 1994, in an article titled "Too Far to Walk: Maternal Mortality in Context," Thaddeus and Maine argued that the inability to access timely and skilled obstetric care was the principal factor contributing to pregnancy-related deaths globally. They attribute delays in accessing critical care to three factors: (a) the delay in the decision to seek care, (b) the delay in reaching the appropriate level of care, and (c) the delay in the provision of care once the health facility has been accessed (Thaddeus & Maine, 1994). This framework has been highly influential in global health policy, shaping development approaches and priorities around the training of skilled birth attendants, increasing facility capacities, building infrastructure to enable access, and encouraging women through public health campaigns to deliver in facilities.

Despite the focus on reducing maternal mortality, severe maternal morbidities—termed *near-miss* mortalities, by Storeng, Murray, Akoum, Ouattara, and Filippi (2010)—and their effects on women's lives have received much less attention. Yet these near-miss obstetric complications are of critical concern; for each woman that dies in childbirth, another 15 to 30 suffer significant maternal morbidities, often with lasting physical, emotional, and socioeconomic consequences (Ashford, 2002; Reichenheim, Zylbersztajn, Moraes, & Lobato, 2009). The vast majority of the literature on obstetric fistula—considered the most severe of maternal morbidities (Wall, 2006)—focuses on clinical aspects of the condition, though some important and recent exceptions exist. Using

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qualitative approaches, researchers have studied women's experiences of living with fistula (Bangser, 2011; Barageine et al., 2015; Mselle, Moland, Evjen-Olsen, Mvungi, & Kohi, 2011; Yeakey, Chipeta, Taulo, & Tsui, 2009), women's quality of life after repair (Drew et al., 2016; Khisa & Nyamongo, 2012; Pope, Bangser, & Requejo, 2011), the difficulty of obtaining information about the condition among survivors (Krause, Lussy, & Goh, 2014; Turan, Johnson, & Polan, 2007), the social production of gendered powerlessness and its implications for fistula occurrence (Hamed, Ahlberg, & Trenholm, 2017), and neglect by nurses that contributes to fistula development (Bangser, et al., 2011; Mselle & Kohi, 2015). In addition, Heller and Hannig's (2017) recent ethnography of fistula treatment in Niger and Ethiopia complicates popular representations of women with fistula as child brides who, after their injury, become social exiles who eventually find redemption through surgical repair. In fact, many women with fistula remain embedded and supported in their communities, though an unexpectedly high number have poor or ambiguous surgical outcomes (Heller & Hannig, 2017).

The purpose of this project was to examine women's experiences of fistula through an analysis of their birth and fistula treatment seeking narratives from the onset of labor through the repair of fistula injuries and reintegration back into communities. Specially, we aimed to identify factors that contribute to prolonged suffering following the development of a fistula. Using data collected from in-depth, semistructured interviews, focus groups, and participant observation, we examined emergent themes from women's fistula narratives, ultimately interpreting them through the lens of the three delays framework. In addition, women's narratives revealed a fourth critical delay—the delay in receiving a diagnosis and accessing fistula treatment.

Background

Obstetric fistula is a traumatic childbirth injury caused most often by prolonged, obstructed labor and delayed intervention. The continuous pressure of the fetus on the bladder or rectum during labor causes the tissues to become necrotic and slough away, leaving an abnormal opening, or fistula, between the vagina and the bladder and/or rectum. The result is incontinence with uncontrollable leakage of urine and/or feces from the vagina. In the majority of cases, the fetus dies of asphyxia and is delivered vaginally once the fetal tissues begin to decompose or via cesarean section once the woman receives emergency obstetric care.

The majority of obstetric fistulas can be treated successfully with surgical closure, but treatment is most efficacious when women receive immediate medical attention (Waaldijk, 1994). Most women who have undergone a successful surgical repair will remain continent, however, as many as 7% to 55% may experience postrepair residual incontinence in the form of stress incontinence, urge incontinence, and urinary urgency and frequency (Kelly & Kwast, 1993; Murray, Goh, Fynes, & Carey, 2002). 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, Arrowsmith, & Hancock, 2008).

Despite evidence of success with treatment, access to care is severely limited due to the costs of transportation and the surgery itself, lack of awareness about the availability of treatment, and lack of health facilities and qualified fistula surgeons (Browning & Patel, 2004). Internationally, the capacity to treat fistula is estimated to be 6,500 cases per year. Surgeons cannot keep up with the new cases, let alone address the enormous backlog of unrepaired fistulas (Browning & Patel, 2004; Wall, 2006), and the social consequences of fistula are extreme. The odor from the continuous incontinence causes shame, stigma, and social isolation for women suffering from fistula. Many women experience divorce and abandonment. Husbands and families often do not understand the cause of fistula and blame the woman herself for the illness. Women living with fistula are rarely employable, commonly experience the loss of family support, and thus are often pushed deeper into poverty as a result of their injury (Bangser, 2007). Women suffering from fistula report serious mental health issues, including depression and suicidal tendencies (Browning, 2007).

Obstetric Fistula in the Ugandan Context

In Uganda, the maternal mortality rate remains high at 343/100,000 (WHO, 2015). Uganda also has one of the highest population growth rates in the world along with a total fertility rate of 6.2 births per woman (Uganda Bureau of Statistics, 2012). Uganda's health facilities, skilled health professionals, and emergency obstetric care systems are most concentrated in urban areas, yet Uganda is one of the least urbanized countries in Africa with approximately 85% of its 30 million people living in rural communities (Uganda Bureau of Statistics, 2007). The availability and utilization of both skilled birth attendants and emergency obstetric care are a major concern. Currently, Uganda has only one doctor and 13 nurses or midwives per 10,000 people, compared with 24 doctors and 98 nurses or midwives per 10,000 people in the United States (WHO, 2012). Despite a national campaign to encourage women to deliver in a health facility, which included the outlawing of traditional birth attendants (TBAs) in 2010, the number of women who have skilled attendants with them at the time of delivery is low; only 42% of women nationwide and 37% of rural women deliver in health care facilities with skilled birth attendants (Uganda Bureau of Statistics, 2007). Thus, the majority of Ugandan women deliver at home with the help of family members or with a TBA, and have no access to emergency obstetric care when needed.

As a result, Uganda has one of the highest obstetric fistula rates in the world; approximately 200,000 women currently suffer from an obstetric fistula, with an additional 1,900 new cases annually (Uganda Bureau of Statistics, 2007). The Ministry of Health has identified obstetric fistula as a major concern since 2001, yet there is currently no dedicated fistula hospital nor sufficient numbers of trained fistula surgeons in Uganda (Hancock & Collie, 2004). Obstetric fistula repair takes place in 16 facilities across the country with treatment augmented within surgical camps led by nongovernmental organizations (NGOs) and staffed by local and visiting surgeons. However, in Uganda, many women with fistula do not seek treatment due to lack of awareness, prohibitive costs, or transportation difficulties. The cost of surgical repair is between US$350 and US$650—an amount of money that is unattainable for the majority of women who suffer from fistulas. In addition, recent studies indicate an unusually high rate of iatrogenic fistula in Uganda, suggesting that more training and supervision is needed for medical officers and physicians in complex cesarean deliveries (Barageine, Tumwesigye, Byamugisha, Almroth, & Faxelid, 2014; Raassen, Ngongo, & Mahendeka, 2014).

Research Site

Soroti is located in the Teso District of eastern Uganda and serves as the administrative center for the Teso subregion, which is one of the most impoverished areas in the country with 53% of the population surviving on less than US$1 per day (Uganda Bureau of Statistics, 2007). Soroti is served by one regional referral hospital, one private hospital, three health centers, and 12 subdispensaries. The regional referral hospital provides tertiary care to a catchment of 1.8 million people and serves as the referral hospital for the surrounding eight districts, though the peripheral health facilities lack the ambulances and telephones necessary for effective referral (Human Rights Network Uganda, 2012; Kaye, 2009). It is the only hospital in eastern Uganda to offer routine fistula repair.

Method

The goal of this research was to use open-ended, semistructured interviews, participant observation, and reciprocal ethnography to examine women's experiences with obstetric fistula with the aim of adding narrative depth to the clinical literature on this devastating birth injury. The Institutional Review Board of Oregon State University approved the research. Local permission was granted by Ugandan health authorities, and verbal consent was obtained from all participants.

Interviews for this project took place primarily between November 2011 and February 2012 with participant observation continuing annually during 1-month long follow-up visits in 2013, 2014, and 2016. Study participants were recruited through a Ugandan NGO dedicated to increasing access to obstetric fistula treatment. Located close to the regional referral hospital, NGO staff members identify women suffering from obstetric fistula in Soroti and surrounding districts through community outreach and fistula awareness activities. Once women with fistulas are identified, the NGO staff members facilitate treatment by providing funds for transportation, medical supplies, psychological counseling,[1] postsurgical care, and social reintegration following treatment.

All women above the age of 18 within the Teso subregion of Uganda who had experienced an obstetric fistula and had either already completed a fistula repair (regardless of the relative success of that repair) or who were preparing for surgery were eligible for participation in this study. There were no participation constraints on the timing of fistula treatment; some women had recently experienced fistula while others had suffered from fistula for many years. Although this study design likely introduced some recall bias for participants, our approach provided the benefit of including women who had lived with fistula for many years before accessing treatment—a condition that is all too common in Uganda, and thus, one that we hoped to capture. We used purposive sampling for recruitment whereby NGO staff members described the study to potential participants during community outreach events, drop-in services at the NGO office, and during visits to the fistula ward at the hospital. Purposive sampling, also called judgment, selective, or subjective sampling, is a nonprobability sampling strategy that relies on a deliberate recruitment of individuals based on a specific set of characteristics or qualities (Bernard, 2006). Participation was voluntary; women self-selected based on a desire to tell their story and were assured that their participation in the study would in no way affect their relationship nor the support service provided by the NGO. A potential limitation of our recruitment strategy is that it excludes the voices of women still suffering from fistula who either do not know about treatment or who know about it, but have not yet been able to obtain treatment.

Our approach also included participant observation (DeWalt & DeWalt, 2011) as the ethnographic foundation for this study. The first author (B.R.) was able to use her positionality as a midwife to assist in the maternity ward at the regional hospital, observing antenatal care, vaginal and cesarean deliveries, and postpartum care. She also accompanied NGO staff members on daily visits to patients in the fistula ward of the hospital and to village-based patient outreach campaigns. Collectively, participant observation allowed us to identify some preliminary thematic categories that we later explored in greater detail during interviews and focus groups.

Individual interviews (*N* = 17) were conducted by Ruder—a nonnative midwife-anthropologist—and local, female translators who were either native *Ateso* or *Kumam* speakers, depending on the study participant's preferred language. Both translators were experienced fistula counselors familiar with the sensitive nature of the subject matter and trained in data collection. All interviews were conducted in the participant's primary language, translated into English by the two local female translators and transcribed. Interviews lasted an average of 1 hour and took place at the NGO office or in participants' homes, depending on the interviewee's preference. As shown in Table 1, we began the interviews by asking participants to describe the birth experience that led to their fistula. Women were also prompted to talk about their lives since developing a fistula. When five interviews were complete, we transcribed and analyzed narratives to produce an initial coding system based on commonly recurring themes. Analysis of the first set of interviews indicated that the process of locating and accessing treatment for the fistula was an extremely distressing, and often overlooked, part of living with fistula. As a result of these findings, we expanded interviews to include explicit questions on (a) the diagnoses and information provided by medical staff following the birth where the fistula occurred and (b) survivors' treatment seeking experiences. Recruitment and interviews continued until no new information contributing to theory building was being supplied and concept saturation was reached (*N* = 17; Charmaz, 2006; Fusch & Ness, 2015; Glaser, 2001).

To assess the reliability and validity of our findings, we utilized reciprocal ethnography (Lawless, 1992) or member checking (Charmaz, 2006), a reflexive technique where research findings are shared with participants during focus groups to allow for further elaboration or critique of the constructs identified during individual interviews. All interview participants were invited and chose to participate in the focus groups. Two focus groups, lasting an average of 2 hours each, were conducted and audio recorded in the participants' native language at the NGO's office, with 10 and seven women participating, respectively. Interview and focus group files were proofread for accuracy following translation and transcription. Transcripts were analyzed for recurring thematic categories using inductive or open coding—an approach whereby emic themes are allowed to "emerge" via a close study of interview transcripts as texts (Charmaz, 2006). Narratives were consensus coded using a process wherein all three authors independently read and coded each transcript, and then met virtually to discuss emergent themes. Themes held in common were identified and those that were unique or divergent were discussed until consensus on the core themes was reached. Thematic categories were continually reviewed and refined by all three authors via close rereadings of transcripts and field notes. The combined use of participant observation, open-ended interviews, and focus groups allowed for the triangulation of emergent themes, while providing greater contextualization of women's experiences with obstetric fistula.

Table 1. Semistructured Interview Guide.

Please tell me the story of the birth that resulted in obstetric fistula.
- Where were you planning to give birth?
- Can you tell me about your labor?
- How long did your labor last?
- Where did you end up delivering?
- Who assisted you?
- What was the outcome for the baby?

Please tell me about your experience living with fistula.
- When did you realize you had an obstetric fistula?
- How did your husband, family, and friends respond?

What were your biggest challenges?

Please tell me about your experience seeking treatment for fistula.
- Tell me about your initial diagnosis.
- How did you learn about fistula treatment?
- How many times did you seek treatment?
- Describe your experience with medical staff when seeking treatment.

How many surgeries have you had for fistula?

Please tell me what you think caused your obstetric fistula.
- Please tell me everything that you think contributed to your injury.

Please tell me what you think could have prevented your obstetric fistula.

Results

As women shared their experiences of the birth that resulted in a fistula and the process of seeking a cure, it soon became clear that participants were using storytelling to try to make sense of their experiences. The chronological details of their stories were punctuated with what Wirtz (2007) has called reflective discourses—a form of therapeutic narrative that enables participants to evaluate, critique, think through, and, in focus groups, compare their suffering: Why did this happen to me? Could it have been avoided? What could have been done to prevent the fistula, or once acquired, how could I have been treated earlier? As women struggled to make sense of their suffering, we were struck by the degree to which emergent themes paralleled Thaddeus and Maine's (1994) three delays model. Participants attributed, and described in great detail, the misery they had endured from prolonged, nonprogressive labors at home (Delay 1), the difficulty of getting to a hospital while laboring once a decision had been made (Delay 2), and then the agony of arriving at a facility, yet still not being able to access immediate care (Delay 3). For fistula survivors, however, we learned that the delays do not end with the delivery of their child. Participants described the pain and suffering, physical and social, that they endured while waiting for a diagnosis and treatment of their fistula. This, we argue, accounts for a fourth delay—the delay in seeking and receiving care for fistula.

Participant Characteristics

Of the 17 interviews conducted, 13 were with women who had already received treatment for their fistulas at the time of the interview; the remaining four interviewees were preparing for surgery. Nine of the 17 women developed the fistula during their first pregnancy, whereas the other eight received the fistula during their fourth or greater pregnancy (participant demographics are summarized in Table 2). The mean age at which the fistula occurred was 20 years, with 10 years of age as the youngest and 35 as the oldest. Five women suffered with their fistula for less than 1 year before successful treatment, whereas the remaining women had the fistula for a mean of 9 years before treatment, with a high of 21 years before surgical repair. Thirteen of their 17 babies died during the labor that produced the fistula, three participants had hysterectomies as the result of uterine rupture, and one participant suffered both vesicovaginal and rectal fistula.

Table 2. Demographic Characteristics, Age at Fistula Occurrence, Marital Status, No. Birth When Fistula Occurred, and Time Living With Fistula Before Receiving Treatment Among Study Participants ($N = 17$).

Characteristics	*n*
Age at fistula occurrence	
Below 18 years	4
18–25 years	6
26–35 years	6
36–40 years	1
Marital status	
Single, never married	2
Remained married	2
Divorced/separated	7
Divorced and reunited	3
Widowed	3
No. pregnancy when fistula occurred	
1st pregnancy	9
3rd pregnancy	1
4th pregnancy	4
8th or 9th pregnancy	3
Time living with fistula before receiving treatment	
1–6 months	4
1–4 years	5
5–9 years	3
10–14 years	2
20–21 years	3

Obstetric Fistula and the Three Delays

The first delay, the delay in the decision to seek care, was attributed to husbands or other decision makers not being present when labor started, anticipated abusive or harsh treatment from midwives at the hospital, a preference for TBAs, or a family history of homebirth that made them less likely to believe facility birth was needed. . The most commonly reported factor involved in delaying the decision to seek care was a lack of financial resources necessary for transportation, medical supplies, and upkeep during the hospital stay. As one participant reported,

> When I started labor at home, my mother-in-law 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." I labored for four days at home. On the fifth day, they just pulled out the dead baby.

For this participant, and many other survivors of obstetric fistula, the decision makers—those who hold the power in the family—never agreed to seek care. Instead she, and thousands of women like her, labor for days at home perpetually suspended in the first delay. In this study, participants reported labors lasting as long as 7 days, as danger signs were missed (or intentionally ignored), resulting in disastrous outcomes for both mother and baby: "My mothers-in-law kept saying it is not yet time. On the third day, the baby's hand came out. Then my uncle rushed me to the hospital on a bicycle, but it was too late."

The second delay—the delay in accessing care—was overwhelmingly attributed to lack of money for transportation. Sometimes husbands were away and did not leave money; other women reported that the family simply did not have enough money for transportation. Additional factors driving this delay included the difficulty of finding viable transportation, particularly at night; impassable roads, especially during the rainy season; and insurgency or political unrest which made travel to a facility too dangerous.

Several women reported making it to the nearest health center, only to experience transportation delays when they were referred to higher level care, as one participant, a mother of two, shared,

> I started labor pains in the garden in the early morning. After breakfast, I went to the Health Center. I was checked by the midwife there, and she assured me I would give birth but just the time, it was not yet the right time. So I stayed in labor the whole day. At around 7:00 p.m. the labor pains worsened, but the baby did not come out. I tried to push the baby and it would not come out. In the morning the midwife again checked and she told me that the baby had lost energy, therefore I needed to be taken to the main hospital. But because of the transportation problem and it still being very early in the morning, we could not go. We reached the hospital at around 2:00 p.m. Getting transport was hard.
>
> When we reached the hospital, the doctor checked me, and I was rushed to the theater. The next morning when I regained consciousness, the doctor told me to have courage because of the news he was about to deliver. He said that the baby had died, and the uterus had also ruptured. They could not repair [my uterus] and had to remove it.

It is important to note that the second delay was reported among participants who lived as close as 3 to 5 miles from the hospital, indicating that infrastructural barriers were significant even within these relatively short distances. Another participant, a mother of four, lived only 5 miles from the hospital. She described this distance as "too far for a woman in active labor to walk"; without the means or a mode of transportation even very short distances can contribute to serious delays. After 2 days of labor, she was eventually pushed to the hospital on a bicycle only to find her baby had already died.

The third delay—the delay in the provision of care—occurred when women arrived at the health facility in labor yet still experienced a prolonged delay before receiving care. Participants reported that this delay was due to shortages of essential supplies at the hospital and severe shortages in the number of medical staff, resulting in what participants often called "negligent care."

Unexpectedly, three of the fistula survivors interviewed had planned hospital deliveries and arrived at the hospital shortly after the onset of labor, and yet acquired their fistula while waiting to receive care at the health facility or at the referral hospital. Overcrowding, staff shortages, and resource scarcity commonly forced women to wait multiple days to receive care, with severe maternal and fetal consequences:

> I started labor in the night and then in the morning I went to the hospital. I stayed there for three days. 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. On the fourth day, they took me to the theater. After the operation, I was told that the child had already passed. After some days, I realized that I was wetting my bed, and as each day passed, the rate of wetting the bed increased.

This woman's story is important because despite having followed the national and international recommendations for safe childbirth—that is, to get to a health facility when labor begins—her birth ended in a fetal demise, a hysterectomy, and an obstetric fistula, after waiting for days in the hospital unattended. Participant observation at the regional referral hospital confirms that this scenario is not uncommon. Labor and delivery wards are almost always full, with the poorest patients lying on mats on the floor, often neglected. Midwives work long hours for a meager salary and must contend with continuous shortages of even the most basic supplies. These factors conspire to create long and often devastating delays in receiving even the most basic of care. Long delays at health facilities, along with the likelihood of neglect and abusive treatment, are well known among rural women, leading some to believe they are better-off delivering in the village with their local TBA.

The Fourth Delay: The Delay in Receiving Treatment for Fistula

In addition to these three delays, survivors of obstetric fistula reported experiencing a fourth delay—the delay in accessing treatment for their fistula. Similar to the three delays identified by Thaddeus and Maine, the fourth delay is a result of the inability to access timely and skilled obstetric care, in this case, to treat their obstetric complication. Participants reported waiting from several months to 21 years to receive treatment. They spoke of this delay in accessing treatment as the most difficult and painful part of their fistula ordeals. Many women did not know about treatment and spent years suffering before learning of the possibility of a cure. Participants also described the experience of returning to their communities with a fistula, which almost invariably resulted in isolation, divorce, and abandonment. Families and communities did not understand the cause of fistula, and women themselves were frequently blamed. Participants described having no pads or means to conceal the incontinence, and no running water to wash away the odor. One participant's story poignantly illustrates the barriers implicated in the fourth delay.

A fistula survivor, who was 38 years old at the time of her interview, came from a large family of seven children and did not have the opportunity to attend school. When she was 14 years of old, she was forced to marry a 16-year-old boy she had never met. Shortly after the marriage, she conceived. She did not attend antenatal care because, at the time, travel by road was unsafe due to political unrest. Likewise, when she started labor, it was not safe to travel to the hospital. She labored at home for 3 days attended only by her mother-in-law. On the fourth day, her mother-in-law was finally able to deliver the baby who died within the hour.

She was devastated by the death of her baby, and what followed intensified her suffering. When she started leaking urine following the birth, her husband's family pressured him to desert her and send her back to her family. Now incontinent, isolated, and mourning the death of her child, she 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 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."

This participant's story is unusual in this regard as she was one of only two women in our study who remained married and felt supported by their husbands following their fistula. Neither she nor her husband had ever heard of an obstetric fistula, and they were unaware that her condition could be treated. When she was around 18 years old, she conceived again. She attended antenatal care this time, but the midwives never told her about treatment for the fistula. When she began labor, she again gave birth at home. Fortunately, the delivery was uncomplicated, and this participant gave birth to a healthy baby girl, followed by five more children in the coming years, all born at home. In her words,

> 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 . . . 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 this participant did not seek out medical care for her births, she and her husband did look for treatment for her fistula. Their first glimmer of hope came when they heard of a hospital in northern Uganda that was offering treatment. They traveled there, and she 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 whatever it was, it was all in vain."

She returned home still suffering from fistula. Eventually her husband heard over the radio that there were doctors coming to a private hospital 60 miles away, so again they traveled in search of treatment. When they arrived, they found 50 women suffering from obstetric fistula waiting to be seen. This participant felt extreme relief to see that she was not alone with her condition, as she met several others, "leaking, just like me." The relief, however, was short lived. As she 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. The white doctor had to leave. The rest of us didn't get treatment."

She and her husband returned home feeling defeated; her only hope was the knowledge that treatment did exist for her condition. However, seeking treatment resulted in an enormous economic burden on her family, as they could not continue to spend precious resources traveling in search of a cure, only to be repeatedly disappointed. Then, in 2005, a staff member from a local NGO visited this participant's village. She met with them, and shortly thereafter with the NGO's help, she again sought treatment. It took two surgeries, but finally after 10 years, she was cured. For the first time in all the years of seeking help, a doctor finally explained to her what had caused the fistula.

The barriers this participant faced in accessing care were not unique. In our study, women commonly reported receiving minimal or inaccurate information from medical personnel and/or receiving a misleading or inaccurate diagnosis. In other participants' words,

> 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.
>
> They just told me that I should go back home. They gave me medicines to swallow, and said I'll be fine. But the problem continued.
>
> When I explained my condition, I wanted to know why I was leaking and the nurse explained that it was too much drip (intravenous) water. The nurse 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. I felt disappointed, especially when I went back home and the local people 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?

Thus, the cause of the fistula was frequently a mystery to participants. Like members of their community, women tended to blame TBAs, doctors, or even witchcraft. These beliefs often were not challenged when women sought medical treatment.

The lack of accurate and clear communication from medical personnel was repeatedly described as a key factor contributing to the hardship participants experienced during the fourth delay, as captured in this participant's reflections during one of the focus groups:

> I was operated on five times. I was not told why the surgeries were not successful. After, the doctor would just tell me to take four or six months and come back. But the reason why it was unsuccessful, I was not told. So I felt that I was going to die with this because there was no treatment for it.

Other participants began to mistrust medical staff. Some talked of being "tricked":

> The tricks from the medical personnel . . . they keep on telling you, "if you take this, you are going to get 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 in 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.

As a result of the fourth delay, participants discussed feeling depressed, hopeless, ashamed, ostracized, and even suicidal:

> That was the worst experience of my life. I felt like 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.

Women who suffered from fistula described enduring harsh, discriminatory treatment from medical personnel. For some, this mistreatment combined with the shame of their condition 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.

The lack of financial resources necessary to access treatment presented an additional barrier. Although user fees were theoretically abolished in Uganda in 2001, charges for transportation, medical supplies, and upkeep during hospital stays, in practice, prohibited fistula survivors from seeking and receiving treatment:

> 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?

Participants described making multiple trips to hospitals and health facilities in search of treatment. Medical staff referred women to higher level hospitals, and radio advertisements announced short-term fistula camps, both of which required financial resources. This referral process, which is routine in high-income nations, resulted in enormous financial costs for victims of obstetric fistula in the Ugandan context:

> At the hospital the doctors checked on me, but I was advised to go back home and come later due to the overwhelming number of patients. When I returned home, my uncle, who had sold the bull for money, spent it all. Therefore, when the time came for me to go back to the hospital, there was no money.

Discussion

Participants' stories describe the profound human costs associated with the three delays and the ways these can result in obstetric fistula, a devastating "near-miss" mortality. Their narratives also call attention to a fourth delay—the delay in receiving treatment for their fistula. For fistula survivors, the fourth delay was at the core of their suffering. This is likely due to the devastating nature and consequences of obstetric fistula—especially social isolation and ostracism. Furthermore, participants' stories elucidate the often-insurmountable barriers women face as they seek treatment. Even women who only waited months for treatment were traumatized by this time, as they were often shunned and rejected by their families when they returned home incontinent. While analyzing their stories, we were continually struck by the realization that these women are the "lucky ones." For every woman who faces challenges in acquiring treatment, many hundreds more are never able to access care.

Women who sought treatment overcame enormous structural barriers. While some women were cured during their first attempt at seeking treatment, many more experienced multiple disappointments at great economic and personal cost. These women demonstrated considerable agency, repeatedly seeking a cure, referred from one hospital to the next, often without a complete or accurate diagnosis. The tragedy of their stories is not only the long waits they endured, the scarce resources wasted, and distances traveled but also the lack of respect they felt they were shown by health professionals as they sought care. Participants described enduring harsh, disrespectful treatment and receiving minimal information from medical personnel. Many also 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. Participants experienced such inaccurate diagnoses and misinformation as cruel and confusing. Most had no choice but to "return home, still leaking and try to find more money to try again."

A body of literature emerging largely from the field of oncology has described the evolution of diagnostic disclosure in biomedicine (Del Vecchio Good, Good, Schaffer, & Lind, 1990; Taylor, 1988), and cultural differences in the extent and quality of the information provided to patients have been well documented (Beyene, 1992; Gordon & Paci, 1997). A limitation of this study is that medical staff were not asked directly about their beliefs and practices around providing a diagnosis to women who experience incontinence after childbirth. However, previous research suggests a few possible causes for this treatment. First, it is important to note that obstetric fistula awareness and treatment campaigns are a relatively recent development with incomplete implementation across Uganda (Velez, Ramsey, & Tell, 2007). Many nurses and medical staff have only recently, if ever, received training on obstetric fistula etiology and prognosis; thus, genuine medical uncertainty may contribute to misdiagnoses.

A second possibility, which may coexist with medical uncertainty, is that the lack of information and inaccurate diagnosis are an extension of the mistreatment and disrespectful care that many women experience during childbirth. Several recent studies that have reviewed decades of research on disrespectful and abusive maternity care (Bohren et al., 2015; Bowser & Hill, 2010; Bradley, McCourt, Rayment, & Parmar, 2016; Freedman et al., 2014), and along with the Universal Rights of Childbearing Women Charter (White Ribbon Alliance, 2011) and the WHO's (2014) statement on the *Prevention and Elimination of Disrespect and Abuse During Facility-Based Childbirth*, have drawn international attention to this pervasive issue. Women in this study corroborated Bohren and colleagues' (2015) findings on the types of mistreatment women experience in childbirth as they shared their own stories of disrespect from health care providers. Furthermore, participants described an escalation of disrespect and cruel treatment during their quest for diagnosis and repair of their birth injury. Fistula survivors described forms of disrespect that included verbal abuse, stigma, discrimination, overt shaming, and targeted humiliation from nurses and midwives, as well as neglect, long delays, ineffective communication, "intentional dishonesty," and health system failures within understaffed and underprovisioned facilities.

As researchers, we grappled with what to make of these stories of misinformation and disrespect. Having witnessed the challenging conditions maternity providers are forced to navigate in Uganda, we find it simplistic to vilify the doctors, nurses, and midwives who sent women home with empty promises of healing that at least some likely knew would not come. Are we to attribute the cases of misinformation to a cultural norm whereby women, and especially poor, fistula-ridden women, are assumed not to be able to understand their condition, and therefore, no viable explanation is forthcoming? Or do fallacious assertions make a strange and tragic kind of sense in a system where providers know a cure is very unlikely to be obtained?

Bradley and colleagues (2016) offered a multilevel framework for understanding the misinformation and other forms of disrespect and abuse in childbirth that exacerbate suffering. Their approach seeks to link the micro-level experience of disrespectful care with meso-level influences such as poverty, gender inequality, poor work environments, and hierarchical/institution-centered thinking and macro-level influences that include colonial legacy, structural inequality, and ineffective health systems, policies, and institutions. Using this framework, it is possible to situate Uganda's maternity care system within a postcolonial context characterized by a highly patriarchal system intent on the institutional control of birthing bodies, massive resource scarcity, and a tendency for skilled providers to leave the country. When combined with pervasive gender inequality, the result may be a maternity care system that functionally delegitimizes women's embodied experiences of childbirth and that all too frequently results in delays that culminate in fistula. In such a system, women may undergo surgery multiple times without receiving any explanation of their diagnosis or for why the surgery was ultimately unsuccessful.

Whereas Bradley and colleagues' conceptual framework recasts blame from individual health workers to larger social and historical forces, Jewkes and Penn-Kekana (2015) have argued that disrespect and shaming of patients may be seen as a strategy health workers employ (albeit unconsciously) as a means of compensating for their own feelings of disempowerment within a hierarchical medical system. Engaging in disrespectful speech and behavior allows for a certain social distancing that begins during medical training (Jewkes, Abrahams, & Mvo, 1998) and continues after initiation into the field. This distancing may enable self-preservation within extraordinarily demanding environments (Hunter, 2004). Difficult working conditions—underprovisioned, understaffed, and overcrowded facilities combined with low pay and low respect—are themselves a form of indirect violence which takes a toll on health care providers (Jewkes et al., 1998) and the women they serve.

Overall, the findings in this study illuminate structural and socioeconomic inequities that create insurmountable barriers to accessing care for many poor, rural, pregnant women. The inability to reach fistula care in a timely manner—what we have called the fourth delay—is a result of macro-level economic forces, social inequality, and structural violence (Farmer, 2003; Galtung, 1969), rather than a personal failure or failure of agency. In Uganda, the impact of 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 delays model and the contextual challenges it describes have 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 pregnant women have a high degree of "choice" in her decision about where to give birth. The intimate narratives fistula survivors provide tell a very different story—a story wherein agency is constrained by poverty and gendered inequality, often with disastrous consequences. Women's experiences of the four delays also extend our understanding of the negative impact of disrespect and abuse in maternity care as they provide a powerful disincentive for women to seek facility-based care, and, all too often, a humiliating experience for those who do.

Conclusion

In conclusion, this study aimed to use ethnographic methods to examine women's experiences with obstetric fistula and to add narrative depth to the clinical literature on this "near-miss" mortality. Findings indicate that women who suffer from fistula navigate multiple barriers in their attempts to access essential obstetric care during labor; these barriers are consistent with the widely cited three delays framework developed by Thaddeus and Maine (1994). However, participants' narratives also extend this scholarship to illuminate a fourth, critical delay—the delay in the diagnosis and treatment of their birth injury. Women's birth and fistula treatment seeking narratives highlight the psychological and social suffering, dehumanizing and disrespectful treatment, and economic burden associated with the fourth delay. As global efforts mobilize to eliminate obstetric fistula, the fourth delay must be more closely examined. In addition to increasing treatment capacity, maternity care systems must also attend to the issues of misinformation, disrespect, and diagnostic disclosure. By widening our lens to reconfigure the fourth delay as a symptom of a larger continuum of disrespect, structural violence, and gendered abuse, the need to intensify global efforts around safe *and* respectful maternity care crystallizes, for safety and respect are inextricable. International efforts focused on reducing maternal mortality must widen their lens to include women who nearly averted death, yet continue to suffer lasting physiologic and psychosocial consequences of their birth experiences.

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Note

1. The nongovernmental organization (NGO) we worked with provides intensive psychological counseling services for fistula survivors, though it is important to note that this is in no way the standard of care in Uganda. Standard fistula care has disproportionately focused on repair of the physical injury with very little, if any, attention paid to the widely reported negative psychosocial sequelae of this birth injury (Tayler-Smith et al., 2013).

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