International Urogynecology Journal (2020) 31:2419–2425
https://doi.org/10.1007/s00192-020-04448-5

ORIGINAL ARTICLE

The changing perception and knowledge of obstetric fistula: a qualitative study

Chi Chiung Grace Chen[1] · Jie Jiao[2] · Gerard Mbabazi[3] · Annelise Long[1] · Rachel Galvao[1] · Denis Rwabizi[3] · Blaise Dushimiyimana[3] · Eugene Ngoga[4]

Received: 15 April 2020 / Accepted: 14 July 2020 / Published online: 13 August 2020

Abstract

Introduction and hypothesis To describe the knowledge and perceptions of obstetric fistula (OF) among affected and unaffected women.

Methods Twenty-five semi-structured interviews were conducted with women who had received OF repair. Three focus groups were conducted: one group of women with urinary incontinence but no OF, one group of women with OF, and one group of women without genitourinary complaints. Interviews and focus groups were conducted using the grounded theory approach. This study took place in two urban hospitals in Rwanda from April to November 2015. Transcripts were coded using MAXDA11 and analyzed using the axial technique and the constant comparative method.

Results Nearly all participants correctly described OF and its symptoms, and 93% of interviewed women attributed OF to complications in vaginal delivery or cesarean section. Several participants described renouncing stigmatizing beliefs after learning about OF from the radio, health workers, or word of mouth. Still, it was found that women with OF were more knowledgeable about OF etiology than women without genitourinary conditions.

Conclusions Compared to prior studies, women's knowledge about OF appears to be more medically based, with media and health workers playing a role in reducing stigmatizing beliefs. These findings support continued investment in OF awareness campaigns, which seem to be increasing knowledge about OF and reducing stigma.

Keywords Knowledge · Obstetric fistula · Perception

Introduction

Obstetric fistula (OF) is a devastating but often preventable complication of childbirth. Prolonged or obstructed labor can damage the birth canal, resulting in an opening/fistula between the vagina and the lower urinary tract or between the vagina and the rectum/anus that leaves women incontinent of urine, feces, or both. While a rare complication in higher income countries, OF remains a public health problem in lower resource settings throughout Sub-Saharan Africa and South Asia. The World Health Organization (WHO) estimates OF affects 2–3.5 million women worldwide with an estimated annual worldwide incidence reaching between 50,000–100,000 women [1, 2].

In more marginalized, remote regions of the world where women tend to deliver at young ages, have little income, and be illiterate, OF can occur when women experience prolonged, obstructed labor without timely access to skilled emergency obstetric care. As a result of the complications of OF, millions of young girls and women live in isolation and as the target of social shaming and cultural stigma. These women are often abandoned by their husbands and shunned by their communities where a woman's status and self-esteem may depend on her marriage and ability to bear children. With this loss of status, women are propelled into further despair,

✉ Chi Chiung Grace Chen
cchen127@jhmi.edu

[1] Department of Gynecology & Obstetrics, Johns Hopkins School of Medicine, 301 Building room 3118 4940 Eastern Ave, Baltimore, MD 21224, USA

[2] Department of Obstetrics & Gynecology, Wayne State University/ Detroit Medical Center, Detroit, USA

[3] Department of Obstetrics & Gynecology, University of Rwanda, Kigali, Rwanda

[4] Rwanda Society of Obstetricians and Gynecologists, Kigali, Rwanda

low self-esteem, poverty, and suffering [3]. Patients' lack of knowledge along with wider community unawareness contributes to the stigmatization of OF. This stigma may further delay patients in seeking treatment.

In past reports, women and men in countries throughout Sub-Saharan Africa were found to commonly attribute OF to "will of God" or witchcraft [4]. While certain studies have found that participants are aware of OF as a medical condition 36.4–100% of the time, another study found that only 3% of participants were able to identify obstetric trauma as the main cause of fistula [5, 6]. As more international healthcare organizations have implemented programs to improve awareness of OF, perceptions about this condition may be changing. Our aim is to describe the knowledge and perceptions of OF among affected and unaffected women. We hypothesize that with the recent influx of education and treatment programs, women are more knowledgeable about OF as a medical condition and have altered their perception of OF etiology. As this is an evolving area with limited current research, we have elected to use qualitative methodology to accomplish our aim.

Materials and Methods

To ascertain a qualitative understanding of women's knowledge and perception of OF, and to compare understanding between women who have and have not experienced gynecological symptoms, data were collected with two methods. Data were obtained using (1) in-depth interviews using semi-structured questionnaires from women with OF [lower urinary tract fistula (LUTF), rectovaginal fistula (RVF)] and women without OF but with urinary incontinence (UI) and/or vaginal prolapse who had undergone surgical intervention and (2) focus groups comprising fistula, UI, or control participants (women with no genitourinary complaints). All interviews and focus groups were conducted by combinations of two authors (GM, DR, BD, CCGC). For the focus group, a non-clinical healthcare employee (house-keeping staff) observed and recorded the participant's body language and behavior in reaction to questions and the participant's interactions while discussing responses to the questions. Grounded theory approach was used to guide the entire study methods including inductively generating theories pertaining to gain participant knowledge and perception of OF [7]. Iterative sampling was also employed by including findings from published studies with data from field experiences in the current study until data saturation was reached. This allowed for an understanding of common themes that was contextually grounded through the process of constant comparison and analysis. The sample size was determined by data saturation. Exclusion criteria included: women < 18 years old, women who were not able to answer questions, and nulliparous women.

In-depth interviews of women diagnosed with OF, women with UI symptoms but no OF, and women with vaginal prolapse symptoms but no UI symptoms or OF, and focus groups of women diagnosed with OF were conducted in Kigali, Rwanda, at Kibagabaga Hospital (district hospital of Kigali) where women from Rwanda with OF, UI and/or fecal incontinence, and/or vaginal prolapse symptoms can present for evaluation and care. Participants for the focus group consisting of women without a diagnosis of OF but with UI symptoms and the focus group consisting of women without a diagnosis of OF and without UI symptoms were recruited using a convienience sampling approach at the Ruhango District Hospital (provincial hospital of South Rwanda); an announcement was made at Ruhango District Hospital inviting women with UI symptoms or no genitourinary symptoms to join the study. The focus group discussions conducted at Ruhango District Hospital were also performed with combinations of two authors aforementioned as the interviewers and one housekeeping staff as the focus group observer. The Southern province was selected as our previous study on risk factors for OF development found 54% of the women in this population were from this province (results not published).

Data were collected in the form of one-on-one interviews. All interviews took place in a hospital facility for ease of recruitment purposes. To reach data saturation, focus groups were also conducted to further assess women's understanding of obstetric trauma etiology. Interviews, which lasted between 10 and 45 min, were carried out by two trained healthcare personnel at University of Rwanda. In-depth interviews were chosen to explore the nuances of participants' perspectives and experiences. Keeping with the grounded theory approach, the interview consisted of minimal questions from a researcher-administered questionnaire to explore participants' unique accounts. Interesting or new insights were followed up with subsequent interviews and focus groups.

The grounded theory approach, as described by Strauss and Corbins, helped guide data collection at three levels of coding: open coding (identifying concepts), axial coding (investigating relationships between concepts), and selective coding (relating these concepts to a core concept) [8, 9]. The coding was completed by two independent coders. Two authors (JJ and RG) conducted the analysis, which was then confirmed by another author (CCGC). To start the process of open coding, individual interviews and focus groups were transcribed verbatim. Data analysis was then completed using MAXQDA 11 (VERBI Software GmbH, Berlin, Germany). Line-by-line coding was done manually, and themes were explored systematically by examining the statement and in context within the whole interview. Axial coding involved using the constant comparative technique, where comparisons were made between different transcripts and identified relationships. Codes that could be grouped according to their subcategories were initially grouped based on their

commonalities. There were several reiterations of categories, which were reorganized to gain contextual understanding and relationships among other themes within the document. Once common themes were identified, the transcripts were then re-reviewed and selective coding was used to identify data that are associated with the main themes. After 25 interviews and three focus groups, saturation was reached, meaning no new themes were emerging from the data. During this process, a note was also made of particular participant quotes which exemplified each theme.

Ethical approval was gained from the Johns Hopkins School of Medicine, Rwandan Ministry of Health National Health Research Committee, and Rwanda National Ethics Committee. All volunteers were provided with written and verbal information in local language and verbal consent was obtained. Confidentiality was assured. Participants were informed that they could decline to answer any questions at any time and could stop the interview at any time. Interview recordings and transcripts were stored within Kibagabaga Hospital, accessible only to the research team. Electronic data were stored in password-protected files.

Results

Twenty-five women underwent one-on-one interviews with a median age of 38 years (19–77 years) (Table 1) and the following conditions: LUTF 48% (12), RVF 20% (5), and UI and/or vaginal prolapse 32% (8) (Table 2). Interviews lasted a median length of 23.5 min. Of the 25 women who were interviewed, 23 discussed their understanding of OF (Table 3). Overall, 78% (18) of the 23 women interviewed who discussed OF understanding were able to describe an OF and its associated symptoms as a medical condition.

We held an additional three focus group discussions to further explore womens' understanding of OF etiology: one group (7 women) consisted of women with UI only, one group (8 women) consisted of women with LUTFs, and the last group (9 women) consisted of women without any genitourinary complaints who presented for routine gynecological care.

Table 1 Baseline characteristics of interview participants

	Participants ($n = 25$)
Age, median (range)	38 years (19–77)
Province	
Kigali	12% ($n = 3$)
North	4% ($n = 1$)
East	36% ($n = 9$)
South	40% ($n = 10$)
West	8% (n = 2)
Occupation	
Housework	8% (n = 2)
Farmer/agriculture	60% ($n = 15$)
Manual	4% (n = 1)
Marital status	
Single	24% ($n = 6$)
Married	48% ($n = 12$)
Aware of OF	18 (78%)

Table 2 Patient pathology and district origin (of note, several patients had multiple diagnoses)

	North	East	South	West	Kigali
VVF or RVF ($n = 16$)	0	7	6	2	1
Chronic 4th degree (n = 3)	0	1	2	0	0
Vaginal prolapse (n = 6)	0	2	2	0	2
Incontinence (n = 9)	1	3	2	2	1

Theme 1: Women with genitourinary conditions (with and without OF) attribute OF to delivery complications

Several sub-themes emerged regarding OF etiology from the perspective of interviewed women who had genitourinary conditions (with and without OF). These themes are summarized in Table 3. Many of these women understood OF as a consequence of obstetric trauma:

> *"Fistula are diseases that affect women, caused by problems that they meet during delivery or when they meet something that may badly injure the vagina and they develop problem of leaking urine or feces pass through the unusual ways."*

> *"I had a labor that did not progress and that lasted for long and that was done at home; I had a severe injury that persisted and it did not heal on its own."*

Beyond discussing the delivery-related causes of OF, some women described other factors that they believed contributed to them having complicated deliveries. Several women had delivered at home without assistance, for various reasons:

Table 3 Interview sub-themes of OF etiology

Sub-theme	% ($n = 23$)
Complications during spontaneous vaginal delivery	87% (20)
Complications during C-section	22% (5)
Curse/bewitching	8% (2)

"It was caused by that home-based complicated delivery, without any help. Because the husband used to come only for sex."

"I was home alone and it was raining heavily, so I was not able to go to the health facility…I delivered but the afterbirth did not come immediately until I tried to put much pressure, what I think lead to the problems I had."

Others attributed OF to complications arising from a cesarean section, whether this was through the delivery process or of iatrogenic causes.

"I think I was injured at the hospital during the [cesarean section] operation, because I think the doctor was in a hurry."

"Fistula is due to cesarean section. It's when you get hurt to the bladder or to the womb after operation."

Only a minority (8%, 2) of the women still drew on traditional beliefs of OF etiology as a curse or secondary to other factors. These beliefs appeared rooted in isolation:

"At first I was the only one in my village, that's why I thought I was bewitched but later I also saw other three women and I said maybe it's a common disease that affects women and then changed my belief after seeing other women suffering the same problem like me."

Both women who discussed their beliefs in a curse etiology did not describe those beliefs as fixed; rather, they attributed these beliefs to the perception of others within their communities and feeling isolated in their condition.

Focus group results yielded similar themes from the one-on-one interviews regarding OF etiology. Within the VVF focus group, 50% (4) of participants attributed OF to complications during vaginal delivery, whether due to prolonged labor, home delivery, or iatrogenic causes, while 50% (4) of participants attributed OF to complications from a cesarean section. Participants in the UI focus group had similar responses.

Theme 2: Among women without genitourinary conditions, shifting views of OF etiology from curse to disease

The control focus group of women without a OF diagnosis and UI symptoms had the most diverse answers in response to OF etiology. Some women described prior stigmatizing beliefs they held about women with OF:

"I don't want to lie, before I knew the disease, I thought it was a disease due to poor hygiene. We could say that they are just dirty and they can't clean themselves. Like someone who does not bathe."

Women in the control group also commented that the etiology of witchcraft causing OF was a more commonly held belief among women from poorer villages, where traditional Rwandan healers tended to perpetuate this idea. None of the control focus group believed OF was caused by non-medical reasons. Despite clarifying that they no longer held these stigmatizing beliefs on cleanliness after learning about fistula from community health workers, the radio, or other women with fistula, participants were still in disagreement about the potential causes of OF:

"I think it is because of multiple pregnancies and working too hard when you are pregnant like lifting heavy things."

"…women (with fistula) have a soft womb, that's how I understand it!"

Some in the control group, a few of whom had heard about OF on the radio, did connect OF to complications during delivery as well:

"I think fistula can be caused by delivering at an early age and at a very old age where your womb is soft and has loosened up, when you deliver at home you might injure yourself and eventually start leaking urine."

There was some disagreement among the participants regarding whether at-home deliveries, as well as cesearean sections, could increase the risk of OF. Women in this group often drew on their own personal experiences or the experiences of people within their communities to identify whether a proposed OF etiology was true or not:

"The reason why I don't think delivery at home causes fistula is that my mother delivered all her thirteen kids at home and she didn't have fistula, and I have not seen anyone who has fistula because they delivered at home."

"I know a woman who went to the hospital to deliver by cesarean section and then she later developed leaking all the time. It was said that she was injured during a cesarean section."

Thus, while some women without genitourinary conditions had received information about OF from community health workers or the radio, many participants' beliefs surrounding OF etiology emerged from their encounters with people in their communities who had fistula. Those who had encountered a woman with a delivery-related fistula tended to agree

that delivery complications could lead to OF, while those who had not were more skeptical of this etiology.

Theme 3: Women with and without genitourinary conditions can identify OF symptoms

Despite some disagreement among women in the control focus group about the causes of OF, women with and without OF were generally knowledgeable about OF symptom presentations:

> *"A patient with fistula, what tells her to go the hospital is that she starts with leaking coming from the vagina or when she has a bowel movement, feces will not pass in its usual way, that's how I understand it."* (Control Focus Group)

> *"Fistula consists of persistent urine or fecal leakage passing through their not usual opening, out of self-control."* (OF Focus Group)

All women with OF described the symptoms of OF as a continuous leakage of urine and/or feces. A few women in the control focus group cited symptoms of urge UI and stress UI as the chief symptom of OF, and among UI focus group participants only one woman believed symptoms of UI indicated an OF. Interestingly, one UI focus group woman thought the symptoms of OF represented a more advanced stage of UI. Overall, most participants from the interviews and focus groups were able to differentiate between UI and OF:

> *"What differentiates us [women with UI] from fistula patients is that they leak urine all the time without control even if we also have almost similar symptoms but we don't leak uncontrollably, another thing is for them they cannot wear something to protect themselves because they will be wet all the time and for us we can at least try to control urine even though you leak before the toilet but it's not the same."* (UI Focus Group)

Usually, in differentiating between UI and OF, participants identified a key feature of OF as continuous urine leakage through the vagina, whereas they described UI as less frequent leakage caused by coughing, heavy lifting, or waiting too long to empty one's bladder:

> *"I think fistula is different from when you have the sudden urge to urinate and leak before you reach the toilet because, for example, when you delay to go to the toilet, you will leak before you even remove your underwear but with fistula it is a disease that comes when you were not thinking about it even."* (Control Focus Group)

As participants described the characteristics of OF, they commonly used the word "disease," and no women used the words "curse" or "bewitching" suggesting that even women who did not have OF tended to perceive OF as a medical condition. Ultimately, most participants, regardless of whether they had OF, UI, or no genitourinary conditions, labeled OF as a disease and were able to distinguish between OF and UI based on knowledge of OF's characteristic symptoms.

Discussion

Overall, women were knowledgeable about OF, particularly the symptoms and etiology behind obstetric trauma and associated complications. Women's understanding of OF etiology seems to be shifting from an ideology based in the occult to that of medical etiology, even among women who did not have any genitourinary conditions. Still, some knowledge gaps about OF etiology remained between women who did and did not have genitourinary conditions.

Women who had genitourinary conditions were more knowledgeable about OF etiology than our control women, in part due to receiving information from their healthcare providers. This was consistent with findings from studies in Benin and Kenya, which found that 70–80% of fistula patients attributed OF to labor complications or surgeon error [10, 11]. Some women with genitourinary conditions in our study came to understand OF from speaking to women with the condition, community health workers, or listening to the radio. Women without genitourinary conditions also reported learning about OF from media or word of mouth, which is consistent with findings from a study in Burkina Faso, where media was the most common source of OF knowledge for urban women, while word-of-mouth was the most common source for rural women [5].

We found that a majority of participants (83.3%) correctly identified OF symptoms regardless of their genitourinary condition status. This suggests that OF symptoms are perceived more often to be the result of a medical condition rather than due to occult causes. This could be due to information from healthcare providers, media, and word of mouth in communities.

Future research and education efforts should focus on raising public awareness about the likely causes of OF, with an emphasis on educational initiatives to address the knowledge gaps between women with and without genitourinary conditions. For example, existing community-based education programs and media campaigns on OF symptoms and repair could also outline OF etiology. Interventions to raise awareness about fistula have shown promise: in Kenya and Tanzania radio campaigns and a fistula hotline resulted in significant increases in the number of patients receiving treatment for OF [12]. A radio serial drama about OF in Nigeria was widely listened to and reduced the prevalence of the belief

that women with OF should be excluded from communities [13]. Additionally, the Campaign to End Fistula's "Fistula Fortnight," in which volunteers recruited patients, mobilized community leaders, and raised awareness about OF, resulted in a significant increase in treatment seeking, particularly when coupled with training for healthcare providers and renovations of OF repair centers [14]. Our asymptomatic women tended to base their understanding of OF etiology on limited encounters with women who have OF, so perhaps a media campaign narrated by someone who has personally experienced OF could be most effective in reducing confusion and stigmatizing beliefs surrounding OF etiology. Ultimately, these interventions' successes and the present study's findings suggest that media and education campaigns are a worthwhile investment in reducing OF stigma and promoting OF treatment.

Our study uniquely enables the comparison of knowledge base and attitudes toward OF from women who have and have not experienced gynecological symptoms by giving voice to women with OF, UI, and no genitourinary conditions. Having this range of perspectives provides a more complete description of women's perceptions of OF than if only one of the groups had been interviewed. Another strength of our study was drawing on participants with a wide range of ages and from different regions in Rwanda, which contributes to the generalizability of our findings. Our study was also strengthened by the utilization of mixed qualitative methods: one-on-one semi-structured interviews and focus groups provided diverse settings for women to discuss their perspectives on OF, and having both methods helped to solidify the saturation of the emergent themes.

Given the setting of our study, many of the fistula patients were interviewed after they received surgical intervention, where they likely received OF education from their healthcare providers. All of our OF patients were sent to our study site by their health center because they had OF symptoms, so even among those we interviewed pre-surgery, women with OF were predisposed to previous knowledge of OF symptoms and etiology. Nevertheless, the control focus group allows for some comparison between women who likely received direct education on OF from healthcare providers and those who did not.

Another limitation of our study is that we limited our interviews to the understanding of women themselves and did not ask about partners' or family members' knowledge. As affected women's partners are often the ones next most intimately involved with the disease process, and play a role in the stigmatization of disease, future studies should investigate if the knowledge base of women's partners is similarly changing.

Our study shows that women in general were aware of OF as a medical condition, particularly its specific symptoms, and expressed an ideology shift from OF etiology based in the occult to a more medically-based understanding. These findings encourage continued investment in OF education campaigns, which seem to help reduce the stigma surrounding OF and enable women to seek treatment in a timely manner.

Acknowledgements We acknowledge the excellent work of Arline Niarlene, MD, on the translation and transcription of study interviews. We would also like to acknowledge the International Organization for Women and Development.

Author contributions J Jiao: Data analysis, manuscript writing, manuscript editing.
R Galvao: Data analysis, manuscript writing, manuscript editing.
G Mbabazi: Project development, data collection.
B Dushimiyimana: Project development, data collection.
CCG Chen: Project development, data collection, data analysis, manuscript writing, manuscript editing.
A Long: Data analysis, manuscript writing, manuscript editing.
D Rwabizi: Project development, data collection.
E Ngoga: Project development, data collection.
PRESENTED AT: IUGA, Cape Town, South Africa, August 3, 2016.

Funding information Unrestricted grant from the Maren Foundation. The award did include external peer review for scientific quality of the grant.

Compliance with ethical standards

Conflict of interest None.

Abbreviations *OF,* obstetric fistula; *VVF,* vesicovaginal fistula; *RVF,* rectovaginal fistula; *UI,* urinary incontinence; *POP,* pelvic organ prolapse; *LUTF,* lower urinary tract fistula; *RVF,* rectovaginal fistula

References

1. World Health Organization (2015) Maternal mortality ratio (modeled estimate, per 100,000 live births). http://www.who.int/mediacentre/factsheets/fs348/en/. Accessed 20 February 2016.
2. Lewis G, De Bernis L (2006) Obstetric fistula: guiding principles for clinical management and programme development. World Health Organization.
3. Mselle LT, Moland KM, Evjen-Olsen B, Mvungi A, Kohi TW. "I am nothing": experiences of loss among women suffering from severe birth injuries in Tanzania. BMC Womens Health. 2011;11(1):49.
4. Wall LL, Karshima JA, Kirschner C, Arrowsmith SD. The obstetric vesicovaginal fistula: characteristics of 899 patients from Jos, Nigeria. Am J Obstet Gynecol. 2004;190(4):1011–6.
5. Banke-Thomas AO, Kouraogo SF, Siribie A, Taddese HB, Mueller JE (2013) Knowledge of obstetric fistula prevention amongst young women in urban and rural Burkina Faso: a cross-sectional study. PloS One 8(12).
6. Kazaura MR, Kamazima RS, Mangi EJ (2011) Perceived causes of obstetric fistulae from rural southern Tanzania. Afr Health Sci 11(3).
7. Glaser B. Basics of grounded theory analysis: emergence vs forcing. Mill Valley: Sociology Press; 1992.
8. Corbin J, Strauss A (2014) Basics of qualitative research: Techniques and procedures for developing grounded theory. Sage publications.

9. Vollstedt M, Rezat S (2019) An Introduction to Grounded Theory with a Special Focus on Axial Coding and the Coding Paradigm. In: Kaiser G, Presmeg N (eds) Compendium for Early Career Researchers in Mathematics Education. ICME-13 Monographs. Springer, Cham.
10. Nathan LM, Rochat CH, Grigorescu B, Banks E. Obstetric fistulae in West Africa: patient perspectives. Am J Obstet Gynecol. 2009;200(5):e40–2.
11. Kavai MM, Chepchirchir A, Kayugira R (2010) Women's knowledge of vesico vaginal fistula in Kenya. Afr J Midwifery Womens Health 4(4).
12. Bangser M (2011) Making Mobile Phones Work for Women with Fistula: The M-PESA Experience in Kenya and Tanzania. EngenderHealth. https://www.fistulacare.org/wp-fcp/wp-content/uploads/pdf/technical-briefs/mobile_phone_brief_updated4.5.2011.pdf.
13. Baptiste D, Kapungu C, Khare MH, Lewis Y, Barlow-Mosha L. Integrating women's human rights into global health research: an action framework. J Women's Health. 2010;19(11):2091–9.
14. Ramsey K, Iliyasu Z, Idoko L. Fistula fortnight: innovative partnership brings mass treatment and public awareness towards ending obstetric fistula. Int J Gynecol Obstet. 2007;99:S130–6.