

Original Research Paper

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

ABSTRACT

Aims: To determine perceived causes, 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 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 with 10 caretakers of the women, and key informants interviews with 10 providers.

Results: Twenty one of the 30 (70%) women living with OF were young, below the age of 25 years, 25 of 30 (83%) lived in rural areas and had OF occurrence at below 25 years of age. Challenges included long period living with OF (21; 70% had lived with OF for 2-9 years), stigma (19; 63%), isolation (7; 23%), loss of marriages (6; 20%), loss of freedom to associate (4; 13%), lack of self-confidence (4; 13%), and inability to work (4; 13%). Additionally, all the women had lost their children at birth due to associated complications; Twelve (41%) women had delivered with assistance of traditional birth attendants. Families were affected by high cost of treatment (13; 43%); the need to provide basic items (10; 32%), and suffered stress (17; 55%). Women coped with OF by bathing frequently (25; 83%) taking refuge in churches (9; 30%), among others.

Conclusion: Challenges of OF are physical, emotional, social-economic and affect entire families. Whereas it is possible to repair OF through surgery, many women had lived with it for several 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 the **process or management** of prolonged obstructed labour, and leaves women with leakage of urine, feces or both [2]. Globally, it is estimated that of the 136 million women who give birth each year, about 20 million experiences a pregnancy-related complication after childbirth [3]. Throughout the world, but mainly in 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 **low income** 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), about two percent of women within the reproductive age **(15-49 years)** have experienced fistula[8]. This translates into an incidence of 1,900 cases occurring annually[9]. In Uganda, studies are needed to contribute toward the improvement of the management of women with OF. The causes of fistula from patients' perspective are not well documented. Society often 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]. **Fistula presents challenges in the life of the women and society and these may vary by context [15-19].** Understanding the challenges that the women and their families face is important in designing comprehensive fistula rehabilitation programs.

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

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. 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 OF attending Mulago hospital fistula clinic, their caretakers, and health providers. Overall, 30 women living OF, 10 members of their families and 10 health care workers in Mulago National referral hospital participated in the study. 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

All respondents consented to participate in the study. The statement on the study was verbally explained and written consent obtained from all respondents including health providers (three doctors and seven nurses), 30 women with fistula and 10 caretakers. For the women with OF, the process of consent was conducted from the clinic and inpatient ward as they waited for surgery. All respondents were assured of confidentiality. A total of 30 women with OF were interviewed. Each interview was conducted using a semi-structured interviewer administered questionnaire and the interview process took at least 20 minutes. Additionally, 10 key informant interviews were conducted with health providers at the VVF unit at Mulago. Two FGDs consisting of 5 individuals in each group were held with 10 patients' caretakers (spouses (3) and relatives (7)). During the Key informant interviews and FGDs, the researcher allowed the respondents free discussion and only guided them whenever they deviated from the subject matter. The respondents in the Key informant interviews and FGDs were purposively selected while the women with OF were consecutively sampled because the researcher could only reach the OF patients who were present at the facility at the time of the interviews.

2.1.5 Data analysis

Quantitative data were entered, cleaned and analyzed using SPSS statistical software and summarized in tables using percentages, mean, median values. The recorded qualitative data were transcribed and translated into English and analysis was done manually using pre-determined themes. Quotes 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 Social demographic characteristics of respondent with OF

The study included 30 semi-structured interviews with women who had OF; 10 Key Informant interviews with health providers and 2 FGDs with caretakers. The thirty women with OF came from various districts in Uganda and were seeking surgical care at Mulago hospital. The distance from their homes to Mulago ranged from 35 to 70 kms. The median age of the OF patients (women) at the time of interview was 27 years (range of 15- 69 years). The median age of the women at the time they sustained fistula was 18 years (range 13 – 69 years). The rest of the social demographic characteristics are shown in *Table 1*.

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

All women with fistulae reported that they had attended antenatal clinics during the course of their pregnancy either at a government facility or private clinic. The rest of the results are shown in *Table 4*.

3.2 Respondents perceptions of causes of fistula

All fistula patients (n=30) perceived injury by surgeon as a main cause of fistula. They also mentioned delivery of big baby, prolonged labour, witchcraft, injury by self retaining catheter; tear caused by baby, TBAs fingers, negligence by care givers, young age, and poverty as outlined in *Table 2*. However, the patients' attendants attributed OF to hospital procedures (51%), health service providers' mistakes (26%), and lack of access to health facility (16%). Other causes reported by attendants included; delays during delivery, negligence by service providers, young age, poverty and unsupportive husbands. All health workers said they had never detected fistula during or after helping women to deliver. Instead, they mentioned delays in the referral system and revealed that difficult or complex deliveries were referred late to the hospital, and these ended up with complications such as OF.

3.3 Challenges of fistula experienced by respondents

3.3.1 Physical Health and psycho-social challenges

Twenty seven (90%) of the women with fistulae reported that fistula had detrimentally affected their health and well being. Eight (26%) women 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) of the 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. **One young girl with fistula was worried about her chance of continuing with her education** ***"My life has changed drastically; I hope my family can take me back to school someday."***

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."***

Seven of the 10 (67%) caretakers expressed stress and depression suffered by women living with fistula compounded by the loss of their babies. **The caretakers said women were isolated and that they had no hope for the cure of 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"***.

3.3.2 Social challenges

The social challenges mentioned by women were isolation, stigma, and lack of self-confidence to participate in public activities such as funerals, weddings, community meetings and church services. The other social challenges are included in *Table 3*.

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

Twenty four (80%) 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 Ugx. Shs 3,000/= (USD 1.5 per day); this cost was met by families, relatives and good Samaritans.

3.4 Coping strategies

The study shows that women with fistulae coped by: keeping in hiding (27;90%) strict hygiene (washing all the time, padding with heavy torn old soft clothes (25; 83%), drinking a lot of water to reduce the smell and sores due to the urine (24;80%), ignoring people's comments (23;75%), prayer (18;57%) seeking refuge with pastors in churches (9;30%), using waterproof (polythene) materials on mattresses (5;17%) and keeping busy with making handcrafts (3;8.9%). All the respondents said they changed clothes all the time, and used perfumes and lotions (See *Table 5*).

DISCUSSION

This study assessed the perceived causes, challenges and coping mechanisms 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 basic items such as clothing and soap; in addition to the social and mental stress. **For the women, the** loss of their children further deprived them of their last source of comfort[20].

Most women no longer enjoyed their marital relationships and at the **time of interview were no longer in their marriages**. 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. **Another study that was conducted in five countries (including four in Africa) found that all the mothers were married and**

still living with their husbands[20]. The higher separation rates in our study might be related to the longer period of time that some of the women had lived with OF. Regarding reproductive rights, they did not even feel interested in getting pregnant again despite their desire to have children.

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] but probably over-emphasized given that surgery is not the commonest cause of OF. Although health workers were implicated, the most common cause of OF in Uganda stems from obstructed labour and delay during labour[7, 11]. This points to a need for further sensitization of communities on the causes and prevention of OF, and other labor related complications. 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 be a problem of inadequate information to the mothers. The underlying reason however is the ineffective health care system, which drives women to seeking delivery support from TBAs instead of trained health providers[12].

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, which is consistent with another study[21].

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.

4. 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[22]. 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.

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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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285 **Table 1: Social demographic characteristic of women with OF**

Characteristic	Number of women (n=30)	Percentage of women (%)
Age at interview		
15-20 years	22	72.0
21-69 years	08	28.0
Number of years of living with OF		
2-9 years	20	67.0
10-39 years	09	30.0
40 years	01	3.0
Parity of women with OF		
Prime para (para 1)	19	63.0
Para 2-6	11	37.0
Marital status		
Married	14	46.6
Single	09	30.0
Separated/Divorced	05	16.7
Widow	02	6.7
Education level of women with OF		
No formal education	06	20.0
Primary	20	66.7
Secondary	03	10.0
Tertiary	01	33.3
Occupation of respondents		
No gainful employment*	12	40.0
Self employed(small retail)	10	33.3
Subsistence farmer	08	26.7

286 *housewife or no work at all

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288 **Table 2: Perceived causes of OF by women attending the fistula clinic in Mulago**

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Perceived cause	Number of women reporting (N=30)	Percentage of women reporting (%)
Injured by surgeon	08	25.3
Delivery of a big baby	07	22.2
Prolonged labor	04	13.3
Witchcraft	03	11.0
Injured by self retaining catheter	02	7.7
Torn by baby	01	4.0
Others*	05	16.5

290 **others included TBAs fingers, negligence by care givers, young age, and poverty*

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Table 3: Showing the types of social challenges faced by women with OF

Social challenge faced by women	No of women with OF (n=30)	Percentage of patients reporting social challenge
Bad smell	12	40.0
Cannot go to church	09	29.9
Isolation/outcast	07	23.3
Cannot visit	02	6.6
Discontinued school	01	3.0

297 **Table 4: Skilled attendance at the onset of labour, Mode of delivery, Pregnancy outcome**

Category	Number of women (n=30)	Percentage of women (%)
Skilled attendance at onset of labour		
Went to health facility(Hospital or health centre)	18	60.0
Stayed at home/ TBA	12	40.0
Days in labour		
1 - 2 days	15	50.0
2 – 4 days	12	40.0
5 – 6 days	02	6.7
7 – 8 days	01	3.3
Mode of delivery		
Caesarean section	18	60.0
Normal vaginal delivery	08	26.7
Instrument assisted vaginal birth	04	13.3
Pregnancy outcomes		
Still birth	21	70.0
Neo natal death	05	16.7
With baby	04	13.3
Reported OS symptoms		
To a skilled health worker*	28	93.3
Witch doctor	02	6.7

298 * Medical officer, Midwife, Nurse

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Table 5 Coping strategies

Category	Number of women with OF (n=30)	Percentage of women (%)
Keep hiding	27	90.0
Strict hygiene*	25	83.0
Drinking a lot of water & eat less	24	80.0
Ignoring people's comments	23	75.0
Prayer	18	57.0
Seek refuge from Pastors and in church	09	30.0
Use polythene material on top of clothes	05	17.0
Keep busy doing handcrafts	03	8.9