Annals of Global Health VOL. ■■, NO. ■■, 2017

ISSN 2214-9996/$36.00
http://dx.doi.org/10.1016/j.aogh.2017.07.003

ORIGINAL RESEARCH

Social Experiences of Women with Obstetric Fistula Seeking Treatment in Kampala, Uganda

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Abstract

BACKGROUND Obstetric fistula is a preventable and treatable condition predominately affecting women in low-income countries. Understanding the social context of obstetric fistula may lead to improved prevention and treatment.

OBJECTIVES This study investigated social experiences of women with obstetric fistula seeking treatment at Mulago Hospital in Kampala, Uganda.

METHODS A descriptive study was conducted among women seeking treatment for obstetric fistula during a surgical camp in July 2011 using a structured questionnaire. Descriptive statistics were computed regarding sociodemographics, obstetric history, and social experience.

FINDINGS Fifty-three women participated; 39 (73.58%) leaked urine only. Median age was 29 years (range: 17-58), and most were married or separated. About half (28, 47.9%) experienced a change in their relationship since acquiring obstetric fistula. More than half (27, 50.94%) acquired obstetric fistula during their first delivery, despite almost everyone (50, 94.3%) receiving antenatal care. The median years suffering from obstetric fistula was 1.25. Nearly every participant's social participation changed in at least one setting (51, 96.23%). Most women thought that a baby being too big or having kicked their bladder was the cause of obstetric fistula. Other participants thought health care providers caused the fistula (15, 32.61%; n = 46), with 8 specifying that the bladder was cut during the operation (cesarean section). Knowing someone with obstetric fistula was influential in pursuing treatment. The majority of participants planned to return to family (40, 78.43%; n = 51) and get pregnant after repair (35, 66.04%; n = 53).

CONCLUSION Study participants experienced substantial changes in their social lives as a result of obstetric fistula, and there were a variety of beliefs regarding the cause. The complex social context is an important component to understanding how to prevent and treat obstetric fistula. Further elucidation of these factors may bolster current efforts in prevention and holistic treatment.

KEY WORDS Genitourinary fistula, Maternal health, Obstetric fistula, Obstructed labor, Social experience, Uganda.

Funding Source: Radulovacki Global Health Scholars Student Summer Fellowship (2011).
Conflicts of Interest: The authors have no conflicts of interest to report from the research team. All authors had access to the data and a role in writing the manuscript.
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■■ 2017: ■■–■■

INTRODUCTION

Obstetric fistula is a preventable and treatable problem that is believed to affect 1.6-3 women per 1000 in sub-Saharan Africa[1,2] and 2% of women in Uganda.[3] In developing countries, the condition is often caused by a prolonged, obstructed labor. Pressure of fetal parts on the mother's pelvic bones causes tissue necrosis, which can create an abnormal connection between the bladder and vagina and/or rectum. This conduit can unfortunately cause uncontrollable leaking of urine and/or fecal matter.[4,5] The delivery often additionally results in a stillbirth, leading to a devastating combination.[6,7]

Development of health care systems that provide obstetric care for all women in higher-income countries has largely eliminated this tragic condition. But obstetric fistula persists in lower-income countries where less comprehensive services are available.[4] The fact that this condition remains prevalent is unacceptable and signals a failing health system for women that does not protect human rights.[8] The presence of obstetric fistula often makes future pregnancies difficult, preventing women from conforming to the social expectation of childbearing.[9] A study in Tanzania that focused on social and cultural aspects of obstetric fistula found that women were often discriminated against in social situations and experienced lack of control from being incontinent. They felt less important because they could not fulfill their societal expectations.[10] A meta-analysis looked at some of the social consequences of obstetric fistula, reporting that marriage and home life were often affected, as well as participation in social and religious occasions.[11] A conclusion from an integrative review on the social effects of obstetric fistula in Africa concluded that obstetric fistula had at least a moderate consequence on social functioning. They also found that stigma and shame were highly prevalent.[12] Other studies have confirmed the high morbidity in the psychosocial realm.[9,13,14]

The focus on obstetric fistula in Ugandan and other studies are often medical, with further need for the elucidation of the influence that social factors play in the prevention and treatment of this condition. How obstetric fistula is socially perceived and how it affects the social lives of those who suffer are also important aspects of this condition. The surgical and medical care alone will not be effective unless they work together with social solutions. Only when we know how women socially perceive the problem and what impediments they face in getting obstetric care will we be equipped to use resources wisely to make fistula prevention and care truly accessible to women. Understanding the social context of this condition may lead to improved preventive measures and holistic treatment, bolstering current efforts.

METHODS

A survey was conducted and designed with qualitative and quantitative components. The study was implemented at Mulago National Referral and Teaching Hospital in Kampala, Uganda. This site provides treatment in both routine and surgical camp settings that is free to patients with obstetric fistula; however, costs of transport and other associated costs are not covered and can be prohibitive. During the surgical camps, many women are provided with surgery in a short period. The public funding attracts a diverse group of patients, particularly because treatment is free as a result of assistance from various nongovernmental organizations.

For this study, participants were identified among those seeking treatment with the help of the medical team during a camp in July 2011. Announcements were made to those awaiting treatment or recovering postoperatively. All those older than 18 or those with parental consent who were seeking treatment for obstetric fistula were eligible to participate. Exclusion criteria included those younger than 18 without parental consent, those with fistula as a result of a nonobstetric cause, and those unable to communicate effectively in Luganda. We used a structured questionnaire was administered orally with a translator who was trained as a nurse and had prior experience with research translation. Interviews lasted between 30 minutes to 1 hour. Informed consent was received in Luganda before the start of the interview with signatures or equivalents recorded as a sign of consent. Participants were given a small sum of money as an incentive to participate regardless of level of completion of the study. Throughout the study, they were reminded that they were free to the leave the interview at any time or skip any question they were not comfortable answering.

Ethical clearance was obtained through Northwestern University's Institutional Review Board and locally at the Makerere College of Health Sciences in the Department of Obstetrics and Gynecology before the start of the study. Paper surveys were transferred to and stored in a Microsoft Excel database, where they were analyzed. Descriptive statistics were computed to describe demographics, marital status, obstetric history, the birth causing the fistula, and social experience. Free response data on the cause of