

ORIGINAL RESEARCH

# Giving Voice to the Experiences of Rwandan Women With Urogenital Fistula



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## Abstract

**BACKGROUND** Urogenital fistula is a debilitating condition that women can develop following obstructed labor. The primary objective of this study was to reveal illness narratives of Rwandan women with urogenital fistula to appreciate their unique experiences. The secondary aim was to identify common themes that emerged when women discussed their experiences living with fistula.

**METHODS** Women presenting for urogenital fistula repair at Kibagabaga Hospital were asked to participate in the study. Eleven participants were asked questions designed to elicit their understanding of their condition and the social and emotional consequences of their fistula. All interviews were anonymous. Transcribed interviews were examined for relative themes to categorize responses into larger domains.

**FINDINGS** Common themes were identified from the interviews on topics of what barriers existed to having a successful delivery, the socioeconomic and psychosocial consequences of developing a fistula, and each woman's understanding of her fistula. Excerpts from patients' illness narratives illustrated these themes.

**CONCLUSIONS** These narratives can be used to appreciate the variations in each woman's understanding of her medical condition and the changes that occurred in her life as a result of her fistula. Through patients' narratives, physicians can improve their appreciation of cultural differences to design targeted educational and preventive interventions.

**KEY WORDS** obstetric fistula, obstructed labor, Rwanda

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## INTRODUCTION

Urogenital fistula is a debilitating condition that women can develop after obstructed labor. An estimated 3.5 million women suffer from urogenital fistula; the majority of whom are found in Africa, Asia, and Oceania.<sup>1,2</sup> A woman who develops obstructed labor may labor for days, eventually delivering a stillbirth. Subsequently, ischemic

trauma may result in a fistula between her vagina and bladder and/or rectum.<sup>3</sup>

A successful delivery may be limited by insufficient access to intrapartum care or inadequate transportation to a health care facility.<sup>4</sup> Women with fistula are typically made to divorce their spouse and banished from their communities, suffering these physical wounds alone.<sup>1,5</sup> However, factors limiting a woman's access to emergency health

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care and the consequences of the resulting fistula vary by woman, cultural beliefs, and the values of her community.<sup>6</sup> These factors should be illuminated and better understood to reveal each woman's unique story, as well as common experiences.

By eliciting patients' illness narratives, physicians may better appreciate the different views and experiences with which a patient approaches health care and how she contextualizes her medical condition.<sup>7</sup> The concept of cultural competency is too often equated with associating race and ethnicity with stereotypical practices.<sup>7</sup> Thus, it is important to encourage patients to share their unique perception of their condition, and to appreciate the existing variation within a patient population. Additionally, dissimilarities amongst patients' experiences, and shared ones, can be used to inform public health interventions for communities with different cultural practices.

Currently, urogenital fistula research largely focuses on demographic characteristics, outcomes, and medical needs of patients. Medical literature focuses on the tragedy of fistula through descriptive statistics, but does not typically reflect what patients think and feel.<sup>8</sup> The primary objective of this study was to begin to reveal illness narratives of Rwandan women with urogenital fistula in order to appreciate each woman's unique experience. The secondary objective was to identify common themes that emerged when women discussed their experiences living with fistula.

## METHODS

This qualitative study explored the experiences of Rwandan women with urogenital fistula. Interviews occurred during a mission trip (February 1-13, 2014) of the International Organization for Women and Development (IOWD) at Kibagabaga Hospital in Kigali, Rwanda. Project approval was received

from the Institutional Review Board of Women & Infants Hospital, Providence, Rhode Island, and the Rwandan Government's National Health Research Committee and National Rwandan Ethics Committee.

The IOWD is a nonprofit organization that pairs American and Rwandan health care personnel to provide surgical care to women with fistula. Preceding each mission, radio announcements inform women of the arrival of US physicians who provide care to women leaking urine and/or feces. Women who identify as needing these services then present for evaluation and possible treatment.

All women presenting to the IOWD team with a confirmed urogenital fistula were eligible for participation. Women without fistula and those <18 years of age were excluded. Once Rwandan government research approval was granted near the end of the mission trip, groups of patients were approached in the tents in which they slept and volunteers were asked to participate in the study. This was purposive sampling. Participating women verbally answered 10 questions, adapted from questions designed by Arthur Kleinman for eliciting patients' illness narratives. An interview guide explored each patient's understanding of her fistula and the psychosocial consequences of her condition (Table 1). Demographic information, including age, marital status, and obstetrical history, was also verbally collected from the women.

US and Rwandan medical students conducted interviews in a private setting in Kibagabaga Hospital. Patients provided informed consent for the study and for audio recording the interviews. Due to high rates of illiteracy among the study population, the Rwandan medical students verbally explained documents in Kinyarwanda. These same students then translated interview responses into English at the time of the interview. Interviews lasted 25 to 60 minutes. Recordings were

**Table 1. Interview Guide**

1. Tell me about your problem of leaking urine and/or feces
2. What do you call this illness/the problem?
3. Why do you think this happened to you?
4. Why do you think you developed this problem when you did?
5. How do you think the fistula works? What does the fistula do inside your body?
6. How do your family members or friends feel about this problem?
7. What could you do before this problem started that you can't do now?
8. Tell me how it feels to leak urine and/or feces everyday
9. What do you fear most about leaking urine and/or feces?
10. What results do you hope for?

transcribed by the US researcher present for the interviews, and the transcriptions were edited for clarity. Pseudonyms were used to protect patient identity.

The interviewees' responses were analyzed for salient themes, and these were then collectively grouped into common threads, which are listed in the Results section and in Table 2. Two authors discussed competing interpretations and these were resolved by discussion. Responses were categorized into larger domains (Table 2). Excerpts are used throughout to illustrate the common themes, and additional pertinent excerpts can be found in Table 3.

## RESULTS

**General Characteristics Participants.** Eleven Rwandan women agreed to participate in the study. Descriptive information is listed in Table 4. Ten women reported urinary incontinence and one fecal incontinence. All but one had received recent surgical repair of their fistula by the IOWD team at the time of the interviews; the other was anticipating repair in April 2014.

Women's ages ranged from 27 to 57 years. Seven were from the southern provinces of Rwanda, and the others were from Kigali, eastern, western, and northern provinces. Local health care centers provided transportation to Kibagabaga Hospital for many, whereas others used their own money.

The majority of women were married at the time of the interview. Two women's husbands were incarcerated (since 1995) for committing genocide

crimes. Donathille's husband disappeared in 2004 during a conflict in the Democratic Republic of the Congo (DRC) while her family was there as genocide refugees. Seraphine's husband was killed during the genocide.

The 3 women who were "separated," were abandoned by their husbands after they developed a fistula. Esperance identified as "single" as she had never been married, but the father of her children also abandoned her after she began leaking. Claudine was married, but her husband took another woman after she developed fecal incontinence. These women now either live alone with their children or have returned to live with their parents.

All of the women reported developing incontinence after a delivery. Each woman consulted nearby health centers for prenatal care at least once during the pregnancy associated with fistula development. Ten women ultimately delivered in a health care center or district hospital. Seven women had a stillbirth during the inciting event. Of the 4 surviving babies, 1 died shortly after delivery.

**Barriers to a Successful Delivery.** The greatest barrier to successful delivery was a delay in care. Reasons for delay were multifaceted. Recurring themes included inaccessible health care, late transfer to a larger district hospital, and a cultural expectation of home delivery.

**Inaccessible health care.** Lack of transportation and a great distance to local health centers accounted for 4 women's delayed presentation. Three of these women began to labor when they were home alone. In their husband's absence,

**Table 2. Salient Themes Across Illness Narratives**

1. Barriers encountered preventing a successful delivery
  - Inaccessible health care
  - Late transfer to district hospital leading to delay in care
  - Cultural expectation of home delivery
2. Understanding and identification of fistula
  - Fistula itself perceived as an illness
  - Resulting distrust of health care workers
  - Perception of baby as the causative factor
3. Socioeconomic consequences after developing a fistula
  - Frustration from not providing for loved ones
4. Psychosocial effects of having a fistula
  - Sadness resulting from fistula development
  - Humiliation from community marginalization
  - Anger toward others
  - Coping with odor and leaking
  - Triumph after surgery

**Table 3. Additional Excerpts from Interviews**

Theme	Interview excerpt
Barriers encountered preventing a successful delivery <i>Late transfer to district hospital</i>	[At the health center] I told them that I had already had 1 fistula, and that I must have a cesarean section for this birth. They sent me to the main district hospital. When they sent me the baby was still alive, and when I arrived it was still alive, and then they told me someone else was in the operating room. So I waited until the baby died because they had someone else in the room. (Alphonsine)
Barriers encountered preventing a successful delivery <i>Cultural expectation of home delivery</i>	I labored for 3 days at home, at which point my neighbors came and brought me to the hospital...on the way I felt my baby die. (Esperance)
Understanding and identification of fistula <i>Resulting distrust of health care workers</i>	I thought that the midwives and doctors who helped me deliver cut me when they were pulling the baby out, and that's why I developed this problem. (Vestine)
Socioeconomic consequences after developing a fistula <i>Frustration from not providing for loved ones</i>	I used to tell my husband that I am useless, that I am handicapped. I am not working. (Dorothee)
Psychosocial effects of having a fistula <i>Humiliation from community marginalization</i>	My partner left me because he didn't want to touch me anymore, and I didn't want to have sex. So I told him to leave, to find another woman. And he left...People in my community pushed me away, telling me "you smell bad, you stink, go away." (Dativa)
Psychosocial effects of having a fistula <i>Anger toward others</i>	Not only feeling depressed, but I was also angry, with my kids and the neighbors. I asked myself, why did God, my God, let these things happen to me? (Dorothee)
Psychosocial effects of having a fistula <i>Coping with odor and leaking</i>	When I went to church, each time I would have to go outside 3 times to wring out my skirt. And by the time I returned mass was already over. (Seraphine)
Psychosocial effects of having a fistula <i>Triumph after surgery</i>	[Lifted her skirt and patted her thigh] Now I am dry...I was praying to God, and now he has answered me. (Dativa)
Psychosocial effects of having a fistula <i>Triumph after surgery</i>	I hope I will heal like the others...I want to encourage all women to go to the hospital if and when they have a problem. They shouldn't stay at home when they have problems. Even if their disease cannot be healed, at least they tried to consult a doctor. (Claudine)

**Table 4. General Profile of the Women**

Patient pseudonyms	Age (y)	Marital status	Years of education	Religion	Gravidity/Parity	Years living with fistula
Alphonsine	40	Married	8	Protestant	G5 P5 Lc3 Sb2	—
Dorothee	35	Married	6	Catholic	G2 P2 Lc2	—
Caroline	49	Married	0	Protestant	G5 P5 Lc2 Sb2	22
Donathille	53	Married	9	Catholic	G8 P6 Lc4	14
Claudine	27	Married	3	Protestant	G2 P2 Lc2	7
Beatrice	30	Separated	3	Catholic	G1 P1 Sb1	1
Alexia	30	Separated	6	Catholic	G4 P4 Lc4	4 mo
Vestine	38	Married	4	7 <sup>th</sup> Day Adventist	G11 P11 Lc4 Sb6	1
Dativa	57	Single	0	Protestant	G9 P9 Lc5 Sb4	19
Seraphine	40	Widowed	4	Catholic	G4 P4 Lc1	20
Esperance	48	Separated	0	Catholic	G2 P2 Lc1 Sb1	14

G, gravidity; Lc, living children; P, parity; Sb, stillbirth, otherwise the pregnancy was a miscarriage, intrauterine fetal demise, or the child died after birth.

they were without transportation. Additionally, child care for children at home was a concern. As Caroline reported:

I was at home and I felt like I was having contractions, but my husband was not there. The hospital was not near, and I would've been obliged to walk. I waited three days until my husband came back.

Alexia was able to travel by foot, but the distance was too great:

Previously the doctors had told me that I should not deliver vaginally because I have had three cesarean sections...My contractions started when I was at my farm digging. The health center is two and a half hours away by foot...I walked there alone. On my way there the baby came.

For Donathille, who was living as a refugee in the DRC when she delivered her eighth child, adequate and skilled health care for successful delivery was not available:

I had already been in labor for a day. The doctor tried to help but he was unsuccessful so he called another doctor. They listened to the baby's heartbeat with their stethoscope until they no longer heard it...they left to go sleep. The next day they came back...he pulled the baby's head from my vagina and cut it off...that's when they started to push on my belly to get the trunk out.

**Late transfer to district hospital leading to delay in care.** Seven women were able to reach a local health center and ultimately transferred to a larger district hospital for delivery. The process of changing locations incurred long delays. Four women were told their babies were alive at their local health center, but dead once they were evaluated at the district hospital. These women all had cesarean deliveries to remove the dead fetus. Transportation was identified as one reason for delay in arrival to the district hospital:

When I was in labor...I went to the health center right away. After 2 more hours of labor they tried to transport me to the district hospital, but the ambulance came late. The baby was already dead by the time I arrived...I was in labor for 40 hours. (Beatrice)

Another woman discovered her baby was dead by the time she reached a hospital, and she was later transferred to another hospital for a cesarean to remove the fetus. Two women successfully delivered a viable infant once reaching a district hospital, one by cesarean delivery, one vaginally.

**Cultural expectation of home delivery.** Two women attempted home delivery until they developed

obstructed labor. Donathille had delivered 7 children at home and was prepared to do the same for the eighth. Esperance also tried home delivery, but developed obstructed labor.

**Understanding and Identification of Fistula.** When asked about the identity and cause of their fistula, the women had a limited understanding of their condition.

**Fistula itself perceived as an illness.** By the time of the interviews, all women knew they suffered from a fistula. Many had discovered their incontinence while in a health care facility and were told they had a "fistula" at that time. Some women initially identified their incontinence as "a curse," "an incurable disease," or an "illness." Claudine called her fecal incontinence "worms," originally suspecting an infection as the reason she leaked stool. Many viewed the fistula as an unusual illness:

In the whole district, I saw that I was the only one who had this problem . . . I thought it was a rare disease. (Vestine)

I felt that this illness was related to death. It felt worse than AIDS. I couldn't work; I couldn't do anything. I was wet. (Alphonsine)

The majority realized they were leaking urine or feces, but one woman believed it was liquid from her uterus, another thought it was water from her abdomen, and a third supposed it was water from her whole body:

I thought all of the water in my body was flowing out, through my vagina...When I pushed on my belly, to see if it would cause more water to leak, it did...I felt thirsty all the time. (Seraphine)

**Resulting distrust of health care workers.** Most women identified an event occurring almost immediately before discovering their incontinence as the causative factor of the fistula. Five women expressed suspicions that their fistula was due to a mistake made by health care workers. Two women reported:

Three days later (after cesarean delivery) the nurses took me to bathe, and that's when I noticed the leaking...at first I thought that the nurse who bathed me did not do it correctly, and that's what caused me to start leaking. (Esperance)

At first I thought I had worms...I went to the hospital to take medicine, but it made the problem worse...Then I started to think maybe what caused the problem was when the midwives cut me to make my vagina bigger. (Claudine)

One woman blamed herself, believing she had taken too long to reach the health center. Two women thought the fistula developed because their bladder accidentally burst during labor.

**Perception of baby as the causative factor.** Three women reported the fistula was a result of their baby's actions. Caroline recounted the reason for her obstructed labor was, "I thought he (my baby) was lost, in my thigh...he wasn't in the right place." Another believed that her baby's large size contributed to her fistula and worried "maybe it was the baby that harmed me, scratched me." Donathille reported:

When I saw the leakage I thought that my uterus had ruptured, and the liquid was coming from my broken uterus. I knew what a bladder was, but I thought that it was fine...the baby who was dead inside me caused the uterus to rupture. I thought I could never become pregnant again.

**Socioeconomic Consequences After Developing Fistula.** All 11 women identified as farmers, but 2 were no longer able to work due to their fistula. Every woman reported decreased productivity in farming as a consequence of her condition.

**Frustration from not providing for loved ones.** Five women were the sole providers for their children or parents. For many, this responsibility was compounded by the abrupt abandonment by their partners because of their fistula, leaving each woman to assume a greater role in her household. Many women expressed significant distress over their limited capacity to fulfill their role as farmers. Even those still married struggled. Reasons for an inability to farm included fear of others witnessing the incontinence, generalized weakness or pain, or fear that farming would worsen the fistula.

Before I was working as a farmer, digging and gathering food to sell for money. But now I can't work because I am leaking all of the time. I thought that if I worked harder it would make the leaking worse. And I don't even have anyone who can help me care for my children. (Alexia)

**Psychosocial Effects of Having a Fistula.** Many women lacked support from family, partners, or society. The women expressed feelings of depression, shame, and anger as a result of coping with daily incontinence. Despite this, all women were hopeful their situation would improve and they would be able to work again to support their families.

**Sadness resulting from fistula development.** The women were stoic, barely acknowledging pain

from their recent surgery and demonstrating little emotion throughout the interviews. But when specifically asked about emotional consequences of their fistula, each expressed feelings of depression and sadness. These emotions grew from isolation from society or family, concern that the fistula was an illness, and frustration with an inability to find a way to heal.

When I noticed the problem my first thought was to kill myself [*crying, wiping tears away*]. I become upset when I think about this...Now things are okay, now I can smile (since I had surgery). (Beatrice)

At the time they developed the fistula, many women were told there was nothing to be done. Some women took this to mean they would never be healed, thus several have lived with their fistula for decades without seeking treatment, believing that none existed.

I felt so depressed...I thought, "I have no life left, I don't know what I'm going to do. There's not even a treatment for this...I should commit suicide." I waited for my husband to leave the next day, and then I went to a place in my village where the water flows rapidly for making electricity. I stood on the banks and thought about throwing myself in the water. (Seraphine)

**Humiliation from community marginalization.** Feelings of shame arose from changes in behavior and attitudes of husbands, family members, and neighbors.

When I arrived home leaking and without a baby, my husband chased me away...before I came here, I felt like I wasn't complete, like I was half of a person. (Caroline)

I do not have friends anymore because everyone around me, except my husband and my children, thought that it was a contagious disease. Nobody approached me. They gossiped about me, "don't talk to her because she will contaminate you." (Vestine)

Some women received support from their partners and families. Dorothee's husband was her source of encouragement and hope. She referenced their marriage oaths to support each other in good times and bad. Two other married women reported they were no longer sexually active because their husbands did not want to hurt them or make the problem worse. Others received help from members of their church community or neighbors. Seraphine's neighbors collected money to financially support her.

**Anger toward others.** Two of the women reported feeling angry. Anger was directed toward those who rejected them, those they had assumed would protect them, and others who did not have to suffer the way they did.

When people passed me they would pinch their noses. It made me feel angry...I looked at others who are able to work and get what they need, and for me it was impossible. (Alexia)

**Coping with odor and leaking.** Several women discussed the daily struggle of their condition: the uncomfortable physical symptoms, the daily chore of making diapers from cloth to go to market or church, and the difficulty of frequently changing and cleaning their clothes.

Even while I am walking the skin of my legs is irritated. (Beatrice)

Clothes were a problem, washing them every time...I don't have money to always buy new clothes. And it's a problem, to always have to wash them. They get old because of the washing. (Donathille).

**Triumph after surgery.** Ten women were postoperative at the time of the interviews, frequently expressing happiness, and the hope they were finally cured. Religious faith was predominant: Six women referenced praying to God for a cure or hoping to go to church to thank God for the surgeries they received.

I was operated on, and now I can sleep well and wake up dry...When someone is beautiful again, nobody can push her away. Now when I show my siblings that I am healed, that I am cured, they are going to accept me. (Seraphine)

When I return in April, I am hopeful that I will finally be cured. I want to go to church and ceremonies and be normal again [*waving her arms in the air, smiling*]. ...Even though I had this tragedy of leaking urine and my partner left me, I really believe and hope I will be cured by you, that IOWD will treat me, as you can see through the eyes of God. (Esperance)

## DISCUSSION

These narratives illuminate the extraordinary challenges the women have faced, and the variation among the women's background, milieu, and understanding of their fistula. Through these narratives, the voices of patients who usually silently suffer can be used to improve care of women with urogenital fistula.

In Rwanda, 95.8% of women attend  $\geq 1$  antenatal care visit, and 68.9% have an institutional

delivery.<sup>9,10</sup> These statistics similarly describe the women who participated in the study, all of whom had some antenatal care for the pregnancy associated with fistula development, and all but 1 ultimately delivered at a health facility. The maternal mortality ratio (MMR) per 100,000 live births in Rwanda is 540 compared with neighboring countries DRC, Tanzania, and Burundi with MMR's of 580, 790, and 970, respectively.<sup>9</sup> Although health care access is relatively increased in Rwanda, the stories highlight the need to improve triage in local health centers, the prompt transfer of patients to larger district hospitals, and the skill of physicians in performing cesarean deliveries and episiotomies.

This cohort of patients was comparable to other African women suffering from urogenital fistula. Studies in Ethiopia, Nigeria, and Niger similarly identify a population of young, poorly educated women who are frequently divorced by their husbands and communities as a consequence of fistula.<sup>11–13</sup> In a cohort of Ethiopian and Bangladeshi women with fistula, researchers observed high rates of major depression (23.3%–38.8%) and mental health dysfunction.<sup>14</sup>

A study of 10 interviews of northern Ghanaian women with fistula also discovered themes of transportation barriers to reaching health care centers, social stigmatization as a result of the fistula, and decreased productivity leading to deepening poverty.<sup>15</sup> Unlike the Rwandan women in this study, all of the Ghanaian women began labor at home with unskilled traditional birth attendants. A recurring theme in the interviews was every labor starts and ends naturally. This belief unfortunately led to a delay in recognizing obstructed labor and often blaming complicated labor on the laboring woman for presumed adultery or some other evil doing. Uncovering this reason for delay in care demonstrates the importance of inquiring how cultural beliefs can affect a woman's delivery.

Differentiating the Rwandan women from others with fistula in Sub-Saharan Africa is the unique context in which the Rwandan women live: post-genocide Rwanda. In 1994, >800,000 Rwandans were killed and 2 million people were displaced outside of Rwanda due to ethnic and political divides.<sup>16</sup> One study found rates of traumatic exposure and post-traumatic stress disorder of 94.1% and 24.8%, respectively, in a population of Rwandans 8 years after the genocide.<sup>17</sup> Women particularly suffered as targets of sexual violence, and increasing

numbers of women suddenly found themselves the head of households after the genocide. In this new role, many women faced legal and cultural obstacles in claiming farming land because of their gender.<sup>18</sup> Several women who participated in this study personally experienced loss in the genocide. Such psychological burden adds additional complexity to the suffering these women experience from their fistula.

The women had limited understanding of what a fistula is, and timing appeared critical in how each woman identified the cause of her fistula. Insufficient education and lack of exposure to others with fistula may account for their poor understanding. Appreciating what a patient understands can help guide efforts in patient education. For some women, it may have been fruitful to realize their condition was not contagious or fatal, and it was not their fault they developed incontinence.

Recurrent themes of marginalization by community or family members, turning toward religion for prayer and hope, and feelings of inadequacy in providing for loved ones emerged from the interviews. The latter strongly reflects a sense of responsibility and fixed perception of how to fulfill the role of mother, wife, and provider. One can infer that each woman's sense of self was greatly wounded as a result of her fistula, and many perceived a curative surgery as identity restoring. Although some acknowledged an operation would fix the incontinence, the majority focused on how surgery would enable them to achieve wholeness as a woman who could again provide for her family and participate in her community.

To our knowledge, this is the first study that explores oral narratives of Rwandan women living with fistula. It is important to elicit narratives from different groups of women to highlight the ways culture can inform a woman's experience. This information can be used to adapt public health interventions to match need.

Rwandan government research approval was not received until the final 3 days of the medical mission trip, and thus the limited number of Rwandan women who were approached to participate in the study were primarily postoperative, which could have greatly influenced their responses during the interviews. Responses may have been constrained due to the discomfort of sharing intimate details,

particularly in the presence of recording devices. Language translation is inherently flawed, and the meaning of a statement could have been altered. Additionally, the Rwandan medical students served as translators, but are not professionally trained as such, nor were the medical researchers formally trained in narrative inquiry. The small number of interviews completed is a limitation to appreciating the scope of variation among the patient population and not reaching saturation; however, in-depth interviews were obtained that will help enrich understanding.

Collectively, these women braved enormous hardships. Gender inequality, lack of education, delayed access to professional health care, and poverty all had a role in these illness narratives. Globally, increasing access to emergency obstetrical care, improving patient understanding of the importance of skilled birth attendants, and increasing the social status of women are a few necessary steps toward preventing urogenital fistula. On an individual level, offering support to each woman and tailored education about her condition may help to empower.

## CONCLUSION

This study highlighted subtle variations of each woman's narrative, and how cultural context can inform illness narratives. These findings are a reminder that each patient is different, and her attitudes and understanding of her condition may vary by the context in which she lives. We hope that through adopting the interview guide used in this study, physicians will have a rubric for gathering patients' illness narratives and use them to guide their practice of caring for women with fistula. Additionally, public health interventions can use illness narratives to provide targeted educational and preventive interventions.

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