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Authors

Nalubwama, Hadija
El Ayadi, Alison M
Barageine, Justus K
[et al.](#)

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Perceived Causes of Obstetric Fistula and Predictors of Treatment Seeking among Ugandan Women: Insights from Qualitative Research

Hadija Nalubwama^{1,*}, Alison M. El Ayadi², Justus K. Barageine^{1,3}, Josaphat Byamugisha¹, Othman Kakaire¹, Susan Obore¹, Haruna Mwanje¹, Suellen Miller²

¹Department of Obstetrics and Gynaecology, Makerere University College of Health Sciences, Mulago Hill, Kampala, Uganda

²Department of Obstetrics, Gynaecology and Reproductive Sciences, University of California, San Francisco, 550 16th Street, San Francisco, USA

³Department of Maternal and Child Health, Uganda Christian University, Cblock Path, Mukono, Uganda

Abstract

Many obstetric fistula patients remain untreated or present late to treatment despite increasing surgical availability in Uganda. We explored women's perceptions of the cause of their obstetric fistula and their treatment seeking behaviours, including barriers and facilitators to timely care access. In-depth interviews and focus group discussions were conducted from June–August 2014 among 33 women treated for obstetric fistula at Mulago Hospital, Kampala. Data were analysed to describe dimensions and commonalities of themes identified under perceived causes and treatment seeking experiences, and their intersection. Perceived obstetric fistula causes included delays in deciding on hospital delivery, lengthy labour, injury caused by the baby, health worker incompetence, and traditional beliefs. Treatment seeking timing varied. Early treatment seeking was facilitated by awareness of treatment availability through referral, the media, community members, and support by partners and children. Barriers to early treatment seeking included inadequate financial and social support, erroneous perceptions about fistula causes and curability, incorrect diagnoses, and delayed or lack of care at health facilities. Our study supports broad educational and awareness activities, facilitation of social and financial support for accessing care, and improving the quality of emergency obstetric care and fistula treatment surgical capacity to reduce women's suffering.

Résumé

De nombreux patients atteints de fistule obstétricale restent non traités ou se présentent tardivement au traitement malgré une disponibilité chirurgicale croissante en Ouganda. Nous avons exploré la perception qu'ont les femmes de la cause de leur fistule obstétricale et de leurs

*For Correspondence: hnalubwama@yahoo.com; Phone: +256.772.623.793.

Contribution of Authors

All authors conceived and designed the study. HN conducted data collection. HN and AE analysed the data and prepared the initial draft of the manuscript. JB, JB, OK, SO, HM, and SM reviewed and revised the manuscript. All authors approved the final manuscript.

comportements de recherche de traitement, y compris les obstacles et les facilitateurs pour un accès rapide aux soins. Des entretiens approfondis et des discussions de groupe ont été menés de juin à août 2014 auprès de 33 femmes traitées pour fistule obstétricale à l'hôpital de Mulago, Kampala. Les données ont été analysées pour décrire les dimensions et les points communs des thèmes identifiés sous les causes perçues et les expériences de recherche de traitement, et leur intersection. Les causes perçues de la fistule obstétricale comprenaient des retards dans les décisions d'accouchement à l'hôpital, un travail prolongé, des blessures causées par le bébé, l'incompétence des agents de santé et les croyances traditionnelles. Le calendrier de recherche du traitement variait. La recherche précoce d'un traitement a été facilitée par la sensibilisation à la disponibilité du traitement grâce à l'aiguillage, aux médias, aux membres de la communauté et au soutien des partenaires et des enfants. Les obstacles à la recherche d'un traitement précoce comprenaient un soutien financier et social inadéquat, des perceptions erronées sur les causes et la curabilité des fistules, des diagnostics incorrects et un retard ou un manque de soins dans les établissements de santé. Notre étude soutient de vastes activités d'éducation et de sensibilisation, la facilitation du soutien social et financier pour l'accès aux soins et l'amélioration de la qualité des soins obstétricaux d'urgence et du traitement chirurgical de la fistule pour réduire la souffrance des femmes.

Keywords

Obstetric fistula; perceived causes; treatment seeking; maternal morbidity; Uganda

Mots-clés:

Fistule obstétricale; causes perçues; recherche de traitement; morbidité maternelle; Ouganda

Introduction

Globally, two million women are estimated to be living with untreated obstetric fistula, mainly in sub-Saharan Africa and Asia, with an annual incidence of between 50,000 to 100,000 cases¹. Uganda has approximately 200,000 women living with fistula and 2,000 annual incident cases². Obstetric fistula surgery is freely and routinely available at Mulago National Teaching and Referral Hospital, in five of Uganda's 13 regional referral hospitals, and in other private not-for-profit hospitals². A nation-wide increase in the availability of fistula treatment services has been facilitated by the Ugandan National Fistula Technical Working Group which was established in line with the United Nations Population Fund's (UNFPA) Global Campaign to End Fistula².

Despite the progress made in improving the availability of obstetric fistula treatment services in various Ugandan hospitals coupled with a high treatment success rate², many women and girls affected by obstetric fistula do not access treatment. Those seeking treatment often present late, in some instances only after decades of suffering from this devastating, but largely treatable condition³. The 2011 Uganda Demographic and Health Survey found that 38% of women of reproductive age who had experienced obstetric fistula-related symptoms had never sought treatment⁴, which is substantially higher than the Ugandan

Ministry of Health estimate of 3%². Various studies have identified treatment seeking for obstetric fistula in Uganda and elsewhere in sub-Saharan Africa as low and delayed^{2,3,5}, and shaped by a variety of factors influenced by socio-economic status including knowledge of treatment availability; costs of surgery, transport and lodging; and geographic access^{3,6,7}. Health systems factors also substantially contribute to delays in care including a lack of local skilled providers, and limited equipment and supplies^{3,8-10}.

Other literature suggests that women's perceptions of the fistula cause may have an important influence on their treatment seeking behaviour. A systematic review of barriers to obstetric fistula treatment in low-income countries noted that women who believed that their fistula was caused by medical error, a curse, or an infliction by God were less likely to seek treatment at a health facility¹¹. An Ethiopian study similarly found that women reporting their fistula was caused by a curse were significantly less likely to seek medical care for fistula treatment¹⁰. However, the majority of studies on treatment seeking behaviour for obstetric fistula in Uganda and elsewhere have employed quantitative methodologies, which have not allowed for a detailed exploration of women's perceptions of the causes of their fistula development and treatment seeking processes.

Thus, an in-depth exploration of beliefs around obstetric fistula from the perspectives of the affected women and how these relate to their treatment-seeking decisions and behaviours is critical for understanding how to overcome low and delayed treatment seeking for this condition. Lessons from women's narratives could facilitate the design of appropriate and focused programs to address misconceptions about obstetric fistula causality and curability and may mitigate delays in accessing obstetric fistula treatment. We have drawn upon the socio-ecological model to understand the dynamic interrelations among various personal and environmental factors (relationship, community, and societal factors) which influence human behaviour^{12, 13} to explore Ugandan women's perceptions of the cause of their obstetric fistula and their treatment seeking behaviours, including barriers and enablers to accessing fistula surgery.

Methods

Study design and setting

We conducted a qualitative study from June-August 2014 among women who had undergone fistula surgery at Mulago Hospital in Kampala, Uganda, 6-24 months before recruitment. This study was nested within a larger mixed methods study assessing social reintegration of women following surgical fistula repair. Mulago Hospital provides routine fistula surgery and is an International Federation of Gynaecology and Obstetrics (FIGO) accredited training centre for comprehensive treatment of fistula. Approximately 300 women are surgically treated for obstetric fistula at Mulago Hospital annually. Women are referred for treatment from other hospitals, health centres, and private clinics, or learn about the services from friends, relatives, and radio advertisements.

Study participants

The participants were recruited from patients who had fistula surgery 6 to 24 months prior to recruitment. Women were eligible for participation if they spoke Luganda or English, had provided a telephone number, lived within 100 km of Mulago Hospital, and were able to provide informed consent. Of the 46 women reached, thirty-three were recruited. The remaining 13 were excluded due to language barrier (n=1), no interest in participating (n=1), and the rest (n=11) were not contacted due to achievement of data saturation.

Data collection

Study staff administered a short quantitative survey to all participants to capture socio-demographic characteristics (age, tribe, religion, socioeconomic status, marital status, and educational attainment) and obstetric history. Participants subsequently participated either in in-depth interviews (n=16) or in one of four focus group discussions (FGD; n=17). Women were asked open-ended questions on perceived obstetric fistula causes and their treatment seeking behaviours.

Data analysis

The quantitative survey data were analysed to describe participant characteristics using Stata version 14 (StataCorp, College Station, TX). Transcripts from in-depth interviews and focus group discussions were coded using inductive and deductive codes within Atlas.ti software. Coded data were analysed thematically to describe the different dimensions and commonalities of each theme, their distribution across demographic variables, perceived causes, and treatment seeking experiences. Thematic analysis occurred concurrent with data collection to assist in achievement of theoretical saturation. Individual women's trajectories were tracked within the FGD data given the aim of the analysis.

Results

Socio-demographic profile of the study respondents

The 33 study participants ranged in age from 18 to 51 years, with approximately one-third between 18-24 years and another third between ages 25-34 years (Table 1). Most participants reported having developed obstetric fistula before age 25 years (56%), including seven women (22%) who developed it before age 18. The majority of participants lived with their husbands (76%) at the time of data collection. Most had attained some primary education (70%), and many worked outside the home (67%), mainly as farmers. Husbands provided primary financial support for 64% of respondents. Most had a radio at home (88%) and a mobile phone (88%). For the pregnancy leading to the fistula, most women reported delivering in a government hospital (73%); the majority of infants did not survive (70%). Length of time lived with fistula varied substantially across respondents: 18% had lived with fistula for less than three months; however, 33% reported having lived with it for more than 10 years.

Perceived causes of obstetric fistula

Perceived causes of obstetric fistula varied across study participants, and included individual, systems-focused, and cultural factors. Five subthemes emerged as primary from participant narratives: delays in making a decision to go the hospital due to confusion around labour signs, lengthy labour, injury caused by the baby during delivery, health worker incompetence, and traditional beliefs in witchcraft.

Delays in making a decision to go to hospital due to confusion around labour signs—A few respondents attributed their fistula development to delaying in making the decision to seek immediate help with delivery at a medical facility. They described confusion around the labour symptoms they were experiencing, only acting after the damage had occurred, as illustrated in the following quotes:

I was surprised because I didn't feel any pain [when I was in labour]. What happened was that I just saw fluids ooze out, and in no time, the baby was out. When I reached the health facility, they referred me to Mulago Hospital. When I reached Mulago, they told me that the baby was dead and that I was to undergo surgery. (FGD participant, aged 33 years)

I think the baby was overdue because I felt labour pains the whole day and didn't go [to the hospital] that day I didn't know that the pregnancy had a problem, I would just pad myself ... but I felt the baby kicking so hard and got confused. So, we went to a clinic [the following day]. (Interviewee, aged 22 years)

Lengthy labour—Some participants attributed the fistula to their failure to push the baby out after becoming fatigued by a lengthy labour. However, this was never reported as independently leading to fistula; other underlying factors were noted as jointly contributing to the development of the condition such as delivering in villages where obstetric care skills were believed to be inadequate, malpresentation of the baby in the womb, carrying a big baby and having a catheter in place while pushing the baby:

[My family members] took me to the village [to give birth] [My labour lasted all night. When the traditional birth attendants told me to push the baby so hard in the morning, I was already so tired, I couldn't any more. I knew that the fistula occurred because of me going to give birth from the village where they made me push the baby so hard and eventually got tired. (Interviewee, aged 20 years)

I knew I couldn't push the baby out; I couldn't sit or stand but just lay down. I was tired. (Interviewee, aged 26 years)

Since I was pushing for all those hours with the catheter already inserted, I think it was the cause of the leaking. (Interviewee, aged 28 years)

Injuries caused by babies during delivery—A common perception among respondents was that the fistula resulted from actively being injured by their babies during delivery. Some respondents believed that their babies had either kicked their bladders in a struggle to get out of the womb or damaged their bladder through some other mechanism. In their narration, they explained:

I thought that maybe the baby was trying to get out and it somehow injured my bladder because [he] had died in my womb and I suspected that he probably kicked my bladder. (Interviewee, aged 26 years)

I think maybe the baby damaged my bladder. Some people told me that it is the baby that damaged it. (Interviewee, aged 22 years)

Perceived health worker incompetence—Health worker incompetence in handling obstetric cases was blamed for obstetric fistula development by some study respondents. The practices displayed by health workers that participants perceived as incompetent included conducting vaginal examination with their hands, intentionally fatiguing women to hasten labour progress, manual placental manipulation, giving the wrong medication, and being absent when most needed, thus delaying necessary caesarean operations, among others. Participants also expressed general mistrust of certain health professionals. These concerns are elaborated by the quotes below:

I think it is not good to trust young doctors because they checked me (in the vagina) to feel the baby with their hands and also made me climb a steep road (to help labour progress) which made me feel so tired and I think that was the cause of the fistula. (Interviewee, aged 22 years)

My time of delivery was bad because those who were supposed to operate me were not present. They were just about to come but I went into labour so I had to push and it's then that I got that problem. (FGD Participant, aged 47 years)

I told the nurse that the other health worker had suggested that since I was operated before for my last delivery, I should not be given [Pitocin], but she insisted.... I complied and she gave me the medicine.... She told me to push, and I pushed for about three hours without delivery.... She called the doctor and the doctor said that they had wasted a lot of my energy yet I had to be operated! (Interviewee, aged 28 years)

Other respondents were of the view that their fistulae were accidentally caused by health workers during emergency caesarean operations in efforts to save their lives after a difficult labour. Below are some of their experiences:

I acquired the fistula after I underwent emergency Caesarean (section). The surgical scar was oozing out fluids so they took me back to the theatre and accidentally they injured my urinary bladder. (Interviewee, aged 19 years)

It is either the doctors who injured it ... because they were rushing since I was in a bad state, and they said, 'let's rush to save your life'. So, I think that in that process, they injured it. (Interviewee, aged 26 years)

Traditional beliefs in witchcraft—Some participants reported that family and community members told them that witchcraft was associated with their fistula development. Stepmothers, who are often believed traditionally to be wishing for the worst to happen to their stepchildren, were mentioned as bewitching participants while others were believed to be possessed by evil spirits that necessitated visiting the traditional healer.

Others scared me by saying that my stepmother bewitched me with a condition of endless leaking.... My mother would accuse my stepmother and she would take me to some traditional healers...; at times I believed that I was bewitched. (Interviewee, aged 22 years)

Some community members came and told him (husband) that my fistula may be caused by evil spirits. (FGD Participant, aged 37 years)

Facilitators of and Barriers to Treatment Seeking

We captured data on the time that elapsed between women's fistula development and when they decided to seek obstetric fistula treatment. Our analysis revealed that a few women made early attempts to seek treatment, ranging from within days through several months after its development. Others spent a longer time, in some instances waiting a decade or more before they sought treatment. Respondents explained the reasons behind the varied lengths of time they took to seek obstetric fistula treatment. Various individual, interpersonal, social and community enablers and barriers to early obstetric fistula treatment seeking were noted. Facilitators of treatment fell under two major themes, awareness of treatment availability and social support. Barriers included inadequate financial support to access treatment, lack of social support, ignorance about the cause of fistula, erroneous perceptions about fistula curability, knowledge limitations about treatment availability, and health system limitations, such as incorrect diagnoses made by health workers and a lack of functional fistula treatment centres.

Awareness of obstetric fistula treatment availability—A main enabler to treatment seeking was participants' awareness that treatment for obstetric fistula was available. Respondents who sought obstetric fistula treatment early, i.e., within three months of fistula development, tended to have learned of its availability early through timely advice from either a health worker, a family member or another community member. One woman described taking advantage of her social network to learn where to access early treatment for her fistula:

After [having lived with fistula for] two months, I remembered that among my friends I have a health worker.... So when I talked to her, told me, 'Why did you take this long before telling me?' She informed me that Mulago offers that treatment. (Interviewee, aged 39 years)

Similarly, radio announcements about obstetric fistula treatment availability facilitated early obstetric fistula treatment seeking among several patients who had been previously unaware of where treatment could be accessed.

Social Support—Respondents who had supportive families, particularly partners and adult children, sought obstetric fistula treatment earlier than those without. It was common among the early treatment seekers to mention that their husbands were proactive in ensuring that they got obstetric fistula treatment by seeking out information, bringing them to the treatment centres or financially facilitating their transport and residency at the treatment centres. Below are some of their narrations:

It was immediately; I didn't take long as [my husband] immediately went out to speak with different people to find a solution to my problem. (Interviewee, aged 37 years)

My children in Mubende heard [a radio announcement] and called me to inform me that they were going to repair patients with fistula. They encouraged me to come.... They told me to just come and find them at Mubende hospital so that they give me money. (FGD Participant, aged 50 years)

Inadequate financial support to access treatment—Respondents stated that they often wanted to go for obstetric fistula treatment earlier than they actually did, but were not financially capable. They noted that family savings had already been depleted during the childbirth and associated hospitalization. Other respondents attested to having been aware of free treatment availability but could not afford the transport fare to the treatment centres. Some respondents complained that they had sought treatment but were requested to pay exorbitant amounts of money that were out of their reach to receive care, which made them delay treatment. These sentiments are presented in the quotes below:

It took me a full year [to get surgery] I didn't have the transport fare to bring me here. It's just that we had just left here at Mulago after my delivery and all the money was used up, so, [my husband] suggested that we should first work such that we get money to bring me back to the hospital. (Interviewee, aged 27 years)

The doctor that did a check up on me and told me that I had a hole on my bladder and needed an operation asked for 800,000 Ugandan Shillings (USh; \$222 USD), but my salary in arrears wasn't even worth 300,000 USh (\$83 USD)! My boss told me that I should keep working [to raise the money]. (Interviewee, aged 28 years).

Lack of social support—For some respondents, their late treatment seeking for obstetric fistula treatment was due to lack of social support. While some respondents reported failing to identify someone to stay with them during admission at the obstetric fistula treatment centres, which were often located far away from their homes, others did not know the physical locations of these treatment centres and thus needed people with this knowledge to help them access these treatment centres.

I told you I spent eight years not knowing where to seek treatment, then I spent another ten years [not accessing it because] they said treatment is in Kitovu Masaka district but I had no relatives to stay with that side. (Interviewee, aged 51 years)

One participant discussed how she overcame this lack of social support when her friend offered to come with her to access surgery:

They announced the availability of fistula repair on the radio several times.... Mama Gulo heard it and asked me; why don't you work and go to Kampala? I told her, 'I don't know that place; how will I go to a place I have never been to?' She told me 'You look for money, when you get it and they announce again, we will go.' (Interviewee, aged 35 years)

Erroneous perceptions about fistula causes and curability—Some respondents observed that they had not bothered to seek treatment thinking that fistula was incurable, a view that was also shared by some family and community members. Below are some extracts from the interviews:

My family never knew that such an illness could be healed and even me, [over] the fourteen years I had spent with the illness, I never thought I would heal. Even when I came to the hospital, I was just giving it a try to see if I can heal or not. (FGD Participant, aged 38 years)

I knew that I would live with that condition until I die; even those who could see me were telling me that this illness was incurable. (Interviewee, aged 22 years)

As presented previously in the earlier section on women's perceptions of the cause of their fistulae, participants had varied opinions on what was responsible for the development of their fistulae. Some were ignorant or misinformed, believing that evil spirits were responsible for their condition, and these women were inclined to seek help from traditional herbalists and witch doctors. They only resorted to modern healthcare settings after failing to be cured in the traditional setting, which increased the amount of time they lived with the condition. The following quotations reflect some of their shared experiences:

My mum then said, 'Now you see! I told her that her stepmother is bewitching her but she insists that it is the bladder!' She would take me to some traditional healers and some but still there wasn't any difference after one year. (Interviewee, aged 22 years, lived with fistula for 1.5 years)

I sold off my three cows to seek treatment from 'abatyaasi' (traditional healers), but they failed to cure me.... After [having lived with fistula for 12 years], I heard an announcement over the radio and my sibling living in Mityana advised me that I should not seek treatment from those traditional healers anymore but instead go to Mulago. (FGD Participant, aged 40).

Others hoped for spontaneous or miraculous healing through prayers and thus sought divine interventions from pastors, also causing a delay in seeking for medical interventions:

When I had just got fistula, I came to the Prophet Kakande such that they can pray for it and I get healed but all was in vain. (Interviewee, 30 years old)

Health facility limitations—Although some respondents had made attempts to seek treatment for obstetric fistula, several were let down by health facility inadequacies which fell under the two sub themes of misdiagnosis and lack of skilled human resources.

Some respondents reported having made immediate attempts to seek treatment for obstetric fistula but they unfortunately sought it from incompetent health workers who misdiagnosed them, which resulted in unnecessary treatments and delayed receipt of proper care. Two women described their experiences with incorrect diagnoses:

When I realized that I was leaking, I came to the hospital and I was told that the intestinal membrane had a problem. I was prescribed some drugs which I took for

a long time without healing. (Interviewee, aged 22 years, lived with fistula for 4 years)

Two days after I had been operated in Nkozi Hospital, I had a continuous leakage of urine. I told the doctors about it.... They told me that I sat on a dirty toilet and contracted an infection. So they gave me drugs to treat the same.... I didn't go back to the hospital but remained with my leakage. (Interviewee, aged 50 years, lived with fistula for 35 years)

Other respondents had made an early attempt to seek medical treatment for obstetric fistula, yet were not successful since the treatment facilities they accessed did not have the necessary human resources to handle obstetric fistula cases. Some facilities only handled fistula patients periodically when visiting foreign specialists were present. The foreign surgeon visits occurred infrequently and the surgeons could only operate on few of the many cases in need of care. Women also complained about delays in surgery at some hospitals. In some instances, they were required to wait at the facility for many weeks before undergoing surgery because the wards were full or the health workers were unavailable. The following quotations describe women's experiences with delays at health facilities:

I was at the hospital in Mubende when I realized that I was leaking, and they frankly told me that they don't handle such conditions like mine.... When I was referred to Kitovu Hospital, the health workers told my husband that the foreign surgeon had just finished operating the women and that he would come back in August; it was February. (Interviewee, aged 37 years)

I was then brought to Mulago Hospital where we were told that it was going to take some time before the repair because health workers had a busy schedule. I spent some time here and when it was coming to a month we were taken to Kayunga Hospital where we were repaired. (Interviewee, aged 19 years)

The hospital staff told me to start coming every Friday which I did; they couldn't hospitalize me at that time because the wards were full. After some time they hospitalized me. (Interviewee, aged 32 years).

Discussion

Our study participants' understandings of the causes of their obstetric fistula and their treatment seeking behaviours were structured by a variety of factors operating at multiple levels. Our delineation of women's beliefs about fistula and the individual, interpersonal, community, and societal factors that guided their seeking and access of treatment have highlighted important targets for educational, policy, and health systems efforts to improve women's experiences with fistula.

Some of our study participants were broadly aware of the biological processes and discussed the delays in resolving the prolonged labour that had resulted in their development of fistula; however, cause attribution varied widely, and a lack of reproductive health knowledge was evident across many of the women's narratives. Those participants who described decision-making delays to seek delivery care evidenced a general lack of knowledge of

obstetric danger signs. Other studies in Uganda and elsewhere have also identified confusion or failure to recognize danger signs as strong contributors to delays in expectant mothers' care seeking to avoid adverse outcomes^{3,14}. Surprisingly, none of our participants associated the delay at home with an often-cited cultural expectation of home delivery being a sign of a 'real woman'^{8,15-17}. This may be due to changes spurred by intensive efforts by the Ugandan MOH to increase facility-based births, particularly given Uganda's emphasis on prevention of mother to child HIV transmission. It is also possible that correct fistula attribution to prolonged or obstructed labour in our study could have been influenced by health information received by participants when accessing fistula surgery; however, it has been reported elsewhere^{6,8,18}.

Health workers' incompetence and neglect during delivery, which resulted in delay of necessary caesarean sections, was also blamed for fistula development in our study. This theme is consistent with studies in other countries around obstetric fistula, including in Nigeria and Tanzania^{8,19}. Our study participants' narratives depicting receipt of poor quality of delivery care are quite concerning, and emphasize the need to support nation-wide capacity development for high quality and respectful delivery care overall, and in the handling of emergency obstetric cases in particular.

Our study also found that cultural beliefs around magic, witchcraft, or evil spirits featured in cause attribution of fistula by women and their family members. These study findings are consistent with other research from Ethiopia and Nigeria where obstetric fistula was either believed to have resulted from witchcraft from mothers-in-law or step-mothers or it was a punishment from nature for inappropriate behaviour such as infidelity^{10,20}. Local cultural beliefs in such causes of disease and in miraculous healing have been shown to influence behaviours around treatment seeking in this study and elsewhere²¹⁻²⁴. These findings call for targeted efforts to demystify such skewed beliefs and to consider cultural belief structures in provider education, including outreach to traditional practitioners and religious institutions.

In this study, various financial, social, health system and cultural factors were responsible for the great variation in time to biomedical treatment seeking. Awareness about treatment availability was a key factor that facilitated early treatment seeking, and demonstrated the instrumental role of health workers, radio announcements and community members. The important role of awareness-building for obstetric fistula and treatment availability has been identified elsewhere¹⁸, and calls for intensified promotion and use of various mediums to increase public awareness about fistula and fistula treatment in Uganda. Similarly, our study found that social support was critical for facilitating early treatment, particularly due to the shame and isolation associated with obstetric fistula²⁵, which requires broader family and community engagement in outreach activities.

Key barriers contributing to delays in accessing medical care included inadequate financial support. While fistula treatment is free in many facilities in Uganda, transportation and other associated costs were unable to be met by many women. Peripheral costs associated with fistula treatment feature heavily in studies on barriers to fistula care^{3,26}, calling for national strategies to facilitate broad coverage to ensure all patients are able to access treatment, regardless of their economic status.

Study participants also encountered significant challenges in receiving treatment once they had reached the treatment centres due to skilled surgical workforce shortages. While efforts have been intensified over the past decade to train physicians in the surgical management of fistula, it is a highly specialized field and the lack of skilled providers is a broadly recognized impediment to treatment across sub-Saharan Africa^{3,6,13,20}. Continued attention to this critical human resource crisis will help women access care in a timely manner to reduce their physical and psychological suffering.

While our study has highlighted some very important factors that structure treatment pathways for Ugandan fistula patients and suggests some important targets for improvement, both the particular sample of participants and the number of participants impose some limitations. Our participants all accessed fistula treatment at Mulago Hospital, the national teaching and referral hospital of Uganda, located in the capital city of Kampala. It is possible that women affected by fistula living outside of the catchment area for Mulago, or indeed, who face larger barriers to accessing care due to the geographic distribution of fistula treatment facilities across Uganda and neighbouring countries may hold different perspectives.

Ethics, Consent and Permissions

Written informed consent was obtained from all participants. The study received ethical approval from the University of California, San Francisco Committee on Human Research (IRB#: 12-09573), the Makerere University College of Health Sciences Research and Ethics Committee (Ref: 2014-052) and Uganda National Council for Science and Technology (ADM 154/212/01).

Conclusion

Our study findings have identified important targets for educational, policy, and health systems efforts that will contribute to improving women's access to fistula treatment in Uganda. In order to further efforts to ensure prompt treatment for fistula cases and improve women's fistula-related outcomes, it is clear that education and awareness activities regarding obstetric fistula risks, causes and management must be increased to ensure broad reach among women, their families and communities. Furthermore, these educational and awareness-raising activities must be broadly targeted to ensure that community leaders and health workers, including traditional healers and religious personnel, are able to identify women with fistula and help them to rapidly access medical care. Programming and referral networks must be amplified to ensure that women have the social and financial support necessary to access care. Finally, national and international focus on improving the quality of emergency obstetric care and increasing the surgical capacity to meet the population-level needs is essential if prompt treatment for obstetric fistula is to be realized, reducing women's suffering from this condition.

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Table 1:

Socio-demographic profile of study participants with obstetric fistula in Uganda (n=33)

	n	%
Current Age		
18-24 Yrs.	10	30.3
25-29 Yrs.	6	18.2
30-34 Yrs.	5	15.2
35-39 Yrs.	6	18.2
40-51 Yrs.	6	18.2
Age at Fistula Development		
Under 18 Yrs.	7	21.9
18-24 Yrs.	11	34.4
25-29 Yrs.	7	21.9
30-34 Yrs.	4	12.5
35-39 Yrs.	3	9.4
Living Situation ^b		
Alone	3	9.1
Husband	25	75.8
Adult children	1	3.0
Other	4	13.2
Educational Attainment		
None	2	6.1
Any Primary	23	69.7
Any Secondary	8	24.2
Working outside of housework		
Yes	22	66.7
No	11	33.3
Primary Financial Support		
Self	11	33.3
Husband	21	63.6
Other	1	3
Wealth		
Piped Water (house, yard or plot)	5	15.2
Flush/pour flush toilet	2	6.1
Electricity	10	30.3
Radio	29	87.9
Television	13	39.4
Mobile phone	29	87.9
Refrigerator	3	9.1
Delivery Location		
Government-run Facility	24	72.7
Private Facility	9	27.3

	n	%
Infant Survival		
Died	23	69.7
Survived	10	30.3
Time Lived with Fistula		
<3 Months	6	18.1
2-11 Months	9	27.2
1-5 Years	4	12.2
6-10 Years	2	6.1
More than 10 Years	11	33.4

^b with or without young children

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