

Original Research Paper

Living with obstetric fistula: challenges and coping strategies among women attending the fistula clinic at Mulago hospital, Uganda

ABSTRACT

Aims: To determine challenges and coping mechanisms of women living with obstetric fistula (OF) in Uganda.

Study design: Cross-sectional study

Place and duration of the study: Mulago National Referral Hospital Uganda – January to July 2009.

Methodology: Thirty women with OF were interviewed on the challenges, coping mechanisms and perceived causes of OF using semi-structured questionnaires. Additional data on perceived causes of OF was obtained through 2 focus group discussions and 20 key informants interviews with 10 providers, 2 spouses and 8 patients' caretakers.

Results: Majority of the women with OF were young (70% were below the age of 25 years), lived in rural areas (83%) and had OF occurrence at less than 25 years of age. The challenges included the long period living with OF (70% had lived with OF for 2-9 years), loss of marriages (20%), isolation (23%), loss of freedom to associate (13%), lack of self-confidence (13%), inability to work (13%), and stigma (63%). Additionally, all the women had lost their children at birth due to associated complications; 41% of the women had delivered with assistance of traditional birth attendants. The families were affected by the high cost of treatment (43 %); the need to provide basic items (32 %), and suffered stress (55%). The women coped with fistulae by bathing frequently (85%) and taking refuge in churches (30%), among others.

Conclusion: The challenges of OF are physical, emotional, and social-economic and affect entire families. Whereas it is possible to repair the OF through surgery, many women had lived with it for many years and were coping through non-effective social measures. These findings highlight the need to strengthen strategies to prevent OF and enhance OF rehabilitation services for affected women and their families.

KEY WORDS: *Obstetric fistulae, Challenges, Coping, Perceived causes, Misconceptions, Uganda*

ABBREVIATIONS:

OF	Obstetric fistula
UDHS	Uganda Demographic Health Survey
VVF	Vesico vaginal fistula
ANC	Antenatal care
IRB	Institutional review board

1. INTRODUCTION

Obstetric fistula (OF) is a devastating injury sustained by women due to prolonged obstructed child birth[1]. OF is an opening between the vagina and the bladder and/or the vagina and the rectum resulting from prolonged obstructed labour, and leaves women with leakage of urine, feces or both [2]. It is estimated that of the 136 million women who give birth each year, about 20 million experiences a pregnancy-related injury after childbirth [3]. Throughout the world, but mainly in parts of sub-Saharan Africa and Asia, it is conservatively estimated that more than 2 million young women live with untreated OF. Compounding this catastrophic physical trauma, in almost all cases, the woman suffers the loss of her baby. Without treatment, women are frequently ostracized and they withdraw from their communities out of shame. Some are rejected or abandoned by husbands and families. Many are unable to work or earn a living, driving them deeper into poverty[4]. In countries where quality obstetric care is available, fistula was eradicated half a century ago[5]. However, in developing settings where access to obstetric care is limited, large populations of women still experience fistula[6].

Obstetric fistula (OF) represents an important public health problem in Uganda[7]. The actual prevalence of this condition remains unknown, but the Uganda Demographic Health Survey (UDHS) 2011 estimates that two percent of women within the reproductive age have experienced fistula[8]. This equates it to an incidence of 1,900 cases occurring annually[9]. In Uganda, very few studies contribute toward the improvement of the management of OF.

Society perceives OF as a curse or sorcery[10] while the traditional birth attendants (TBA) perceive OF to be caused by caesarean section, physician using metal forceps to pull out the baby[11]. Other studies report OF as being perceived to be caused by a full bladder at child-birth and failure to use gloves during child delivery [12].

There are efforts by Government and other partners to address OF through surgery by ensuring all the referral hospitals in Uganda offer free OF services.[13]. Partners like United Nations Population fund (UNFPA) initiated a campaign to end fistula focusing on a three pronged strategy prevention, treatment and reintegration in 53 countries including Uganda[14].

The objectives of this study were to describe the perceived cause of fistula, challenges faced by women living with OF in Uganda and how they cope with OF.

2. MATERIALS AND METHODS

2.1.1 Study design

This was a cross sectional study in design. It employed qualitative methods of data collection.

2.1.2 Study site and setting

The study was conducted in the fistula unit of Mulago National Referral and Teaching Hospital in Kampala, the capital city of Uganda. The hospital provides comprehensive fistula care for women including surgery, pre- and post-operative counseling and postnatal care. The patients are seen in a weekly clinic where both screening and follow up is provided. About 300 new patients are seen per year and operated on by expert surgeons. The unit is accredited by the International Federation of Gynecology and Obstetrics (FIGO) as a training centre and provides training for local and international fistula care teams.

2.1.3 Target population

The target population constituted of women living with fistula, members of their families who were attending to them and health care workers in Mulago National referral hospital. The study was carried out in the Hospital because of the stigma associated with the condition of OF and difficulty of reaching women living with OF within the community.

2.1.4 Sampling and data collection

During the study, respondents were identified and written or verbal consent sought for face-to-face interviews which were conducted from the clinic and inpatient ward as they waited for surgery. The respondents were assured of confidentiality. Each interview was conducted using a semi-structured interviewer administered questionnaire and the interview process took at least 20 minutes. The research allowed the respondents free discussion and only guided them whenever they deviated from the subject matter. A total of 30 women with OF were interviewed through in-depth semi-structured interviews. Additionally, key informant interviews were conducted with several categories of respondents including; 10 patients' attendants/caretakers (spouses and relatives) and 10 health providers at the VVF unit at Mulago. Purposive sampling was used because the researcher could only reach the OF patients who were present at the facility at the time of the interviews. For other sub-categories in the sample, random sampling was used to select participants. Two FGDs of 5 each were held with caretakers. The participants were also selected purposively.

2.1.5 Data analysis

SPSS statistical software was used to generate percentages and mean values associated with variables of interest. The recorded information was transcribed and translated into English. Qualitative data analysis was done using themes. Quotations were extracted from transcripts based on pre-determined themes and used to illustrate and emphasize the voices and points made by the respondents.

3. RESULTS

3.1 Population characteristics

The study included 30 in-depth interviews with women who had OF; 10 KIs with providers and 2 FGDs with caretakers. The thirty women with fistula came from different districts to Mulago for the surgical OF Camp. They came from upcountry districts ranging from between 35 to 70 kms outside Kampala.

The mean age of the OF patients (women) at the time of interview was 28 years and the median age was 27 years. The youngest was 13 and the oldest was 69 years. Seventy percent of respondents were below 25 years. Thirty percent of the women were single and 47% were married at the time they first experienced the symptoms of OF. Majority of the respondents had attained primary education (66.7%), 10% secondary education and 3.3% post secondary, while. 20% had never attained any formal education. Thirty three per cent were self-employed, and 26.7% were peasants. Forty per cent did not have any specific employment.

The median age of the women at the time they sustained fistula was 18 years, the mean age was 21 years. The range was 13 – 69. Seventy two percent (72 %) had OF occurrence at less than 25 years while 10 women were above 20 years when it occurred. The majority of the women reported that they sustained the fistula at their first (62%) or second pregnancy (34%). None of the women interviewed had been pregnant more than six times when the fistula occurred.

3.1.1 Antenatal care (ANC) attendance, mode of delivery, and pregnancy outcomes

All women reported that they had attended antenatal clinics during the course of their pregnancy either at a government facility or private clinic.

Of these, slightly more than half (59 %) went to the hospital or other health facility when labor commenced while 41% of the women either stayed at home or went to a traditional birth attendant. Sixty percent of the women delivered by caesarian section and 25% had a normal delivery while 14.3% had instrumental assisted vaginal delivery. Overall, 40% of the women spent 3-4 days in labor. The longest time reportedly spent in labor was seven (7) days.

Seventy percent of the deliveries ended up in stillbirths and 18.5% as neonatal deaths. Ninety two percent of the women reported that they had sought professional assistance from a nurse, midwife or medical officer when they recognized the OF symptoms. All the women reported that they had detected the OF symptoms early, within seven days after delivery.

3.2 Women's perceptions of causes of fistula

Twenty five percent of the women with OF indicated that the problem is caused after injury of the bladder accidentally during birth by clinical instruments by doctors, 22% attributed it to delivering of a big baby. Patient-attendants were asked to explain their understanding of the causes of fistula in order to share with them their own experience. 51% cited the hospital procedures and providers' mistakes as prevalent reasons for the fistula problem. Delay during delivery as revealed by three or 26% was the next common cause reported. While 16% attributed the problem to the lack of access to facilities and one woman blamed the negligence of health provider. Other causes cited by a health worker included the young age of women giving birth, poverty and unsupportive husbands. All health workers said they had never detected fistula during or after helping women to deliver. Instead, they revealed that difficult or complex deliveries were referred late to the hospital, and these ended up in such complications as OF.

3.3 Challenges of fistula experienced by respondents

3.3.1 Number of years with fistula:

At the time of the study, all the women had been living with the fistula for over a year. Nine women (30%) reported to have endured OF for more than 10 years, 70% had lived with it between two and nine years, and one woman had lived with OF for 40 years. The women reported that the challenges had continued for several years hence affecting their quality of life.

3.3.2 Health and psycho-social challenges:

Twenty seven out of 30 (90%) of the women said that fistula had detrimentally affected their health and well being. Some women (26%) reported cases of sores and inflammation, pains in the abdomen and back, and headache. All of them reported constant wetness, loss of appetite and weight and inability to work normally. Three (3) women reported that they had suffered constant anxiety and depression, with some expressing deeply held fears, such as not ever getting cured, not being able to have more or any children and never being able to have sexual relations or marry again. Some of the young girls were worried about their chances of continuing with their education. One young girl who was raped related ***"My life has changed drastically; I hope my family can take me back to school some day."***

After injury all the women who were married stopped having sex with their spouses. All the respondents did not enjoy the freedom of association among their families and within the community. One young woman spoke of her ordeal: ***"I am suffering from self pity, I cry a lot because I feel useless. I'm now very thin because of worries; I pray that this condition would just go away."***

A majority (67%) of the caretakers expressed stress and depression suffered by women living with fistula compounded by the loss of their babies, their isolation and their belief that there was no cure for the condition. One family member said: ***"we thought all will be well when she had her first operation however there seemed to be no change in her condition after the operation, and now she has completely lost hope of recovery"***.

Twenty six out of thirty (84%) of the women experienced isolation. Fourteen percent had even isolated themselves due to shame or as a result of the stigma surrounding the condition. Seventy three per cent lacked self-confidence to participate in public activities such as funerals, weddings, community meetings and church services. Sixty three percent (63%) reported that they had been stigmatized. Twelve (40%) women reported that they were living with a bad smell, 30% could not attend church, while 23% had experienced serious isolation from families and community groups.

However one man who was interviewed as a spouse said ***"It is I who made her get to this condition, I cannot have sex with her, but I will make sure she gets medical care. My friends have been telling me to abandon her and take her back to her parents but I won't she is still my wife"***.

3.3.3 Economic challenges

Eighty percent (80%) of the women reported that they were not working. Those that were working were involved in small business to help them raise funds to meet medical costs and other basic needs of life.

They were not involved in businesses that required strict hygiene, such as working in restaurant or selling food. It was indicated by the health care givers that on average treating OF costs Uganda shillings 600,000 (USD 250) which these patients could not afford. They were sponsored by several charitable organizations for this treatment. The average amount of money reported to be spent on basic needs within the home for a fistula patient was Ug. Shs 3,000/= (USD 1.5 per day); this cost was met by families, relatives and good Samaritans.

DISCUSSION

This study assessed the coping mechanisms and challenges faced by women with OF. The challenges of OF are huge, and encompass physical, emotional, social, economic and spiritual aspects. Some women had lost their jobs and could not find work because of the stigma associated with the condition while others reported that they were not able to provide for themselves and their families as a result of not being able to work.

Families were significantly affected by fistula due to the costs of treatment and for basic items such as clothing and soap. The majority of patients also indicated that their families suffered from stress and worry about the fistula affected woman. All the women interviewed reported to have lost their children and as such lost their last source of comfort.

Most women no longer enjoyed their marital relationships. They disclosed that when husbands got to know that they had OF they abandoned them and were not willing to have sex with them again. Even where a husband remained socially supportive to the victim, they no longer enjoyed sexual relationships as the condition disgusts most men. Regarding reproductive rights, they did not even feel interested in getting pregnant again despite their desire to have children. Others thought that probably the condition could worsen and lead them to death in case they got pregnant again. This is an indication that the patients lacked knowledge and information about post-operative conditions.

Although surgical accidents were cited as the key causes OF, a good number of respondents gave varied causes, including witchcraft. The association of OF with medical injury is valid [1-3, 5, 10] Although health workers were implicated, the most common cause of OF in Uganda stems from obstructed labour and delay during labour[7, 11].The high level of ANC utilization and improved access to health services in Uganda does not tie with the continued occurrence of OF.The immediate reason for the mismatch could most likely be a problem of inadequate information to the mothers. The underlying reason however is most likely the ineffective health care system, which drives women to seeking delivery support from TBAs instead of trained health providers[12]. This issue however requires further study.

Various desperate attempts by women with OF, especially to maintain hygiene so as to minimize the effects of OF are remarkable, but largely inadequate and should thus be augmented by comprehensive interventions that include timely surgery and psychosocial support. Women were supported by their parents (mothers) and other relatives, which indicate that their overall relationship with the family continued. Some women also maintained relationships with friends, interacted with fellow patients, and joined religious groups for emotional support.

The limitation of this study is that it is based on the views of a small number of fistula patients with their relatives and health workers involved in their care, and may not be generalized to the entire OF situation in Uganda. However, it highlights the missed opportunities for OF prevention at various levels and the limited access to timely interventions as well as the severe consequences of OF, which are all key findings in terms of informing OF interventions.

CONCLUSION

The challenges of OF are huge, and encompass physical, emotional, social, economic and spiritual aspects. Patients' perceptions of the causes of fistula are somewhat different from what is known in literature, although many are consistent with it. Misconceptions about OF could hinder mothers from seeking medical treatment. Women with fistula cope by problem-based and emotion-based strategies. But these strategies are far too inadequate to deal with the enormous challenges of OF.

Ineffective health systems and rural poverty appear to be the key underlying factors behind the occurrence of OF and the challenges. These findings can help in policy formulation, counseling the affected women, and designing educational programs targeting spouses, families and the community to address the challenges faced by the women.

CONFLICT OF INTEREST STATEMENT: None

ETHICAL APPROVAL:

This paper is part of research done by JK (lead author) for Master in Public Health Leadership of Uganda Christian University in 2009 and it went through the standard Institutional Review Board for technical and ethical review and approval.

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