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CLINICAL ARTICLE

Fistula awareness among sisters of women with fistula

Alice X. Zheng [a], Alexander H. Harrington [a], Stephanie A. Love [b], Linda D. Thélémaque [b], Frank W.J. Anderson [a,*]

[a] Department of Obstetrics and Gynecology, University of Michigan Medical School, Ann Arbor, USA
[b] Uganda Village Project, Iganga, Uganda

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ABSTRACT

Objective: To determine whether sisters of women with obstetric fistula (OF) were aware of their sisters' condition, in order to inform the development of survey questions that adapt the sister-based method to fistula rate estimation. *Methods:* Twelve women with OF and 20 of their sisters were interviewed using semi-structured questionnaires in rural Uganda in 2007. Topics included fistula awareness and perceptions of causality. *Results:* Eleven women had vesicovaginal fistula and 1 had rectovaginal fistula. Three were primiparous at time of fistula occurrence; 6 had a parity of 6 or more. Nineteen sisters were aware their sister had OF; 12 became aware at the time of occurrence. The majority of participants (fistula patients and their sisters) associated OF with mistakes made by hospital personnel or problems during procedures. *Conclusion:* Sisters were generally aware of OF within their family. Larger studies are needed to assess the validity and reliability of the sister-based method in capturing fistula through household surveys. In the present study, there was a widespread perception among fistula patients and their sisters that fistula is caused by medical procedures. More research is needed to understand this perception, and program development efforts are required to improve patient perceptions of hospital care.

1. Introduction

Obstetric fistula is a major morbid condition resulting from neglected obstructed labor, and is thus caused by the same health system deficiencies that lead to maternal mortality [1,2]. Estimates of the prevalence of obstetric fistula vary widely and there is "little basis for any of the numbers quoted in the published and gray literature" [3]. Adaptation of the sister-based method, which is used to obtain an indirect estimate of maternal mortality, may be a useful tool to estimate fistula prevalence in the community [3,4].

Obstetric fistula is an isolating condition, and prevalence estimates may not be amenable to population-based methods of ascertainment; however, if the sisters of those with the condition were aware, estimates could be generated. The symptomatology of obstetric fistula could be confused with other causes of urinary incontinence that may also be related to obstetric lacerations or muscular tears. Differentiating these causes of urinary incontinence may be difficult via any survey methodology. The 2005 Malawi Demographic and Health Survey (DHS) used urinary incontinence as a fistula symptom and reported a crude fistula rate of 16 per 1000 live births [5]. In the 2007 Uganda DHS, 2.6% of women aged 15–49 years reported "uncontrollable leakage of urine or stool from her vagina" [6].

The aims of the present study were to determine whether women whose sisters had been diagnosed with obstetric fistula were aware of their siblings' condition and to explore their attitudes toward the origin and cause of the fistula so that direct and accurate survey questions could be developed to measure fistula prevalence.

2. Materials and methods

Adult women with obstetric fistula in central eastern Uganda were recruited from July 9 to August 16, 2007. A convenience sample was generated in conjunction with the obstetric fistula repair referral program of the Uganda Village Project. The recruitment script for the fistula repair program recruited women who had experiences of "difficult labor" and who were subsequently "leaking urine and/or feces." Trained community health workers of Ibulanku Community Health Clinic, Iganga, Uganda, identified potential repair candidates via word of mouth, referral through local leaders and traditional birth attendants (TBAs), and other community outreach methods. Participants for the present survey study were simultaneously recruited and, upon agreeing to participate, were asked to identify up to 2 adult sisters for potential interview (they were asked to providing names of sisters, village names, and/or husbands' names). Participants agreed to have their diagnosis discussed with their sisters. Each sister was later approached in her home and told that she had been "referred by a sister with obstetric fistula," without giving names.

Face-to-face interviews using semi-structured questionnaires were conducted by trained Uganda Village Project interviewers and

* Corresponding author at: Department of Obstetrics and Gynecology, University of Michigan Medical School, L4000 Women's Hospital, 1500 E. Medical Center Drive, Ann Arbor, MI 48109-5276, USA. Tel.: +1 734 615 4396; fax: +1 734 763 5992.
E-mail address: fwja@med.umich.edu (F.W.J. Anderson).

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interpreters. The interviews, which lasted between 30 minutes and 2 hours, were digitally recorded and translational inconsistencies were re-examined during transcription. Participants with fistula were asked about their experiences acquiring and living with fistula; causes and timing; and awareness in their family about the condition. Sister participants were asked about their awareness of fistula and their perceptions of cause. Women with unrepaired fistula were provided transport to a free surgical repair camp at Kitovu Mission Hospital, Masaka, Uganda, through the Uganda Village Project. Participation in the study was not required for referral for repair, and those seeking repair but not interviewed were also referred. Fistula diagnoses were validated by review of medical and surgical repair camp records.

The study was approved by the Institutional Review Board of the University of Michigan, Michigan, USA, and Makerere University, Kampala, Uganda. Descriptive statistical analysis was conducted using Excel 2010 (Microsoft, Redmond, WA, USA). For qualitative analysis, a codebook was developed based on transcripts, from which themes were extracted.

3. Results

Average age at time of interview among the 12 women with obstetric fistula was 38 years (range, 20–60 years) (Table 1). Eleven women had vesicovaginal fistula (VVF) and 1 had rectovaginal fistula (RVF). Three women were primiparous at the time of fistula occurrence and 6 had a parity of 6 or more. The average number of sisters among fistula patients was 3.4. The women came from more than 10 villages within 4 districts of Uganda. Six were married at the time of the interview. Occupations of obstetric fistula patients included farmer (n = 8), business/peddling (n = 2), and peasant/no occupation (n = 2). After fistula occurrence, 7 women experienced a change in their living situation. Some women were divorced but remarried, whereas others remained married and their husbands took on additional co-wives. Overall, family members were sympathetic to women, and 7 received financial or other support from family members. The main constraint to this was family members' own poverty and financial obligations.

Table 1
Demographics of participants with fistula.[a]

Characteristic	Value
Age	38.3 ± 15.1 (20–60)
No. of sisters	3.4 ± 1.6 (1–6)
Parity at fistula occurrence	
1	3 (25.0)
2–5	3 (25.0)
>5	6 (50.0)
Living situation	
Alone	2 (16.7)
Husband	5 (41.7)
Other family	5 (41.7)
Marital status	
Married	6 (50.0)
Divorced	4 (33.3)
Widowed	1 (8.3)
Never married	1 (8.3)
Occupation	
Farmer	8 (66.7)
Peddler	2 (16.7)
Peasant	1 (8.3)
None	1 (8.3)
Education level	
Primary 3	1 (8.3)
Primary 4	3 (25.0)
Primary 5	1 (8.3)
Primary 7	2 (16.7)
Senior 2	1 (8.3)
None	4 (33.3)
Change in living situation after fistula	
Yes	7 (58.3)
No	5 (41.7)
Any support from others	
Yes	7 (58.3)
No	5 (41.7)
Type of fistula	
VVF	11 (91.7)
RVF	1 (8.3)

Abbreviations: RVF, rectovaginal fistula; VVF, vesicovaginal fistula.
[a] Values are given as mean ± SD (range) or number (percentage).

The average age of the 20 sisters interviewed was 37 years (range, 21–70 years). They were mostly farmers (n = 16). Seven lived with the sister who had obstetric fistula, 12 did not, and 1 did intermittently. All 20 sisters were aware of obstetric fistula as a health condition and 19 were aware that their sister had the condition (Table 2). One knew her sister had become ill after delivery but did not know that the condition was fistula because it was kept secret for personal reasons. Twelve sisters became aware of the fistula at the time of occurrence. Ten had been present at delivery or health staff had informed them of the fistula during hospital visits. Among the sisters not immediately aware, the delay (a few months to a few years) resulted from the woman with fistula keeping it a secret or healthcare workers not informing the sister. They eventually found out when the sister told them or when they directly observed lack of control of urine or feces. Most sisters were aware of medical symptoms experienced by women with fistula, notably lack of control of urine or feces (n = 15) and smell (n = 7).

The majority of women with fistula associated the condition with delivery (n = 8) rather than labor (Table 2). In particular, 6 women specifically believed that healthcare workers or hospital procedures had caused their fistula. One (patient 12) described how she started to leak urine immediately after she had been operated on following delivery. Another woman (patient 4) believed that her situation had been caused by a urinary catheter. One woman (patient 9) had a similar experience, believing that her catheter had left a hole. A phrase commonly used by women with obstetric fistula was "burst bladder."

Twelve of the sisters also believed that the condition was caused by delivery or operation. Five claimed that the healthcare worker (nurse, doctor, or midwife) directly caused their sister's fistula, and 1 blamed the village TBA. The theme of an operation causing a burst bladder was also prominent among sisters (Table 2).

4. Discussion

The present study demonstrated that sisters are generally aware of obstetric fistula within their family and could be asked explicitly about the condition in community-based surveys. Sisters were made aware in a timely fashion, which supports the use of the sister-based method as a proxy measurement of obstetric fistula prevalence and indicates that biases related to the conduct of the present study did not influence the awareness of fistula. The only sister who was unaware was involved in a complicated personal situation.

Since the time of data collection in the present study, the sister-based method has been used to estimate the prevalence of obstetric fistula in Malawi [7]. Respondents were asked about constant loss of urine and/or feces after delivery, time of occurrence, and duration of symptoms experienced by themselves, their sisters, or anyone they knew. The study identified 575 women with the condition from 3282 interviews: 266 (46.3%) respondents; 75 (13.0%) sisters; and 234 (40.7%) other women.

Key next steps for the sister-based method include validation of potential survey questions describing fistula that can be added to household surveys (e.g. the DHS). The present study did not specifically address methods to distinguish fistula from other causes of urinary incontinence but all participants who self-identified as experiencing fistula were validated with medical records. Given that a majority of sisters were aware of the temporal relationship of

Table 2
Experiences of women with fistula and awareness of their sisters.

Participant	Age at fistula occurrence, y	Sister aware of fistula	Birth outcome	Marital status	Fistula type	Perceived cause(s) of fistula	Duration of symptoms	Length of awareness (informer)	Medical consequences	Social issues
Patient 1	18		Born dead	Divorced	VVF	God/labor	20 y		No urine control	Husband left
Sister 1A		Yes				Nurse burst bladder		20 y (nurse)	No urine control	Husband left
Sister 1B		Yes				God/midwife in clinic burst bladder		20 y (nurse)	No urine control	Husband left
Patient 2	30		Born alive	Divorced	VVF	Delivery	20 y		No urine control	Suicidal, depression, divorce, left church
Sister 2A		Yes				Delivery		20 y (nurse)	No urine control, smell	Divorce
Sister 2B		Yes				Labor		20 y (nurse)	No urine control, smell	Divorce
Patient 3	27		Born alive	Married	RVF	Prolonged labor/bike accident made it worse	7 y		No stool control, no pleasure from sex, weight loss	Husband left
Sister 3A		No				Delivery/"busted bladder"/AIDS		N/A	N/A	
Sister 3B		Yes				Lack of nutrients/birth initial cause/bike accident made it worse		6 y (nurse)	Feces from vagina	
Patient 4	29		Born alive	Married	VVF	Delivery/doctor tore bladder	1 y		No urine control, smell	
Sister 4A		Yes [a]								
Patient 5	18		Born dead	Divorced	VVF	Cesarean	14 y		No urine control	Family abuse, husband left
Sister 5A		Yes				Delivery/operation/doctor burst bladder		9 y (sister)	No urine control	
Patient 6	36		Born dead	Widow	VVF	Delivery	17 y		No urine control	
Sister 6A		Yes				Delivery		17 y (hospital)	No urine control	
Patient 7	15		Born dead	Never married	VVF	Herbal drugs/healthcare worker burst swollen bladder after delivery	4 y		No urine control, smell	Suicidal
Sister 7A		Yes				Delivery		4 y (observation)	No urine control, smell	Suicidal
Patient 8	29		Born alive	Married	VVF	Doctor burst bladder while operating	17 y		No urine control, pain	Husband left
Sister 8A		Yes				Complicated delivery		17 y (hospital)	Don't know	
Sister 8B		Yes				Complicated delivery		17 y (hospital)	Don't know	
Patient 9	13		Born alive	Divorced	VVF	"Drainage tube" punctured bladder after delivery	6 y		No urine control, pain	
Sister 9A		Yes				Delivery		6 y (observation)	Smell	Husband left
Sister 9B		Yes				Long labor		5 y (doctor)	No urine control	
Patient 10	18		Born dead	Married	VVF	Long labor/bewitched	4 y		No urine control, fatigue	Divorce
Sister 10A		Yes				Delivery/child's death		4 y (sister)	No urine control	
Sister 10B		Yes				Delivery		4 y (sister)	No urine control, smell, pain	Husband abuse
Patient 11	37		Born dead	Married	VVF	God/obstructed labor/late hospital transfer/cesarean	8 mo		No urine control, pain	Social isolation
Sister 11A		Yes				Operation/delivery/bladder pierced		8 mo (hospital)	No urine control	
Sister 11B		Yes				"Traditional village birth attendants spoiled her"/ bladder burst during operation		7 mo (sister)	No urine control, smell	
Patient 12	27		Born dead	Married	VVF	Labor/heavy bleeding	10 mo		No urine control	
Sister 12A		Yes				Midwife pierced bladder		8 mo (sister)	No urine control	
Sister 12B		Yes				Labor		8 mo (sister)	No urine control, smell	Antisocial effects

Abbreviations: RVF, rectovaginal fistula; VVF, vesicovaginal fistula.
[a] Interview was terminated per patient request.

fistula to labor and/or delivery, questions specifying urine leakage following a difficult delivery would be helpful.

The present study also uncovered a widespread perception that fistula is caused by either hospital personnel (nurse, doctor, or midwife) or medical procedures (cesarean delivery, urinary catheter); this was far greater than the perception that long labor or delays cause the condition, which highlights a breakdown in communication between healthcare providers and women with fistula. The belief that cesarean delivery and other medical procedures cause fistula—rather than relieve obstruction—has important implications for women's willingness to seek hospital care for labor and/or delivery.

This negative association is a relatively new finding, which has been reported in the literature only in recent years and which varies widely between studies. In a study in Uganda, 84% of 340 women with fistula who were interviewed believed that doctors had accidentally pierced their bladder [8]. Most women were satisfied with their hospital care at delivery but some did experience abuse or neglect from healthcare workers [8]. In a study in Nigeria, 33 of 130 patients did not believe fistula was caused by prolonged labor [9]. Nine believed that it was caused by a hospital procedure, whereas medical records indicated 5 to be iatrogenic. Only 55.5% of women with fistula would consider cesarean in a subsequent pregnancy.

Although TBAs were not interviewed in the present study, participants' reports of delays in seeking care under TBA management highlight the importance of TBA perception of fistula. A study of TBA perceptions in Uganda found that these birth attendants were willing to refer women to hospitals for high-risk conditions but they held a widespread belief that fistula is caused by hospitals and that their patients would be abused there.

The perception that fistula is caused by hospital procedures, especially cesarean delivery, raises questions about the true prevalence of iatrogenic fistula. To date, only 1 study [10] has investigated iatrogenic causes—specifically, cesarean-related fistula. Hospital records were reviewed in the Democratic Republic of Congo and revealed that, of the 576 women with obstetric urogenital fistula, 229 had undergone cesarean delivery, 55 of whom experienced iatrogenic fistula [10]. Another 28 cases were iatrogenic from manipulations during labor/delivery (manual extraction, placental retention, curettage, symphysiotomy, cesarean hysterectomy, and failed vacuum attempt). Cesarean-related fistula was determined to be a separate clinical entity because it involved mostly vesicouterine or high vesicovaginal fistula with a cervical component.

The present study was limited by its small sample size of 12 women with fistula and 20 sisters. Additionally, language barriers may have affected study quality, despite the use of translators, given the numerous local languages spoken. Also, patient and sister perception of the iatrogenic nature of fistula causation could not be verified by hospital records. Finally, the focus on obstetric fistula did not consider similar symptoms of other urogenital conditions.

The study did not distinguish between specific types of VVF and, thus, cannot determine the true etiology of fistula among participants. Of note, however, Uganda has a cesarean rate of 3% of all deliveries [6]. It is unlikely that all of the women who believed their fistula to be caused by medical procedures truly had iatrogenic fistula. Therefore, it is important to dispel this negative association via patient education on causation in order to improve access to care. More research is needed to understand the incidence of iatrogenic fistula, as well as effective program development to improve patient perceptions of hospital care.

The present study confirms a broader concept that all women, regardless of age and parity, are at risk of developing fistula; furthermore, it shows that women are not always abandoned by husbands and family members after developing the condition.

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Conflict of interest

The authors have no conflicts of interest.

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