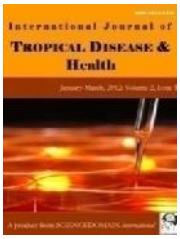

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Living with Obstetric Fistula: Perceived Causes, Challenges and Coping Strategies among Women Attending the Fistula Clinic at Mulago Hospital, Uganda

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Authors' contributions

This work was carried out in collaboration between all authors. Author JK designed the protocol, collected the data, wrote the first complete draft of this paper and was responsible for final submission of the paper. Author JKB supervised the design of the protocol and data collection; reviewed the first draft of the paper and improved it for substantial intellectual content. Authors JKBM and JB participated in data analysis, interpretation of data and manuscript writing and reviewed the paper for substantial intellectual content. Author EK participated in manuscript writing, made substantial comments to the revised version of the paper, and improved it for substantial intellectual content. Author RKW participated in data analysis, interpretation of data and manuscript writing; reviewed the paper for substantial intellectual content. All authors read and approved the final version of the manuscript.

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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

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mechanisms and perceived causes of OF using semi-structured questionnaires. Two focus group discussions were held with 10 caretakers of the women with OF and key informant interviews with 10 health care providers.

Results: Majority of the women (21; 70%) were young (<25 years) had primary education (20; 67%) and had lived with OF for 2-9 years (20; 67%). The main perceived causes of OF were injury by surgeon (8; 27%), delivery of a big baby (7; 23%) and prolonged labor (4; 13%). Nearly all women with OF (27; 90%) reported that OF had detrimentally affected their health and well being; 26 women (87%) lost their children at birth or within the neonatal period. Families were affected by high cost of treatment (13; 43%); provision of basic items (10; 32%), and suffered stress (17; 55%). Women coped with OF by hiding from the general public (27; 90%), maintaining strict hygiene (25; 83%), ignoring people's comments (23; 75%) or resorting to prayer (18; 57%).

Conclusion: Women with OF experienced physical, emotional and socio-economic challenges and coped with OF through non-effective social measures. There is need to strengthen strategies to prevent OF and enhance OF rehabilitation services for affected women and their families.

Keywords: 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 child birth [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 [4]. Some are rejected or abandoned by husbands and families [3]. Many are unable to work or earn a living, driving them deeper into poverty [5]. In countries where quality obstetric care is available, fistula was eradicated half a century ago [6]. However, in low income settings where access to obstetric care is limited, large populations of women still experience fistula [7].

OF represents an important public health problem in Uganda [8]. The actual prevalence of this condition remains unknown but the 2011 Uganda Demographic Health Survey (UDHS) estimates about two percent of women within the reproductive age (15-49 years) have experienced fistula [9]. This translates into an incidence of 1,900 cases occurring annually [10]. 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 [11] while the traditional birth attendants (TBA) perceive OF to be caused by caesarean section or physicians using metal

forceps to pull out the baby [12]. 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 [13].

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 [14]. Partners like United Nations Population Fund (UNFPA) initiated a campaign to end fistula focusing on a three pronged strategy that includes prevention, treatment and reintegration in 53 countries including Uganda [15]. Fistula presents challenges in the life of the women and society and these vary by context [16-20]. 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 Study Design

This was a cross-sectional study that employed qualitative methods of data collection.

2.2 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-operative 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.

2.3 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 with OF, 10 caretakers and 10 health care workers (three doctors and seven nurses) 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.

2.4 Sampling and Data Collection

All respondents provided written informed consent prior to participating in the study. 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. Thirty 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 (KIIs) were conducted with health providers at the vesico vagina fistula (VVF) unit at Mulago. Two focus group discussions (FGDs) consisting of 5 individuals each were held with patients' caretakers (i.e., spouses (3) and relatives (7)). During the process of conducting KIIs and FGDs, we allowed the respondents free discussion and only guided them whenever they deviated from the subject matter. All qualitative interviews were

audio-recorded and transcribed on the same day of interview. The respondents in the KIIs and FGDs were purposively selected while the women with OF were consecutively sampled because we could only reach the OF patients who were present at the facility at the time of the interviews.

2.5 Data Analysis

Quantitative data were entered, cleaned and analyzed using SPSS statistical software and summarized in tables showing percentage distributions across different variables. Qualitative data were analyzed manually using pre-determined 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 Socio-demographic Characteristics of Respondents with OF

Table 1 presents the socio-demographic characteristics of women with OF. Majority of the women were below 20 years of age (22; 72%) had primary education (20; 67%), and were either self-employed or did not engage in any gainful employment (22; 73%). Nearly half of the women (14; 47%) were currently married. Two-thirds of the women (20; 67%) had lived with OF for 2-9 years. 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) while the median at the time they sustained fistula was 18 years (range 13 – 69 years) (Table 1).

Table 1. Social demographic characteristics of women with OF

Characteristic	Number of women (n=30)	Percentage of women (%)
Age at interview		
15-20 years	22	73.0
21-69 years	8	27.0
Number of years of living with OF		
2-9 years	20	67.0
10-39 years	9	30.0
40 years	1	3.0
Parity of women with OF		
Para 1 (primipara)	19	63.0
Para 2-6	11	37.0
Marital status		
Married	14	47.0
Single	9	30.0
Separated/Divorced	5	17.0
Widow	2	6.0
Education level of women with OF		
No formal education	6	20.0
Primary	20	67.0
Secondary	3	10.0
Tertiary	1	3.0
Occupation of respondents		
No gainful employment*	12	40.0
Self employed (small retail)	10	33.0
Subsistence farmer	8	27.0

**housewife or no work at all*

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. However, a substantial number (12; 40%) sought delivery assistance from TBAs as their first point of contact; all the 12 women eventually ended up in the hospital and delivered by caesarian section. Overall, 26 women (87%) lost their babies; 21 had still births while 5 children died within the neonatal period (Table 2).

Table 2. Labour and outcomes of the pregnancy leading to OF

Category	Number of women (n=30)	Percentage of women
Skilled attendance during labour		
Went to health facility	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 – 8 days	3	10.0
Mode of delivery		
Caesarean section	18	60.0
Normal vaginal delivery	8	27.0
Instrument assisted vaginal birth	4	13.0
Fetal outcomes of delivery causing OF		
Still birth	21	70.0
Neonatal death	5	17.0
With baby	4	13.0
To whom OF symptoms were reported		
To a skilled health worker*	28	93.0
Witch doctor	2	7.0

* *Medical officer, Midwife, Nurse*

3.2 Respondents Perceptions of Causes of Fistula

Eight women (27%) perceived injury by surgeon as the main cause of fistula (Table 3). Other causes mentioned included delivery of big baby (7;23%), prolonged labour (4;13%), witchcraft (4;13%) and injury by self-retaining Foleys urinary catheter (2;7%). Caretakers cited hospital procedures, provider negligence, lack of access to health facilities, young age, poverty and unsupportive husbands as causes of OF. 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 OF reported that fistula had detrimentally affected their health and well being while eight (27%) women reported cases of sores and

inflammation, pains in the abdomen and back and headache (data not shown). 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."

Table 3. Perceived causes of OF by women attending the fistula clinic in Mulago

Perceived cause	Number of women reporting (N=30)	Percentage of women reporting (%)
Injured by surgeon	08	27.0
Delivery of a big baby	07	23.0
Prolonged labor	04	13.0
Witchcraft	03	10.0
Injured by self retaining catheter	02	7.0
Torn by baby	01	3.0
Others*	05	17.0

**others included TBA's fingers, negligence by care givers, young age and poverty*

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 (70%) 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 caretaker 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".

Table 4 shows the social challenges experienced by women with OF. The main social challenges experienced by women with OF were bad smell (12; 40%), failure to attend social gatherings such as church (9; 30%), loss of marriages (5; 17%) and isolation (one girl was discontinued from school). One man who was a spouse to one of the women with OF 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".

3.3.2 Economic challenges

As shown in Table 1, twelve (40%) women reported that they were not involved in gainful employment. Those that were working (10; 34%) were involved in small businesses 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 restaurants or selling food. Health care givers indicated that, on average, treating OF costs Uganda shillings 600,000 (USD 250) which these patients could not afford. The women interviewed as part of this study were sponsored by several charitable organizations for this treatment. Women with OF

reported spending an average of Uganda Shillings 3,000/= (USD 1.5) per day on basic needs within the home; this cost was met by families, relatives and "will wishers".

Table 4. 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	30.0
Isolation/outcast	07	23.0
Lost their marriages	05	16.6
Cannot visit	02	7.0
Discontinued school	01	3.0

3.4 Coping Strategies

Table 5 shows the coping strategies adopted by women living with OF. Majority of the women (27; 90%) coped by hiding from the general public; maintaining 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%), and resorting to prayer (18;57%). Others coped by seeking refuge with pastors in churches (9;30%) using waterproof (polythene) materials on mattresses (5;17%) and keeping busy with making handcrafts (3;9%). All the respondents said they changed clothes frequently, and used perfumes and lotions to reduce the bad odors resulting from sores and urine.

Table 5. Coping among women with OF

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

**Keep washing and padding*

4. 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. The majority of the women had lost their babies and some their marriages. In a related study that was conducted in Uganda, all the women had lost their children [4,12]. The loss of marriages due to having OF has also similarly been reported [21-23]. In addition to loss of children and marriage, isolation and lack of gainful employment were prominent challenges. The loss of children, marriages, and isolation creates a lot of stress for the women and could lead to loss of identity [4,24].

Beyond the individual women, the families were also 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 yet existing interventions tend to focus more on prevention and treatment and do not address issues related to social support and reintegration of the affected women into their communities [25]. Thus, interventions for women with OF should extend beyond the medical aspects to address the social and emotional challenges of the women and their families.

Our findings show that women with OF tended to cope through non-effective social measures including hiding from the general public. These findings are in agreement with prior studies that show that women with fistula cope by problem-based and emotion-based strategies [26]. But these strategies are far too inadequate to deal with the enormous challenges of OF. The 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 be augmented by comprehensive interventions that include timely treatment (surgery). However, studies show challenges with accessing surgery, which is also evident in this study where many women had lived with OF for more than two years [27].

Injury by providers and negligence were cited by the women and their caretakers among the perceived causes OF, and some women cited varied causes, including witchcraft. The association of OF with medical injury is valid [1-3, 6,11] 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 [3,8,12,22]. We found that four out of every ten women with OF visited TBAs as their first point of contact at delivery, which has been documented to cause significant delays in getting appropriate care from skilled providers[12,28]. 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 tally with the continued occurrence of OF; the immediate reason for this mismatch could be a problem of inadequate information provided to the mothers. The underlying reason however could be the ineffective health care system, which drives women to seeking delivery support from TBAs instead of trained health providers [13].

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.

5. CONCLUSION

Women with OF experience physical, emotional and socio-economic challenges and usually cope through non-effective social means. The perceived causes among the women and their caretakers highlight various misconceptions and a lack of in-depth understanding of the major causes of OF. These findings suggest a need to educate women and the general public about the causes of OF and management of OF; including a need to design and implement comprehensive interventions to address all levels of OF prevention, treatment and reintegration of affected women into communities.

CONSENT

Not applicable.

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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COMPETING INTERESTS

Authors have declared that no competing interests exist.

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