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ORIGINAL ARTICLE

Childbirth experiences of women with obstetric fistula in Tanzania and Uganda and their implications for fistula program development

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Abstract
Introduction and hypothesis Authors sought evidence from the testimonies of women living with fistula regarding local risk factors for fistula and the impact of fistula on women's lives.
Methods One hundred thirty-seven women recruited from health facilities and at the community level in Tanzania and Uganda were interviewed using quantitative and qualitative methods, including participatory approaches.
Results Women of all ages and parities endured fistula. The testimonies illustrated that physical, socio-economic and cultural constraints, as well as health system failures, led to fistula, and the condition imposed harsh consequences on women's lives. Constraints included deficient maternal health services and personnel, delays in seeking and accessing care, and limited fistula repair services. Women endured severe social stigma and severe economic hardships.
Conclusions Participants' testimonies expand current understanding of women's experience of fistula and point to recommendations that could improve maternal health care, reduce women's risk of fistula, and improve the lives of women living with the condition.

Keywords Maternal morbidity · Obstetric fistula · Tanzania · Uganda

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Introduction

Obstetric fistula is a devastating maternal morbidity which leaves a woman with uncontrollable leaking of urine and/or feces from her vagina. Untreated, fistula leads to debilitating health problems, unremitting wetness and odor, and the stigma surrounding the condition. The impacts of fistula are extreme.

The continued existence of obstetric fistula is a clear marker that health systems are failing to meet women's reproductive health needs. Substantial numbers of women in Tanzania and Uganda—the two countries in the current study—are affected by these near-miss maternal deaths [1]. A proxy measurement of national prevalence in Uganda alone indicates that the condition may be far more common than suggested by the 1990 Global Burden of Disease (GBD). An estimated 2.6% of women of reproductive age (15–49 years) reported experiencing the primary symptom of fistula: "uncontrollable leakage of urine or stool from her vagina" [2]. Based on the population of women in that age

bracket from the most recent national census, this equates to a prevalence of fistula of over 142,000 women in Uganda [3]. Prevalence in Tanzania is not known, and data on incidence in the two countries are also lacking. However, the exceptionally high maternal mortality and low availability of emergency obstetric care in both countries likely indicate high fistula prevalence. Only 5.5% and 3.6% of health centers in Tanzania and Uganda, respectively, are equipped and staffed to provide even basic emergency obstetric care [4, 5]. Moreover, the estimated rate of cesarean births is also extremely low at 3% in both countries [2, 6].

Fistula has only recently gained visibility within national and international development agendas, and contemporary published work on fistula has been described as "woefully inadequate by the standards of 21st century evidence-based medicine" [7]. Epidemiologic data are extremely limited and a recent comprehensive review of literature on fistula concluded that there are no solid population-based estimates of the numbers of obstetric fistulas [8]. The 1990 GBD report estimated that 654,000 women worldwide were living with recto-vaginal fistula [9]; other estimates put the prevalence of women affected by both vesico-vaginal and recto-vaginal as high as 3.5 million [7].

The delivery experiences of women who endured poor obstetric outcomes such as fistula provide important information about the precursors to fistula formation and suggest needed changes to obstetric care. Pregnant women in resource-poor settings commonly face significant obstacles to reaching a facility able to provide quality care at delivery. These obstacles include distance to, and cost of, reaching facilities; costs of medical care; inadequate health infrastructure; lack of equipment, supplies and medications; severely limited human resources; hospital procedures that are socially unacceptable; societal perception that childbirth is a natural event and does not warrant special measures; and institutionally and culturally embedded discrimination leading to feelings of powerlessness and fear at the time of childbirth [10–13]. A number of these obstacles disproportionately affect women [13].

Women's Dignity and EngenderHealth conducted this study on obstetric fistula in Tanzania and Uganda to explore whether women's experiences of their "near-miss" deaths and experiences living with fistula could provide essential information for strengthening maternal health policies and programs and those specifically addressing fistula.

Methods

The study was conducted in three districts and one hospital in Tanzania in 2003 and in four districts in Uganda in 2005. Data included 137 interviews with women with obstetric fistula (61 in Tanzania; 76 in Uganda). Information was also gathered through participatory methods from 391 members of women's families and communities, health care providers, and traditional birth attendants (TBAs) (Table 1). Findings from women are reported here. Due to space limitations, findings from other participants will be reported in a separate paper.

Due to the stigma surrounding fistula and the difficulty in identifying women with the condition, women were recruited at health facilities and through selected community visits. In Tanzania, 52% of the women, and in Uganda 32% of the women, were recruited as they awaited or were recovering from fistula repair at facilities. The remaining women were recruited at the community level by local health workers and researchers who visited villages of women interviewed at the facilities.

Semi-structured in-depth interviews were conducted with women. All survey instruments were developed in English and translated into local languages. Written informed consent was obtained from the women with fistula. The research was approved by the National Institute of Medical Research in Tanzania and the Ugandan Ministry of Health.

Field researchers included staff from Women's Dignity and partners in each of the research sites. Hand-written notes were reviewed following each interview and at the end of each day and then transcribed onto recording forms. Completed forms were translated into English, and a second translator checked the text. A codebook was created for data analysis, and at least two individuals coded each text segment using Atlas-Ti. Revisions were made to the codebook, and data was recoded to ensure consistency. A preliminary report was shared with participants and key stakeholders.

Results

Age and parity at fistula and outcome for infant

The median age of the women interviewed in Tanzania when they sustained fistula was 23 years and 19 years in Uganda (Fig. 1). Nearly 44% of women in both countries had parity

Table 1 Categories and numbers of participants

Participants	Tanzania	Uganda	Total
Women with fistula	61	82[a]	143
Family members	42	63	105
Community members	68	120	188
Healthcare providers	23	21	44
Traditional birth attendants	–	54	54
Total	194	340	534

[a] Six women in Uganda did not participate in in-depth interviews and were involved in problem-tree exercises only

two or higher when they sustained fistula, while approximately 53% of women in both countries were primipara.

The health status of 124 babies was reported; of these, approximately 90% were stillborn or died shortly after birth.

Antenatal care

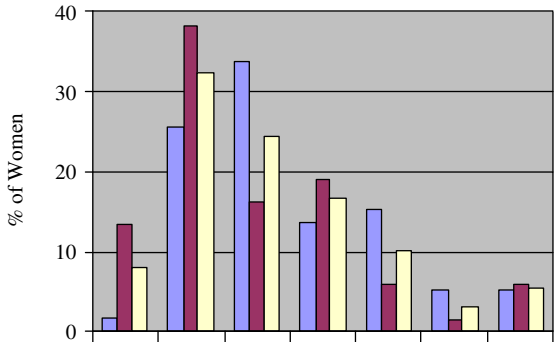
Approximately 84% of the women said they had attended at least two antenatal care (ANC) visits, and 45% had attended ANC on four or more occasions.

In Tanzania, 53% of the women reported being weighed, 11% reported having their height measured, and 34% reported being given some type of medicine. Two women cited being given medication for malaria. No hemoglobin tests, urinalyses, or blood group assessments were reported.

In Uganda, 31% of women reported receiving immunization services, and 15% reported that the health worker listened for the fetal heartbeat. Less than 10% said that they had had their blood pressures checked or were weighed. No urinalyses, syphilis screening, or voluntary counseling and testing for HIV were reported.

Only 12 women reported any counseling by providers on pregnancy, labor, or delivery. The women said they were given only limited explanations as to why they should deliver at a facility.

> "I went to a government clinic for antenatal care three times. On examination the midwife told me that the baby was very big. Although she treated me, she told me that I should go to the health unit at Buyoga for delivery but there was no doctor or operating theatre there" (Woman from Masaka, Uganda, age 33).



	< 15 years	15-19 years	20-24 years	25-29 years	30-34 years	35-39 years	> 39 years
Tanzania	1.7	25.4	33.9	13.6	15.3	5.1	5.1
Uganda	13.2	38.2	16.2	19.1	5.9	1.5	5.9
Both countries	7.9	32.3	24.4	16.5	10.2	3.1	5.5

[a] Tanzania, n=59; Uganda, n=68; both countries, n=127

Fig. 1 Age at fistula. Tanzania, $n=59$; Uganda, $n=68$; both countries, $n=127$

Delivery planning and constraints to facility-based birth

Forty-five percent of the women in Tanzania and 51% of the women in Uganda had planned to deliver at a health care facility, while the remaining had planned to deliver at home. More than half of the women in each country cited constraints preventing them from delivering at a facility in a timely manner, specifically lack of money, transportation and hospital costs, and distance to a facility. Other constraints included lack of access to transport, insufficient information about facility-based delivery, fear of bad treatment by staff, and cultural norms.

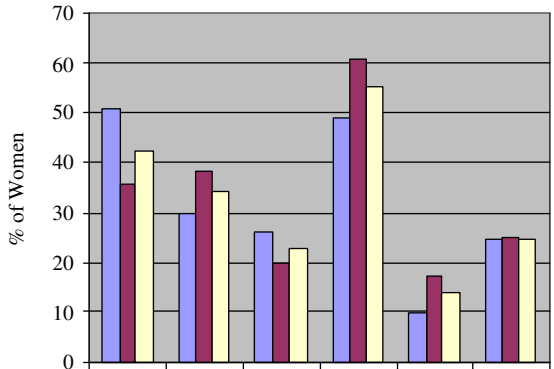
> "The problem of not having money stopped me from going to a health center for delivery because my spouse and my mother-in-law had said they had no money to pay for hospital bills. Even my mother had no money to take me to a hospital. If I had my own money, I would not have delivered in the village, because during antenatal care, the midwife had advised me not to deliver in the village" (Woman from Masaka, Uganda, 26).

> "I wanted to deliver at hospital but I never discussed this with my husband. Our culture discourages us from planning for a baby who is not yet born. Prior planning is believed to bring bad luck so we avoided it. We did not make special arrangements for transportation to hospital because we did not have the money... What influenced our decision the most was the belief that anything to do with pregnancy should remain a secret. In fact one night my husband told me to stop discussing life after giving birth before I had delivered" (Woman from Soroti, Uganda, 29).

Delivery trajectory and delays

Ninety-five percent of the women first attempted to deliver at home, while the remaining 5% were at a facility when labor began. Of the women who began labor at home, 83% eventually tried to reach a facility. Sixty-nine percent of the women in the study faced two or more delays in receiving care when it became clear that there was a complication and labor was obstructed (Fig. 2).

Over half of the women in both countries who began labor at home suffered delays through the failure of family, friends, or the woman herself to recognize complications. Approximately 34% were delayed because of a failure by the TBA or another community-based provider to identify a problem and/or refer the woman to a facility. Twenty-three percent of respondents mentioned delays in seeking care once a problem was recognized. Overall, the length of labor reported by women varied from 6 hours to approximately 6 days.



	D1	D2	D3	D4	D5	D6
Tanzania	50.8	29.5	26.2	49.2	9.8	24.6
Uganda	35.5	38.2	19.7	60.5	17.1	25
Both Countries	42.3	34.3	22.6	55.5	13.9	24.8

[a] Tanzania, n=61; Uganda, n=76; both countries, n=137

Fig. 2 Types of delays experienced by women during labor and delivery. Tanzania, *n*=61; Uganda, *n*=76; both countries, *n*=137. *Key*: *D1* Failure of woman and/or family/friend to recognize delivery problem; *D2* failure of TBA or other community-based provider to identify problem and/or refer woman to a medical facility; *D3* delay in seeking care by family and/or friends after a problem was identified; *D4* delay in transportation to medical facility; *D5* delay in treatment at medical facility due to absence/lack of medical personnel, equipment and/or supplies; *D6* delay in treatment by provider at facility due to failure to recognize problem and/or inattentiveness to woman's needs

> "I realized that there was a problem with my labor when I started passing a lot of blood continuously and we had to rush to hospital" (Woman from Soroti, Uganda, 22).

Delays in transportation to facilities were cited by 49% of the women in Tanzania and 61% of the women in Uganda. Women report reaching facilities by vehicle, ox-drawn cart, bed placed across two bicycles, office chair strapped to a bicycle, and wheelbarrow. Approximately 20% of the women reported having to walk to a facility at some point during their labor.

> "We moved on foot up to the bus stop, but it took us too long because I could only move a bit...Even before we left, my mother had to first sell a goat, and getting a willing buyer wasn't easy. Then when we got to the taxi stand, we had to wait one hour to get to the nearby health center" (Woman from Masaka, Uganda, 19).

Nine percent of the women in Tanzania and 17% in Uganda also cited a delay caused by a lack of provider, supplies and/or equipment at the site, and a quarter in both countries cited delays by providers in recognizing the woman's problem and/or providing appropriate care.

> "The nurses checked me. They advised that I might not have a normal delivery; that it would be by operation... but the doctor was not at the hospital. They tried to reach him but I had to wait another 24 hours before the doctor came to do the operation" (Woman from Soroti, Uganda, 19).

> "The care was not good because I wasted so much time running from one hospital to another searching for blood" (Woman from Soroti, Uganda, age 29).

Experiences with health workers at the time of delivery

Women had varying opinions regarding the care they received during childbirth. Nearly all the women were satisfied with the care they received at their final delivery site because the providers saved their life and/or the life of their baby or because the providers were able to identify their delivery problem correctly.

Eight women in Tanzania and 14 in Uganda indicated abuse and/or neglect by health workers. This included being shouted at or blamed for their condition or being left alone for an extended period of time.

> "The nurse at one facility told me: 'If you don't pay 15,000 Tanzanian shillings ($US15), you will never get a blood transfusion. If you have to die, better die'" (Patient at Bugando Medical Center, Mwanza, Tanzania, 24).

> "Nurses were asking for soda before they would give us service. At one point, they told a patient they wouldn't dress her wound unless she gave them a soda" (Woman from Ukerewe, Tanzania, 29).

Failure to urinate during labor and perceived causes of fistula

Women provided multiple reasons for the cause of their fistula. Eighty-four percent of women in Uganda and 33% of women in Tanzania perceived that their fistula was caused by providers—either the doctor had accidentally pierced the bladder, or the injury was caused by the procedure/instruments used during delivery. Approximately 41% of the women attributed their fistula to delivery delays.

> "I think the doctor cut my bladder while removing the baby" (Woman from Soroti, Uganda, 35).

> "If I had gone to the hospital on time, I would not have fistula" (Woman from Ukerewe, Tanzania, 28.

In addition, 64% of the women in Tanzania and 58% in Uganda said they could not pass urine during labor, passed only small amounts, could only urinate at the beginning of labor, or urinated only once during labor.

Duration and impact of fistula

For all respondents, the time living with fistula ranged from 1 month to 52 years, with a median length of 3 years. Fifty-three percent of the women in Tanzania and 71% of the women in Uganda had been living with fistula for over a year; approximately 42% of the women had been living with fistula for more than 4 years, and approximately 20% of the women had been living with fistula for over 10 years. In Tanzania, the median length of time with fistula was 1.75 years; 3 years in Uganda. The median length of time living with fistula for women recruited at community level was 5 years, compared with 1 year for women recruited at facilities.

Women reported suffering genital sores and inflammation, irregular periods, and exhaustion, as well as anxiety and depression; women also reported an inability to walk normally, most likely due to footdrop. Of the 129 women who reported their marital status, about 25% in Tanzania and 52% in Uganda were divorced, with almost all the separations resulting from their condition. Of the 20 women who were unmarried when they sustained fistula, 69% in Tanzania and all the women in Uganda remained single.

> "My husband said: 'I can't live with a woman who rots my mattress with urine.' He left me and threw out all of my belongings" (Woman from Songea, Tanzania, 20).

Sixty-seven percent of the women in Tanzania and 99% of those in Uganda experienced isolation. They either withdrew from their communities due to shame or were isolated by others as a result of the stigma.

> "I live alone because my father said that he cannot tolerate my smell and threw me out from his house... My partner also never took me for marriage when I got this problem. So I am miserably lonely most of the time. I am unable to talk with community members because most of them abuse me. They curse me that I smell and even call me names like 'ever-wet', 'urinator', and 'ever-flowing'. I can't even go to social gatherings like parties, prayers, or meetings. I fear smelling in front of people and being wet, even at home. I am always indoors or hide in the banana plantation all day. I don't want people to see me" (Woman from Masaka, Uganda, 32).

> "I feel shame. They laugh at me. They turn their lips up, and others leave the moment I enter to take my tea with them" (Woman from Singida, Tanzania, 54).

Approximately 85% of the women said that fistula rendered them unable to perform household chores, work on the farm, or engage in other income-generating activities. Family members had to take up this work or forego the income the woman contributed previously. Payments for soap and the costs of treatment were added financial burdens.

> "Income has decreased because only my husband is working. There are times when we don't have food" (Woman from Singida, Tanzania, 29).

> "As I am regularly sick and have constant backache, I cannot do my duties efficiently. I have a big family of eight children to feed but I cannot cultivate as I used to do which has caused food shortages. I also have no job to earn a living because I spent three and half months in hospital and my shop collapsed during that period. Now, I cannot fully meet the needs of my family and all of my children have dropped out of school due to lack of school fees" (Woman A from Masaka, Uganda, age unknown).

Seeking fistula repair

Prior to the study interviews, 22 women in Tanzania sought and got a surgical repair; of these, six women reported they no longer had fistula. In Uganda, 27 women sought and got a surgical repair; and six women reported they no longer had fistula. An additional 28 women were awaiting initial repairs in the two countries at the time of the interviews. Women who did not seek surgical repair explained that this was largely because they could not reach or afford the limited services available, did not know where to go, or were unaware that repair was possible. All women in Tanzania who sought a repair were able to get it. Nine women in Uganda sought treatment but were not able to get it, largely because the doctor was not available.

> "Unfortunately even in government hospitals, if they prescribe treatment and I'm asked to pay, I have to walk away because I have no money" (Woman from Soroti, Uganda, 21).

> "I did not have hope that I would ever recover because I had not known of any woman with fistula that was repaired" (Woman from Soroti, Uganda, 17).

Women and their families expended significant amounts of money and time to access treatment. Funds were frequently raised by selling land and livestock. Thirty-one percent of respondents in Tanzania and 19% in Uganda reported taking traditional medicine or going to traditional healers for treatment, sometimes for extensive periods at substantial cost.

> "My father took me to one traditional healer for six months. When I failed to heal, he took me to another one where I spent another eight months, also in vain.

In all, my father paid 200,000 Ugandan shillings ($US114), three cows, and three chickens to traditional healers" (Woman B from Masaka, Uganda, age unknown).

All the study participants who had not yet had a successful repair were referred to hospitals for treatment.

Discussion

The narratives of the women participating in this study reveal a continuum of physical, economic, and cultural constraints, as well as health system failures that led to obstetric fistula. Once the women had sustained fistula, the majority of respondents were unable to access surgical repair, most often because they could not reach or afford the limited services available.

Several methodological limitations are acknowledged which may influence findings. The women interviewed are neither a random nor representative sample. No attempts were made to confirm the accuracy of women's recollections including how they may have been affected by recall bias; and women's reports of their experiences were not checked against those of health providers. Lastly, the interviews were not tape-recorded because of the sensitivity of the topic and to allay concerns about voicing criticisms of health services.

Nonetheless, our findings show that obstructed labor can strike women at all ages and parities, including those who have experienced uncomplicated deliveries previously. Popular portrayals of women with fistula often depict young primiparous girls affected by the condition, yet our findings confirm data from other studies that demonstrate that fistula happens to both younger and older women and all parities [14, 15]. While it remains vital to educate communities on the effects of early childbearing, maternal health interventions must inform people that fistula can affect any woman of reproductive age.

Findings also suggest that almost all women attended antenatal care visits at least twice; however, guidance on childbirth was practically non-existent. ANC consultations represent an opportune time to provide education and counseling on childbirth and reproductive health overall, as well as an untapped opportunity to ensure that pregnant women are linked into the health system in case an emergency arises during childbirth. Planning for a safe delivery is an integral part of ANC [16].

Data strongly indicate the need for pregnant women and their families to access skilled delivery assistance. Currently, the proportion of women delivering with skilled assistance in Tanzania is estimated at only 46% and 42% in Uganda [2, 6]. The women interviewed for this study almost invariably attempted to deliver at home first, with large proportions of them reporting lengthy, life-threatening delays when problems were not recognized. Women were often left in labor for days. They then faced substantial, often insurmountable, logistical and financial barriers in accessing appropriate care. These barriers included cost of transport and hospital care, distance to facilities, lack of information about pregnancy complications and the need for skilled delivery care, and lack of skilled health workers at facilities.

Detailed analyses of the expansion of obstetric services—in terms of both infrastructure and trained personnel—and the potentially negative impact of payments required for maternal healthcare were beyond the scope of this study. Nonetheless, the high proportion of women experiencing delays due to lack of money and/or transport clearly point to the urgent need to reduce the physical and financial barriers to adequate obstetric care. Increasing the availability of basic and comprehensive EmOC provided by skilled health workers, with priority to under-served areas, could reduce maternal mortality and morbidity.

Several of the findings merit further investigation. There was a high percentage of women who reported difficulty urinating or only limited urination during the labor that led to fistula. Women's inability to urinate in labor may be a marker for obstructed labor and increased risk of fistula, and as such, is an indication that a woman should be transferred quickly to a facility capable of doing cesarean sections. An observational study examining normal patterns of urination in labor could illuminate the significance of urination difficulties. Bladder monitoring and management by a skilled provider during labor might prove to decrease the incidence of fistula.

The frequency of women's perceptions that their fistula was caused either by the doctor accidentally piercing the bladder or by the procedure/instruments used during delivery is higher than evidence on iatrogenic fistula suggests [15, 17]. The higher instrumentation rate in women with fistulas is likely due to the concurrent obstetric complications in most cases. The study is unable to independently confirm women's reports of surgical error leading to fistula, but the finding does indicate, at the least, deficiencies in communication between health workers and women seeking care.

Given the critical importance of "word-of-mouth" in communities, women's beliefs that medical personnel caused the fistula would potentially act to discourage use of skilled delivery assistance. Women and their families, therefore, need to be given comprehensive information on the medical nature, symptoms, and management of fistula as soon as it is diagnosed, so as to immediately dispel any misconceptions about the condition. The limited data from other locations on women's perceptions of fistula indicate

that correct information on the causes of fistula needs to be included in educational efforts [18, 19]. In addition, postpartum instructions to women with long labors should encourage them to report problems with incontinence so they may be treated as soon as possible after fistula formation. This will assist women in accessing appropriate repair services promptly and avoiding ineffectual and costly traditional methods of treatment.

Future research could usefully include a comparative group of postpartum women who did not endure fistula in order to identify the factors that distinguish women with fistula from women from the same environment who do not get fistula.

Ultimately, women with fistula must be supported to recover lives of health and dignity. The lengths of time that the women had endured fistula and the exceedingly harsh impact of the condition call for the urgent provision of, and expanded access to, fistula repair services. Services and transport to treatment must be available and affordable, ideally at no cost to the woman and her family. Reliable information on where and when treatment is available needs to be disseminated consistently, and communication strategies must be designed to reach remote areas and illiterate women. Radio and outreach through faith-based institutions represent effective, low-cost, communication channels to reach women in rural areas, especially illiterate women [20].

Fistula programs in Tanzania and Uganda, launched since the inception of this study, incorporate many of these programatic features. The Tanzania National Fistula Programme (NFP) disseminates information on fistula services, supports local referral systems linking women to treatment, trains providers in fistula care, reimburses hospitals for services, and conducts advocacy on fistula. The NFP is implemented by Women's Dignity and AMREF/Tanzania in collaboration with the Tanzanian Ministry of Health and Social Welfare and a consortium of stakeholders. In Uganda, EngenderHealth and the Fistula Care Project, together with UNFPA, Women's Dignity and local partners have strengthened fistula education, treatment, prevention, and reintegration efforts. Since 2001, the annual number of repairs performed in Tanzania has increased by 50%, indicating that concerted efforts involving national health services, non-governmental organizations and local communities can achieve significant advances in the provision of fistula treatment [21, 22].

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Conflicts of interest None.

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