

ORIGINAL RESEARCH

# Social Experiences of Women with Obstetric Fistula Seeking Treatment in Kampala, Uganda



Marielle Meurice, MD, Rene Genadry, MD, Carol Heimer, PhD, Galya Ruffer, JD, PhD, Barageine Justus Kafunjo, MBChB, MMed, PhD  
*Iowa City, IA; Evanston, IL; Kampala and Mukono, Uganda*

## Abstract

**BACKGROUND** Obstetric fistula is a preventable and treatable condition predominately affecting women in low-income countries. Understanding the social context of obstetric fistula may lead to improved prevention and treatment.

**OBJECTIVES** This study investigated social experiences of women with obstetric fistula seeking treatment at Mulago Hospital in Kampala, Uganda.

**METHODS** A descriptive study was conducted among women seeking treatment for obstetric fistula during a surgical camp in July 2011 using a structured questionnaire. Descriptive statistics were computed regarding sociodemographics, obstetric history, and social experience.

**FINDINGS** Fifty-three women participated; 39 (73.58%) leaked urine only. Median age was 29 years (range: 17-58), and most were married or separated. About half (28, 47.9%) experienced a change in their relationship since acquiring obstetric fistula. More than half (27, 50.94%) acquired obstetric fistula during their first delivery, despite almost everyone (50, 94.3%) receiving antenatal care. The median years suffering from obstetric fistula was 1.25. Nearly every participant's social participation changed in at least one setting (51, 96.23%). Most women thought that a baby being too big or having kicked their bladder was the cause of obstetric fistula. Other participants thought health care providers caused the fistula (15, 32.61%; n = 46), with 8 specifying that the bladder was cut during the operation (cesarean section). Knowing someone with obstetric fistula was influential in pursuing treatment. The majority of participants planned to return to family (40, 78.43%; n = 51) and get pregnant after repair (35, 66.04%; n = 53).

**CONCLUSION** Study participants experienced substantial changes in their social lives as a result of obstetric fistula, and there were a variety of beliefs regarding the cause. The complex social context is an important component to understanding how to prevent and treat obstetric fistula. Further elucidation of these factors may bolster current efforts in prevention and holistic treatment.

**KEY WORDS** Genitourinary fistula, Maternal health, Obstetric fistula, Obstructed labor, Social experience, Uganda.

**Funding Source:** Radulovacki Global Health Scholars Student Summer Fellowship (2011).

**Conflicts of Interest:** The authors have no conflicts of interest to report from the research team. All authors had access to the data and a role in writing the manuscript.

From the University of Iowa Carver College of Medicine, Iowa City, IA (MM); Department of OB/GYN, University of Iowa Hospitals and Clinics, Iowa City, IA (RG); Department of Sociology, Northwestern University, Evanston, IL (CH); Department of Political Science, Northwestern University, Evanston, IL (GR); Department of OB/GYN, Makerere University/Mulago National Referral and Teaching Hospital, Kampala, Uganda (BJK); and Department of Women's Health-Save the Mothers, Uganda Christian University, Mukono, Uganda (BJK). Address correspondence to M.M. ([mmeurice@uci.edu](mailto:mmeurice@uci.edu)).

## INTRODUCTION

Obstetric fistula is a preventable and treatable problem that is believed to affect 1.6-3 women per 1000 in sub-Saharan Africa<sup>1,2</sup> and 2% of women in Uganda.<sup>3</sup> In developing countries, the condition is often caused by a prolonged, obstructed labor. Pressure of fetal parts on the mother's pelvic bones causes tissue necrosis, which can create an abnormal connection between the bladder and vagina and/or rectum. This conduit can unfortunately cause uncontrollable leaking of urine and/or fecal matter.<sup>4,5</sup> The delivery often additionally results in a stillbirth, leading to a devastating combination.<sup>6,7</sup>

Development of health care systems that provide obstetric care for all women in higher-income countries has largely eliminated this tragic condition. But obstetric fistula persists in lower-income countries where less comprehensive services are available.<sup>4</sup> The fact that this condition remains prevalent is unacceptable and signals a failing health system for women that does not protect human rights.<sup>8</sup> The presence of obstetric fistula often makes future pregnancies difficult, preventing women from conforming to the social expectation of childbearing.<sup>9</sup> A study in Tanzania that focused on social and cultural aspects of obstetric fistula found that women were often discriminated against in social situations and experienced lack of control from being incontinent. They felt less important because they could not fulfill their societal expectations.<sup>10</sup> A meta-analysis looked at some of the social consequences of obstetric fistula, reporting that marriage and home life were often affected, as well as participation in social and religious occasions.<sup>11</sup> A conclusion from an integrative review on the social effects of obstetric fistula in Africa concluded that obstetric fistula had at least a moderate consequence on social functioning. They also found that stigma and shame were highly prevalent.<sup>12</sup> Other studies have confirmed the high morbidity in the psychosocial realm.<sup>9,13,14</sup>

The focus on obstetric fistula in Ugandan and other studies are often medical, with further need for the elucidation of the influence that social factors play in the prevention and treatment of this condition. How obstetric fistula is socially perceived and how it affects the social lives of those who suffer are also important aspects of this condition. The surgical and medical care alone will not be effective unless they work together with social solutions. Only when we know how women socially perceive the problem and what impediments they face in getting obstetric care will we be equipped to use resources wisely to make

fistula prevention and care truly accessible to women. Understanding the social context of this condition may lead to improved preventive measures and holistic treatment, bolstering current efforts.

## METHODS

A survey was conducted and designed with qualitative and quantitative components. The study was implemented at Mulago National Referral and Teaching Hospital in Kampala, Uganda. This site provides treatment in both routine and surgical camp settings that is free to patients with obstetric fistula; however, costs of transport and other associated costs are not covered and can be prohibitive. During the surgical camps, many women are provided with surgery in a short period. The public funding attracts a diverse group of patients, particularly because treatment is free as a result of assistance from various nongovernmental organizations.

For this study, participants were identified among those seeking treatment with the help of the medical team during a camp in July 2011. Announcements were made to those awaiting treatment or recovering postoperatively. All those older than 18 or those with parental consent who were seeking treatment for obstetric fistula were eligible to participate. Exclusion criteria included those younger than 18 without parental consent, those with fistula as a result of a nonobstetric cause, and those unable to communicate effectively in Luganda. We used a structured questionnaire was administered orally with a translator who was trained as a nurse and had prior experience with research translation. Interviews lasted between 30 minutes to 1 hour. Informed consent was received in Luganda before the start of the interview with signatures or equivalents recorded as a sign of consent. Participants were given a small sum of money as an incentive to participate regardless of level of completion of the study. Throughout the study, they were reminded that they were free to leave the interview at any time or skip any question they were not comfortable answering.

Ethical clearance was obtained through Northwestern University's Institutional Review Board and locally at the Makerere College of Health Sciences in the Department of Obstetrics and Gynecology before the start of the study. Paper surveys were transferred to and stored in a Microsoft Excel database, where they were analyzed. Descriptive statistics were computed to describe demographics, marital status, obstetric history, the birth causing the fistula, and social experience. Free response data on the cause of

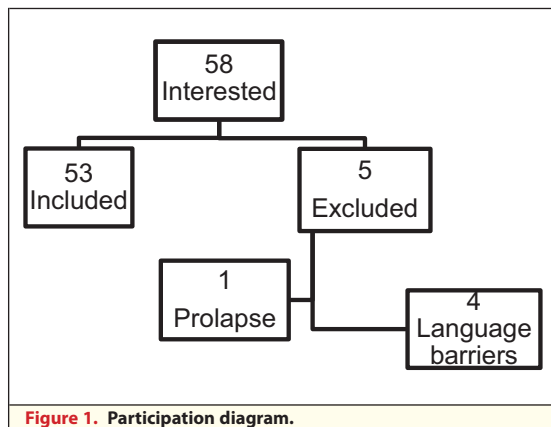


Figure 1. Participation diagram.

the fistula was grouped by theme and then analyzed as described earlier.

## RESULTS

A total of 53 women with obstetric fistula were included in the study and 5 were excluded (Fig. 1). The median age was 29 years old (range: 17-58 years); most identified with some form of Christianity (45, 73.58%; n = 53), lived in an urban residence (33, 62.26%; n = 53), and traveled a median of 4 hours to get to Mulago for treatment (range 5-24 hours). The education level was found to be mostly primary education (34, 64.15%; n = 53), with 5 women without any formal education (9.43%, n = 53) and 3 women with tertiary/college/university (5.66%, n = 53). There were 15 ethnic groups represented in this sample, with 20 reporting Ganda (37.73%, n = 53).

The most common response for current marital status (Table 1) was married (25, 47.17%; n = 53) and the second most common response was separated (13, 43.40%; n = 53). Fifteen women reported that their husband/boyfriend had other wives (28.3%, n = 53). The average age of first marriage was 18.2 years ( $\pm 3.13$ , n = 43). When asked about their “next of kin” or who takes care of them, 29 (56.86%, n = 51) reported husband/boyfriend and 4 had no next of kin (7.84%, n = 51). There were 13 (25.49%, n = 51) whose attendant at the hospital was the same person as their next of kin. Almost half reported a change in relationship status after the occurrence of their fistula (23, 47.92%, n = 48), with 6 remarrying or finding a boyfriend after obstetric fistula occurred.

Patients were most likely to be exclusively leaking urine (39, 73.58%; n = 53), with 13 women having either leaking feces or a combination of urine and feces (22.41%, n = 53). Clinical data were not col-

Table 1. Sociodemographic History

Variable	n	%
Age median (min-max)	29 (17-58)	
Religion		
Catholic	20	37.74
Protestant	14	26.42
Muslim	8	15.09
Pentecostal/saved	11	20.75
Home location		
Rural	19	35.85
Urban	33	62.26
Not recorded	1	1.89
Median transit time to Mulago from home (hr)	4 (0.5-24)	
Education		
No formal education	5	9.43
Primary	34	64.15
“O” level	10	18.87
“A” level	1	1.89
Tertiary/college/university	3	5.66
Current marital status		
Married	25	47.17
Living with a man	2	3.77
Single	9	16.98
Widowed	3	5.66
Divorced	0	0.00
Separated	13	43.40
Other	2	3.77
Polygamous relationship		
Yes	15	28.30
No	27	50.94
Not applicable	7	13.21
Unknown	4	7.55
Age first married (n = 43)		
Average ( $\pm$ SD)	18.2 (3.13)	

SD, standard deviation.

lected on the physical location of the fistula, but the median time suffering from obstetric fistula was 1.25 years (min: 0.038, max: 36, n = 52). The average number of total births per person was 3.32 ( $\pm 2.82$ , n = 52), with a maximum reported 13 births. Most participants were around 20 years old for their first birth ( $19.53 \pm 3.96$ , n = 53). Obstetric history is further characterized in Table 2.

When asked about the birth that caused the fistula (Table 2), 7 reported that they had given birth since getting obstetric fistula. More than half acquired obstetric fistula during their first delivery (27, 50.94%; n = 53). During this birth that resulted in obstetric fistula, almost every participant received some form of antenatal care (50, 94.34%; n = 53) and the majority had at least 4 visits (30, 56.60%; n = 53).

**Table 2. Obstetric and Reproductive History**

Variable	n	%
Type of fistula		
Leaking urine	39	73.58
Leaking feces	9	16.98
Leaking both urine and feces	4	7.55
Not recorded	1	1.89
Median number of births (n = 52) (min-max)	3 (1-13)	
Age at first birth		
Median	19	
Minimum	13	
Maximum	30	
Did most recent birth cause obstetric fistula		
Yes	46	86.79
No	7	13.21
Number of birth causing obstetric fistula		
Median	1	
Min	1	
Max	13	
First birth caused fistula	27	50.94
Antenatal visits		
Yes	50	94.34
No	3	5.66
Four or more antenatal visits	30	56.60
Fetal outcome		
Live birth	19	35.85
Stillbirth	31	58.49
Neonatal death	2	3.77
Did not respond	1	1.89
History of cesarean section	31	58.4
Fetal outcomes with history of cesarean section		
Still birth	24	77.42
Live baby	7	22.58

Stillbirth was the most common neonatal outcome (31, 58.49%, n = 53), followed by live birth (19, 35.85%; n = 53).

When discussing how obstetric fistula affected the social lives of those seeking treatment (Table 3), the majority reported being treated differently in one or more settings (28, 52.83%; n = 53). These statistics may underestimate the social effects of obstetric fistula because many women reported avoiding social interactions and thus said they were not treated differently. The most commonly reported situation was being treated differently by their husband (21, 44.68%; n = 47), with the second most common being treated differently by in-laws (9, 34.62%; n = 26).

One explained that “once he knew he never turned back,” when describing her husband’s reaction to her condition.

**Table 3. Social Experience of Obstetric Fistula**

Variable	n	%
Unaware of obstetric fistula before getting it	43	81.13
Since acquiring obstetric fistula, treated differently*:		
By husband (n = 47)	21	44.68
By children (n = 32)	6	18.75
By in-laws (n = 26)	9	34.62
By other family members (n = 47)	11	23.40
By faith community (n = 37)	6	16.22
At work (n = 16)	4	33.33
At social functions (n = 22)	1	4.55
Reported 1 or more experience of different treatment	28	52.83
Lifestyle/participation changed in:		
Social functions (n = 52)	51	98.08
Religious life (n = 51)	36	70.59
Community groups (n = 39)	29	74.36
Community/village meetings (n = 38)	24	63.16
Business/market (n = 31)	13	41.94
Relationship with husband (n = 46)	31	67.39
Relationship to peers (n = 40)	24	60.00
Relationship with children (n = 44)	19	47.50
Relationship to in-laws (n = 27)	16	61.54
Relationship to other community leaders (n = 36)	13	36.11
Reported 1 more changes in lifestyle/participation	51	96.23
Reports situation where she was embarrassed by her condition	41	77.36
Know other treated for obstetric fistula before coming to Mulago	31	58.49
If yes, did it influence their decision to get treatment (n = 31)	26	83.87
Will return to family after treatment (n = 51)	40	78.43
Wanted children after treatment	35	66.04
Median (min-max)	1 (0-5)	
Local names for those suffering from obstetric fistula (n = 14)		
One who is watery— <i>Namazzi</i>		
Suffering from bladder problem/condition— <i>“Kawago,” “abulwadde bw’akawago,”</i>		
Dripping urine— <i>Batonya omusulo</i>		
It is raining— <i>“enkuba etonya”</i>		
Rags— <i>Biwero</i>		
Those leaking urine— <i>Abatonya omusulo</i>		
The rain is raining— <i>Enkuba etonya</i>		

\* Some patients were reported not applicable (NA) because they were no longer attending.

Another described her first husband, saying that he stayed by her side for two operations and attended to her and provided help and money. However, when he saw no improvement, he stopped coming and giving

her money. But she remarried and her second husband was very kind. Another woman shared that since she got this condition, she doesn't go to social events because she was fearful of what would happen.

When asked how their participation changed in different social settings, almost all participants reported a change (51, 96.23%; n = 53). The most commonly described were changes in participation at social functions (51, 98.08%; n = 52), in community groups (29, 74.36%; n = 39), and in religious life (36, 70.59%; n = 51).

A woman described her participation in social functions as "worried and very unhappy" and that she would "sit until others go away and then she can move."

One woman reported in her religious life that, "I cannot sit for long in the mosque without going outside." Another said she couldn't go because she couldn't stand up. Yet another was told not to come to church because was leaking urine, unclean, and was not allowed to join the prayers.

In the relationship with participants' husbands, one reported that "sex is very difficult [...and she] feels lots of pain" and another that she "feels ashamed of the feces."

It was common to have experienced an embarrassing event related to obstetric fistula (41, 77.36%; n = 53).

One woman explained that she was at a funeral service and clothes got wet and she felt ashamed.

Another reported attending a wedding and feeling ashamed that she has soiled her clothes.

Feelings of shame were pervasive throughout the descriptions of social interactions. Despite this, 48 of 53 reported having someone who was especially kind to them while they had their fistula—oftentimes describing family members contributing to treatment costs or encouraging them to seek treatment.

Participants were asked about what they thought caused obstetric fistula (Table 4). Most participants believed the baby was the cause of obstetric fistula (21, 39.62%; n = 53)—for example, 11 felt that the baby was too big (20.75%, n = 53), 6 reported that the baby "kicked the bladder" (11.32%, n = 53), 1 reported that the baby died (1.89%), another reported that the "baby stayed without coming out" (1.89%), and 2 others did not specify how the baby contributed to their condition (3.77%, n = 53). Almost a fourth of the participants attributed their fistula directly to the labor and/or delivery (14, 26.42%; n = 53).

**Table 4. Perceived Cause Obstetric Fistula**

Variable	n	%
Patient perspective of cause of obstetric fistula (n = 53)		
Caused by baby	21	39.62%
Caused by labor/delivery	14	26.42%
Caused by delay	11	20.75%
Caused by provider	10	18.87%
Caused by TBA/Unskilled birthing attendant/home delivery	3	5.66%
Other	5	9.43%
Unknown	2	3.77%
Patient's report of others' perspective of cause of obstetric fistula (n = 46)		
Caused by provider	15	32.61%
Caused by labor/delivery	8	17.39%
Caused by baby	8	17.39%
Caused by delay	7	15.22%
Caused by not accessing hospital/home delivery	4	8.70%
Caused by curse	2	4.35%
Other	7	15.22%

TBA, traditional birthing attendant.

Some specified that the labor was long (10, 18.87%; n = 53) or that it was painful (1, 1.89%; n = 53), and others did not specify how the labor and delivery contributed to their fistula (3, 5.66%; n = 53). There were participants who recognized that delay—either at their home or in getting to the hospital, for example—were responsible for their fistula (11, 20.75%; n = 53). A similar number of people blamed their health care provider for directly causing their fistula (10, 18.87%; n = 53). In this group, 5 participants specifically said that a doctor cut them during the operation (presumably meaning the cesarean section; 9.43%, n = 53). Another blamed the vaginal examination for her problems. Three participants reported either giving birth at home or having their birth attended by an unskilled person or traditional birthing attendant (5.66%, n = 53). There were 5 other causes reported: being young, being cursed, having a full bladder, having had multiple previous children, and losing energy during the process (9.43%, n = 53). Finally, 2 did not have any explanation for the cause of their fistula (3.77%, n = 53).

When asked about what other people the participants knew thought was the cause of obstetric fistula, the responses were different (Table 4). There were more reports of obstetric fistula being caused by health care providers (15, 32.61%; n = 46), with more than half of them specifying that it was during

the operation that the obstetric fistula formed (8, 17.39%;  $n = 46$ ). Labor and delivery was also discussed as a cause, as well as the baby being large or kicking the bladder. Delay was reported by 7 (15.22%,  $n = 46$ ); for example, people were blaming the study participant because she didn't come to the hospital immediately. Two participants reported that people believed that obstetric fistula was caused by a curse (4.35%,  $n = 46$ ).

People say she has “been cursed because they’ve never seen that condition before.”

There were other reports of financial difficulty in getting to the hospital as the cause, issues with transportation, young age, and having many children.

One individual said that people think she's the one who caused it because she “refused to push it out.”

Another reported that she got obstetric fistula because she didn't use local medicines that would have softened her bones.

Fourteen participants reported that there were local words used to describe obstetric fistula or those suffering from obstetric fistula, which mostly revolved around describing urine leaking, rain, water, or rags (Table 3). Five participants reported using local treatments, such as the traditional birthing attendant giving capsules, traditional medicines to put in water and sit in or drink, and local medicines to be taken during pregnancies.

A minority knew about the condition before acquiring it (20, 37.74%;  $n = 53$ ), but the majority knew someone treated for obstetric fistula before coming to Mulago for their treatment (31, 58.49%;  $n = 53$ ). Many of those who knew someone before getting treatment reported that it influenced their decision to come to seek treatment (26, 83.87%;  $n = 31$ ). After treatment, most reported that they would be returning to their family (40, 78.43%;  $n = 51$ ) and most were interested in having at least 1 more child after their repair (35, 66.04%;  $n = 53$ ).

## DISCUSSION

This study represents a preliminary descriptive analysis of some of the social factors that influence the experience of obstetric fistula of those seeking treatment at Mulago National Referral Hospital in Kampala, Uganda during a fistula camp during the summer of 2011. With 53 participants, a preliminary understanding of the social context of obstetric

fistula can be gleaned. The average participant in this study was around 30 years old, from an urban setting, either married or separated, had acquired obstetric fistula during her first pregnancy during which she had antenatal care, experienced a change in her social situation, and was hoping to return home to her family and get pregnant after her repair. Embarrassment and shame were commonly expressed during the interviews. Patients did not see the health care system as the root cause of the fistula, but rather blamed the direct causes such as delay, the baby size, delivery methods, medical errors, and so on.

There were a higher number of participants who hailed from urban areas, which has been found in other obstetric fistula studies.<sup>15</sup> Additionally, there was an older age of marriage reported, which conflicts with some of the understanding that obstetric fistula is acquired by mothers who get pregnant at very young ages<sup>4</sup>; the variety of ages that are affected have been found in other studies in Uganda.<sup>9</sup> This may be explained by the nonrandom sampling method that was employed, which may have resulted in a group of participants who are relatively advantaged and able to seek treatment.

Many participants remained married or had found a new partner since acquiring obstetric fistula. Unsurprisingly, the occurrence of the fistula caused a change in their relationship—which has been characterized in Uganda from the male perspective.<sup>16</sup> This change may be particularly devastating in a culture where women often depend on their partners for their livelihoods. Many were provided for by husbands or boyfriends, which may have helped them gather the resources necessary to seek treatment, even if it was provided free of cost. The median of only 1.25 years of suffering from the condition also supports the idea that this could be a higher resource population, although even a year with this condition would be devastating. Additionally, the finding of 3 women with college level education was particularly unusual. These college-level women could have had iatrogenic fistula, but this was not established because data regarding fistula location were not collected.

The high level of antenatal care is a paradoxical result also found in the study in Niger.<sup>15</sup> This means that women are seeking and acquiring care during their pregnancy but presumably have enough delay in accessing care during their delivery to acquire obstetric fistula. Further study is required on the level, type, and quality of services that are being provided at these antenatal care visits, if adequate education on obstetric fistula prevention is provided, and why patients are able to access this antenatal care but not

able to get adequate care to prevent obstetric fistula at the time of delivery. A study from Tanzania focused on women who were unable to access prompt care during their delivery and concluded that social and financial factors contributed, as well as the need for more trained personnel for adequate care on arrival at a facility.<sup>10</sup> Again, this finding in our study in part may be due to the nonrandom sampling that captured participants with the resources to seek care and may not be representative of the average sufferer of obstetric fistula.

The social lives of the participants in this study were altered because of their medical condition. Many were treated differently in different social situations and through their different relationships (ie, with husband, in-laws). Additionally, their engagement in social situations was affected by their condition. These facts help to support the previously known social implications of this devastating disease. There were pervasive reports of obstetric fistula causing embarrassment and shame throughout the accounts of the participants. Even though the average amount of time living with the fistula was a median of around a year, many reported having significant difficulty during that time. Interestingly, most of the examples that women gave for how their participation had changed or how an embarrassing situation occurred were a time when this happened in public. This means that social situations remain important for these women in those cases. In a low-resource setting, lack of means to accessing incontinence products if surgery is unavailable may further exacerbate the ability to cope with their medical condition.

Further understanding how the participants and people that they know conceptualize the cause of the disease is particularly important in regard to improving education. A study in Nigeria found that health care providers differed in their understanding of the cause compared with patients, with providers more likely to believe that obstetric fistula was caused by patients choosing to give birth at home as a result of traditional practices versus patients' reports of attempts to deliver in a facility and that obstetric fistula was caused by lack of adequately skilled staff or other issues at the facility.<sup>17</sup> In our cohort, ideas such as obstetric fistula being caused by the baby kicking the bladder, curses, or a health care provider who cut a hole in the bladder were all reported. These beliefs may hinder prevention efforts, particularly if there is mistrust of a provider's examination or necessary cesarean section interventions. A project in rural Uganda asked similar questions to patients and family members and had similar findings of feeling that pro-

viders or the hospital were responsible.<sup>9</sup> Another study in Rwanda found similar mistrust of medical providers, blaming the provider for directly causing their problem in certain accounts.<sup>18</sup> Given the high prevalence of antenatal care in our cohort, there is certainly hope that better preventative education could be provided to women. The fact that only about a third had heard about obstetric fistula before delivery may indicate that obstetric fistula was not a priority in antenatal care. However, given limited resources it is understandable that not every topic can be covered.

Although less likely, it is possible that the cesarean section itself could have contributed to some of the cases of fistula. A recent study in Ethiopia found increasing numbers of "high" fistulas that occurred after the cesarean section rather than "low" fistulas, which are more commonly caused by obstructed labor.<sup>19</sup> A review article recently published also supports the idea that there may be more iatrogenic fistulas than previously thought.<sup>20</sup> Further clinical examination would be required to clarify the true cause of the fistulas in this study and in other women in Uganda experiencing obstetric fistula. The fact that there were higher resourced patients (eg, those with college education) as well as a relatively high rate of live births (19, 35.85%) could indicate a subset of the population had iatrogenic injury. A total of 31 (58.4%) of the participants had delivered by caesarian sections. The subset who had a live birth were less likely to have delivered by cesarean section than the group with other fetal outcomes (7, 36.8% vs. 24, 72.7%). As stated before, the study was not designed to differentiate between iatrogenic and obstructed labor as the cause of the fistula. Another study is needed to investigate this.

Despite some of these possible misconceptions there were many more commonly described true causes of obstetric fistula, such as difficult delivery, delay at home or in getting to the hospital, and giving birth without a qualified attendant. In these situations, education alone may not be sufficient in preventing obstetric fistula. Rather, determining how to get women to timely emergency obstetric care might be most helpful. Reinforcing these concepts during antenatal care may be helpful in prevention.

Several women reported local words being used to describe their condition. Understanding and continuing to gather these terms may be helpful in bolstering awareness campaigns that could ultimately help with prevention as well as decreasing stigma. Additionally, advertisements for treatment might also be better understood. Knowing someone else who had obstetric fistula was reported as being

a factor that led to the patient seeking treatment. Using these networks and/or having a spokesperson talk about her experience are possible ways to also add to the current efforts in improving treatment and prevention.

Understanding that most women intended to return home to their families and have future pregnancies is important in perioperative counseling as well as in understanding this population's goals. Focusing on the importance of family planning may be important, as well as discussing expectations after surgery and, if possible, how to proceed with a future healthy pregnancy and delivery. Further research may be needed to determine the outcome of social reintegration after repair. One study done in Tanzania looked specifically at psychological well-being after repair, reporting improved mental health 3 months after discharge, but this improvement was not found if leaking continued. They found it important to educate on the possibility that the repair might not be successful in resulting in complete dryness and to provide coping skills if this was the case.<sup>21</sup> A study in Malawi found similar rates of interest in future childbearing and reported that reintegration was relatively easy for these women. However, women continued to have difficulty in their lives relating to fertility and relationships.<sup>22</sup> A study in Uganda on reintegration is currently underway.<sup>23</sup>

This study is limited by its small sample size and short study period. Additionally, the nonrandom sampling only captured those able to get to Mulago for treatment and may have socioeconomic and regional biases that may not be applicable to all women suffering from obstetric fistula in Uganda. Additionally, bias may be introduced in translation and analysis, particularly because the primary author does not speak Luganda. There were particular difficulties in

estimating years and there were cultural nuances discovered during the study in the understanding of marriage—with a much broader interpretation than what is most commonly understood in the United States. Despite these limitations, this information still represents primary accounts of women suffering from obstetric fistula, adds to the body of knowledge on the social experience of obstetric fistula in Uganda, and may be helpful particularly to prevention and treatment efforts in the region surrounding Kampala.

## CONCLUSIONS

To conclude, this study represents a preliminary analysis of the social context surrounding the experience of obstetric fistula for women seeking treatment at Mulago National Referral Hospital in Kampala, Uganda. The demographic information, social effects of obstetric fistula, and understanding of the cause of obstetric fistula are all important aspects of this study that have ramifications for prevention and treatment efforts for this complex condition. Further work must be done to fully characterize how obstetric fistula affects women in Uganda, particularly those living more remotely who may not be represented in this study. The high rates of antenatal care are a promising aspect of the findings, with potential for improved counseling on the of the cause and what to do in order to prevent it. Further understanding of whether obstetric fistula is being caused iatrogenically may also be important. Capturing populations unable to seek treatment, although challenging, would provide more generalizable information that may lead to better prevention and treatment for those who are in the most need. Overall, obstetric fistula is a tragic, preventable, and treatable condition that must be studied further so that it can be ended.

## REFERENCES

1. Adler AJ, Ronsmans C, Calvert C, Filippi V. Estimating the prevalence of obstetric fistula: a systematic review and meta-analysis. *BMC Pregnancy Childbirth* 2013;13:246.
2. Maheu-Giroux M, Filippi V, Samadoulougou S, et al. Prevalence of symptoms of vaginal fistula in 19 sub-Saharan Africa countries: a meta-analysis of national household survey data. *Lancet Glob Health* 2015;3:e271–8.
3. Uganda Bureau of Statistics (UBOS) and ICF International. *Uganda Demographic and Health Survey 2011*. Kampala, Uganda and Calverton, MD: UBOS and ICF International; 2012.
4. Wall LL. Obstetric vesicovaginal fistula as an international public-health problem. *Lancet* 2006;368:1201–9.
5. Neilson JP, Lavender T, Quenby S, Wray S. Obstructed labour. *Br Med Bull* 2003;67:191–204.
6. Ahmed S, Anastasi E, Laski L. Double burden of tragedy: stillbirth and obstetric fistula. *Lancet Glob Health* 2016;4:e80–2.
7. Cowgill KD, Bishop J, Norgaard AK, Rubens CE, Gravett MG. Obstetric fistula in low-resource countries: an under-valued and under-studied problem—systematic review of its incidence, prevalence, and association with stillbirth. *BMC Pregnancy Childbirth* 2015;15:193.
8. Osotimehin B. Obstetric fistula: ending the health and human rights tragedy. *Lancet* 2013;381:1702–3.
9. Women's Dignity Project & EngenderHealth. *Sharing the Burden: Ugandan Women Speak About Obstetric Fistula*. Dar es Salaam, Tanzania: EngenderHealth; 2007. Available at:



- <https://www.engenderhealth.org/files/pubs/localized/uganda/sharing-the-burden-ugandan-women-speak-about-obstetric-fistula.pdf>. Accessed September 17, 2016.
10. Mselle LT, Kohi TW. Living with constant leaking of urine and odour: thematic analysis of socio-cultural experiences of women affected by obstetric fistula in rural Tanzania. *BMC Womens Health* 2015;15:107.
  11. Ahmed S, Holtz SA. Social and economic consequences of obstetric fistula: life changed forever? *Int J Gynaecol Obstet* 2007;99(Suppl 1):S10-5.
  12. Roush KM. Social implications of obstetric fistula: an integrative review. *J Midwifery Womens Health* 2009;54:e21-33.
  13. Siddle K, Mwambingu S, Malinga T, Fiander A. Psychosocial impact of obstetric fistula in women presenting for surgical care in Tanzania. *Int Urogynecol J* 2013;24:1215-20.
  14. Semere L, Nour NM. Obstetric fistula: living with incontinence and shame. *Rev Obstet Gynecol* 2008;1:193-7.
  15. Meurice ME, Genadry RR, Bradley CS, Majors B, Ganda SO. Identifying barriers to accessing information and treatment for obstetric fistula in Niamey, Niger. *Proc Obstet Gynecol* 2016;6:Article 1.
  16. Barageine JK, Faxelid E, Byamugisha JK, Rubenson B. "As a man I felt small": a qualitative study of Ugandan men's experiences of living with a wife suffering from obstetric fistula. *Cult Health Sex* 2016;18:481-94.
  17. Phillips BS, Ononokpono DN, Udofia NW. Complicating causality: patient and professional perspectives on obstetric fistula in Nigeria. *Cult Health Sex* 2016;18:996-1009.
  18. Kay A, Nishimwe A, Hampton BS. Giving voice to the experiences of Rwandan women with urogenital fistula. *Ann Glob Health* 2015;81:636-44.
  19. Wright J, Ayenachew F, Ballard KD. The changing face of obstetric fistula surgery in Ethiopia. *Int J Womens Health* 2016;8:243-8.
  20. Hilton P. Trends in the aetiology of urogenital fistula: a case of "retrogressive evolution"? *Int Urogynecol J* 2016;27:831-7.
  21. Wilson SM, Sikkema KJ, Watt MH, Masenga GG, Mosha MV. Psychological symptoms and social functioning following repair of obstetric fistula in a low-income setting. *Matern Child Health J* 2016;20:941-5.
  22. Drew LB, Wilkinson JP, Nundwe W, et al. Long-term outcomes for women after obstetric fistula repair in Lilongwe, Malawi: a qualitative study. *BMC Pregnancy Childbirth* 2016;16:2.
  23. Byamugisha J, El Ayadi A, Obore S, et al. Beyond repair—family and community reintegration after obstetric fistula surgery: study protocol. *Reprod Health* 2015;12:115.