

GYNECOLOGY

Characterizing persistent urinary incontinence after successful fistula closure: the Uganda experience

Rahel Nardos, MD, MCR; Laura Jacobson, MPH; Bharti Garg, MBBS, MPH; L. Lewis Wall, MD, DPhil; Alice Emasu, MBA, MSW; Bonnie Ruder, PhD

BACKGROUND: Obstetric fistula is a devastating childbirth injury. Despite successful closure of the fistula, 16% to 55% of women suffer from persistent urinary incontinence after surgery.

OBJECTIVE: This study assessed the type and severity of persistent incontinence after successful fistula closure and its impact on the quality of life of Ugandan women post-fistula treatment.

STUDY DESIGN: This cross-sectional study enrolled women with a history of obstetric fistula repair who continued to have persistent urinary incontinence (cases, N=36) and women without incontinence (controls, N=52) after successful fistula closure. Data were collected in central and eastern Uganda between 2017 and 2019. All the participants completed a semistructured questionnaire. Cases underwent a clinical evaluation and a 2-hour pad test and completed a series of incontinence questionnaires, including two novel tools designed to assess the severity of incontinence in low-literacy populations.

RESULTS: Cases were more likely to have acquired a fistula during their first delivery (63% vs 37%, $P=.02$), were younger when they developed a fistula (20.3 ± 5.8 vs 24.8 ± 7.5 years old, $P=.003$), and were more likely to have had >2 fistula surgeries (67% vs 2%, $P\leq .001$). Cases reported a much higher rate of planned home birth for their index pregnancy compared to controls (44% vs 11%), though only 14% of cases and 12% of controls actually delivered at home. Cases reported higher rates of pain with intercourse (36% vs 18%, $P=.05$), but recent sexual activity status (intercourse within the previous six

months) was not significantly different between the groups (47% vs 62%, $P=.18$). Among cases, 67% reported stress incontinence, 47% reported urgency incontinence, and 47% reported mixed incontinence. The cough stress test was successfully done with 92% of the cases, and of these, almost all (97%) had a positive cough stress test. More than half (53%) rated their incontinence as “very severe,” which was consistent with objective findings. The 24-hour voiding diary indicated both high urinary frequency (average 14) and very frequent leakage episodes (average 20). Two-hour pad-tests indicated that 86% of cases had >4 g change in pad weight within 2 hours. Women with more severe incontinence reported a more negative impact on their quality of life. The mean score of the International Consultation on Incontinence Questionnaire-Quality of Life was 62.77 ± 12.76 (range, 28–76, median=67), with a higher score indicating a greater impact on the quality of life. There was also a high mental health burden, with both cases and controls reporting high rates of suicidal ideation at any point since developing fistula (36% vs 31%, $P=.67$).

CONCLUSION: Women with obstetric fistulas continue to suffer from severe persistent urinary incontinence even after successful fistula closure. Both stress and urgency incontinence are highly prevalent in this population. Worsening severity of incontinence is associated with a greater negative impact on the quality of life.

Key words: obstetric fistula, persistent incontinence, post-fistula incontinence, stress incontinence, urgency incontinence, Uganda

Introduction

Poor access to timely and quality obstetric care puts women in low-resource countries at a high risk for obstetric complications such as prolonged obstructed labor. Obstructed labor can lead to ischemic injury of the bladder and/or bowel, leading to fistula formation. Obstetric fistula is estimated to range from 1.2 per 1000 live births in South Asia to 1.60 per 1000 live births in

sub-Saharan Africa.¹ Within sub-Saharan Africa, Uganda has a high lifetime prevalence of women reporting symptoms consistent with the presence of a fistula (14 per 1000 women of reproductive age).²

Obstetric vesicovaginal fistula repair has a generally favorable surgical outcome in the hands of skilled surgeons, with successful closure of the fistula in 87% to 93% of cases.^{3–5} The rate of closure is lower for less-experienced surgeons, and it is also influenced by other clinical risk factors such as previous unsuccessful fistula surgery or more extensive injuries.^{6,7} In women who have had successful fistula closure, between 16% and 55% of them^{8,9} may still experience chronic persistent urinary incontinence that severely impacts their quality of life.^{10,11} This has been termed

by some as “the continence gap.”¹² Few studies have highlighted the prevalence of persistent post-fistula incontinence, and even fewer have investigated the type and severity of incontinence or its impact on women. In a large prospective cohort study of obstetrical fistula patients (N=401) from Malawi, researchers reported that Although 93% of women had successful closure of their fistula, 23% had persistent urinary incontinence.¹⁰ The risk factors for persistent incontinence included age, number of years living with fistula, number of previous attempts at fistula repair, and clinical characteristics of the fistula itself. In our own study in Ethiopia where we compared women with and without persistent urinary incontinence after successful fistula closure, women with incontinence

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AJOG at a Glance

Why was this study conducted?

This study investigated the type and severity of persistent incontinence after successful fistula closure and its impact on the quality of life of Ugandan women.

Key findings

Women with persistent urinary incontinence after fistula closure were more likely to have developed their fistula during their first delivery, were younger when they developed the fistula, and were more likely to have gone through more repeat fistula surgeries than women who were not incontinent after fistula repair.

What does this add to what is known?

Persistent urinary incontinence after successful fistula closure has a substantial negative impact on the quality of life. Both stress and urgency incontinence are highly prevalent and severe in this population. A worsening severity of persistent incontinence is associated with a greater negative impact on the quality of life.

tended to be younger and had developed their fistula with their first pregnancy.¹¹ They reported both stress (98%) and urgency (94%) incontinence, and nearly half reported constant urinary leakage with significant impact on their quality of life.¹¹ We hypothesized that these observations would be similar in other populations suffering from obstetric fistula.

This article draws from a mixed-method, community-led project run by TERREWODE, a Ugandan nongovernmental organization (NGO) that has been providing clinical and social reintegration services for fistula victims since 2001. This study aimed to better understand the type, severity, and impact of persistent incontinence following successful fistula closure in Ugandan women. An additional aim of this project was to test two novel low-technology tools created for use with low-literacy populations suffering from urinary incontinence.

Materials and Methods

This was a cross-sectional study conducted in central and eastern Uganda between October 2017 and May 2019. Ethical approval was obtained from the institutional review boards at Makerere University School of Public Health (Kampala, Uganda), Uganda National Council of Science and Technology, and Oregon Health & Sciences University (Portland, OR). The study participants

were screened and recruited by staff from TERREWODE. Translators, who are also trained fistula counselors, obtained consent using documents that had been translated into three local languages (Ateso, Kumam, and Lugandan). The study questionnaires were administered by the last author (B.R.) with the assistance of the female TERREWODE translators. The inclusion criteria involved women having a history of previous obstetric fistula repair who were between the ages of 18 and 80 years old. The exclusion criteria included women with clinically-proven obstetric fistulas who were younger than 18 years or older than 80 years, were currently pregnant, had a current urinary tract infection, or who had a history of urinary diversion surgery. Women who qualified for the study were divided into cases (women with successfully closed fistula who report persistent urinary incontinence) and controls (women with successfully closed fistula who did not report persistent urinary incontinence).

The cases were clinically evaluated by a fistula surgeon to confirm the absence of a current fistula. This was done using a standard clinical technique, in which the bladder was filled through a small transurethral catheter with 200 to 300 mL of sterile saline colored with methylene blue dye. The catheter was then clamped, and the vagina was examined with the patient in the lithotomy position. Patients with a documented unclosed

fistula were excluded from the study and were directed to a fistula surgeon for further care. Following the dye test, the catheter was removed, and a cough stress test was performed with a full bladder with the patient in a standing position.

All the participants completed a semistructured demographic and psychosocial questionnaire. The cases also participated in an in-depth interview; an analysis of the qualitative findings are forthcoming. The cases completed a series of urinary incontinence-specific questionnaires, including the validated International Consultation on Incontinence Questionnaire-Urinary Incontinence Short Form (ICIQ-UI SF) to assess the frequency, volume of loss, and impact of urinary incontinence.¹³

The severity of incontinence, as captured by the ICIQ-SF, was categorized into grades: slight (scores ranging from 1–5), moderate (6–12), severe (13–18), and very severe (19–21). The cases also completed the International Consultation on Incontinence Questionnaire Lower Urinary Tract Symptoms Quality of Life questionnaire (ICIQ-LUTSqol) to assess the impact of urinary incontinence on their quality of life.^{14,15}

In addition, the cases completed two novel low-technology tools designed for use with low-literacy populations having incontinence. The first tool—the Post-Fistula Incontinence Severity Scale (PFISS)—is designed to assess the perceived severity of a patient's incontinence after successful surgical fistula closure using a pictorial questionnaire.¹⁶ The cases were shown culturally-appropriate pictures of a woman experiencing varying levels of incontinence and were asked to choose the picture that matched their experience. They also completed a 24-hour-voiding diary modified for use in low-literacy populations. The women recorded their voiding and incontinence episodes over 24 hours using a paper-strip method.¹⁷ They were provided with a large envelope containing strips of white and pink colored paper affixed to the envelope (~2×40 cm). They were instructed to tear off a small piece of white paper every time they voided and to tear off a small

piece of pink paper every time they leaked urine. The strips of paper were then placed into the envelope. The envelopes were collected 24 hours later, and the strips of paper were categorized and counted to document the frequency of voids and urinary incontinence.

The data were analyzed using Stata (version 15; StataCorp, College Station, TX). Cases and controls were compared using independent two-sample *t* tests (continuous data) and the Chi-square test or Fisher exact test (categorical data). Continuous data are presented as mean±standard deviation (SD) after checking for normality; the categorical data are presented as frequency and percentage. We reported the average (SD) for International Consultation on Incontinence Modular Questionnaire-Quality of Life (ICIQ-QoL) and PFISS and frequency (percentage) for categories of ICIQ-SF. The Spearman rank correlation coefficients were calculated between ICIQ-SF & ICIQ-QoL, between ICIQ-SF and PFISS, and between ICIQ-QoL & PFISS. Values between 0.4 and 0.6 were considered as moderate correlation.

We utilized three multivariable logistic regression models. First, we assessed the predictors of post-fistula incontinence. Our primary outcome was post-fistula incontinence as evaluated using the ICIQ-SF questionnaire. We utilized binary variables (moderate to severe incontinence [8–18 scores] and very severe incontinence [19–21 scores]). Confounders were chosen on the basis of clinical knowledge as to which predictors are likely to affect incontinence. We used the total number of surgeries to close the fistula (categorized into ≤ 2 and > 2), number of days in labor (continuous variable), age at development of fistula (continuous variable), and number of deliveries before fistula (continuous variable) as confounders. Second, we used a multivariable logistic regression model to assess the association of “very severe” incontinence with social discrimination and used the current age and age at marriage as confounders. Third, we evaluated the association of “very severe” incontinence with physical abuse (kicked, slapped, or beaten),

TABLE 1
Demographics of women who have undergone obstetrical fistula repair (N = 88)

| Characteristics | Controls (n=52) | Cases (n=36) | Pvalue |
|--------------------------------------|-----------------|--------------|-------------------|
| Age, y (Mean±SD) | | | |
| Current age | 30.3±9.9 | 34.7±11.8 | .06 ^a |
| Age at first marriage | 17.5±2.8 | 17.5±2.6 | .98 ^a |
| Age at first birth | 18.1±2.3 | 17.7±2.8 | .42 ^a |
| Age at fistula development | 24.8±7.5 | 20.3±5.8 | .003 ^a |
| Education, n (%) | | | |
| None | 8 (15) | 9 (25) | .52 ^b |
| Some primary education | 38 (73) | 23 (64) | |
| Some secondary education | 6 (12) | 4 (11) | |
| Current marital status, n (%) | | | |
| Married | 30 (58) | 15 (42) | .08 ^b |
| Divorced/separated | 15 (29) | 19 (53) | |
| Never married | 7 (13) | 2 (5) | |
| Occupation, n (%) | | | |
| Employed | 45 (87) | 35 (97) | .13 ^b |
| Not employed | 7 (13) | 1 (3) | |
| Financial support, n (%) | | | |
| Self | 28 (54) | 21 (58) | .68 ^b |
| Others | 24 (46) | 15 (42) | |

Cases: women with persistence urinary incontinence after successful fistula closure.
Controls: no urinary incontinence after fistula repair after successful fistula closure.
SD, standard deviation.
^a Independent two-sample *t* test; ^b Chi-square or Fisher exact test.
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controlling for current age, age at marriage, and total number of surgeries. A *P* value of $<.05$ was considered to be significant.

Results

A total of 110 women were screened for this study, and 88 women were enrolled after meeting the inclusion criteria. Of these 88 women, 36 had persistent incontinence (cases) and 52 did not (controls). Cases were slightly older than controls at the time of this study (34.7±11.8 [range: 18–78; cases] vs 30.3±9.9 [range: 17–59; controls]; *P*=.06). Only 11% of cases and 12% controls had education above primary school. There was no significant difference between these two groups in the age at first marriage or at first childbirth,

educational status, marital status, occupation, and source of income (Table 1).

Cases tended to have acquired their fistula at a younger age than the controls (20.3±5.8 vs 24.8±7.5 years; *P*=.003). Most of the cases developed a fistula during their first delivery (63% vs 37%; *P*=.02), and they had more than two surgeries (67% vs 2%; *P*<.001) compared with the controls (Table 2). They also reported a greater negative impact of their condition on their day-to-day life and on their physical and mental wellbeing. Both cases and controls reported high rates of suicidal ideation at any point since developing a fistula (36% vs 31%, *P*=.67). Cases reported a much higher rate of planned home births for their index pregnancy than the controls (44% vs 11%), yet

TABLE 2
Clinical history and circumstances surrounding childbirth (N = 88)

| Fistula history | Controls (n=52) | Cases (36) | Pvalue |
|---|-----------------|------------|--------------------|
| Developed fistula at their first birth, n (%) | 19 (37) | 22 (63) | .02 ^a |
| At least 1 delivery since fistula, n (%) | 9 (17) | 9 (25) | .38 ^a |
| Planned location of delivery, n (%) | | | |
| Home | 6 (11) | 16 (44) | .002 ^a |
| Health Center | 30 (58) | 13 (36) | |
| Hospital | 16 (31) | 7 (19) | |
| Actual place of delivery, n (%) | | | |
| Home | 6 (12) | 5 (14) | .91 ^a |
| Health Center | 7 (13) | 4 (11) | |
| Hospital | 39 (75) | 27 (75) | |
| Time with fistula before seeking treatment (y), n (%) | | | |
| <1 | 32 (63) | 12 (38) | .07 ^a |
| 1–5 | 8 (16) | 10 (31) | |
| >5 | 11 (21) | 10 (31) | |
| Number of fistula surgeries, n (%) | | | |
| 1–2 | 50 (98) | 12 (33) | <.001 ^a |
| >2 | 2 (2) | 24 (67) | |
| Number of deliveries before fistula | | | |
| Mean±SD | 2.5±2.5 | 1.2±2.0 | .01 ^b |
| None, n (%) | 19 (37) | 22 (63) | .02 ^a |
| ≥1 | 33 (63) | 13 (37) | |
| Number of deliveries since fistula, n (%) | | | |
| None | 43 (83) | 27 (75) | .38 ^a |
| ≥1 | 9 (17) | 9 (25) | |
| Days in labor at index delivery, (mean±SD) | 2.5±1.9 | 3.0±1.4 | .21 ^b |

Cases: women with persistent urinary incontinence after successful fistula closure.

Controls: no urinary incontinence after fistula repair after successful fistula closure.

SD, standard deviation.

^a Chi-square or Fisher exact test (n [%] reported); ^b Independent two-sample t test (mean±SD reported).

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ultimately, 75% of both groups delivered in the hospital; only 14% of cases and 12% of controls actually delivered at home. The rest delivered at health centers. The cases reported higher rates of pain with intercourse (36% vs 18%, $P=.05$), but recent sexual activity status (intercourse within the previous 6 months) was not significantly different between the groups (47% vs 62%, $P=.18$) (Table 3). The cases also reported

greater food insecurity than the controls (81% vs 46%; $P=.002$).

Overall, 67% of cases subjectively reported stress urinary incontinence, and 47% reported urgency incontinence, with 47% of cases reporting both urgency and stress incontinence (mixed) and 53% reporting “leaking urine all the time.” The cough stress test was successfully done with 92% of the cases, and of these, almost all (97%) had a positive

cough stress test. The 24-hour voiding diary done using the paper-strip method (Methods) indicated both high urinary frequency (average 14) and very frequent leakage episodes (average 20). Two-hour pad-tests indicated that 86% of cases had >4-g change in pad weight within two hours (Table 4).

There was a moderate positive correlation between the ICIQ-SF and the PFISS (Spearman correlation

TABLE 3
Women's clinical, mental, and psychological characteristics after fistula closure (N = 88)

| Impact of fistula | Controls (n=52) | Cases (n=36) | P value ^a |
|--|-----------------|--------------|----------------------|
| Sexually active (last 6 mo) | 32 (62) | 17 (47) | .18 |
| Pain with intercourse | 9 (18) | 13 (36) | .05 |
| Were offered postop family planning | 32 (62) | 21 (58) | .76 |
| Currently using family planning | 11 (21) | 4 (11) | .22 |
| Discrimination before surgery recorded | | | |
| Never/seldom | 33 (63) | 21 (58) | .63 |
| Often/always | 19 (37) | 15 (42) | |
| Abused while fistula present | 18 (35) | 19 (53) | .09 |
| Abused after fistula repair | 6 (12) | 9 (25) | .10 |
| Report being hopeful about the future | 46 (88) | 31 (86) | .63 |
| Experiencing food insecurity | | | |
| No/rarely | 27 (52) | 7 (19) | .002 |
| Sometimes/often | 24 (46) | 29 (81) | |
| missing | 1 (2) | 0 (0) | |
| Personal experience of suicidal ideation | | | |
| Never | 23 (44) | 12 (33) | |
| Seldom | 12 (23) | 9 (25) | .67 |
| Often/always | 16 (31) | 13 (36) | |
| Missing | 1 (2) | 2 (6) | |
| Had made a plan for suicide | 9/28 (32) | 7/22 (32) | .66 |
| Have attempted suicide | 4/28 (14) | 3/22 (14) | .43 |

Only those who answered yes to suicidal ideation (since developing a fistula, have you ever thought about killing yourself?) (n=28) were asked if they had plans for or attempted suicide.

Cases: women with persistent urinary incontinence after successful fistula closure.

Controls: no urinary incontinence after fistula repair after successful fistula closure.

^a Chi-square or Fisher exact test.

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coefficient=0.47; $P=.0063$) and between the ICIQ-SF and the ICIQ-QoL (Spearman rank correlation coefficient=0.60; $P=.0002$). The mean score of the ICIQ-QoL was 62.77 ± 12.76 (range, 28–76; median=67), with a higher score indicating a greater impact on the quality of life (Table 5).

Multivariate regression analysis showed that women with >2 surgeries had a higher risk of “very severe” incontinence (adjusted odds ratio [aOR], 6.8; 95% confidence interval [CI], 1.1–43.7; $P=.04$) after controlling for days in labor, age at development of fistula, and number of deliveries before fistula. We also found that women with “very severe” incontinence had a

significantly higher risk of experiencing discrimination or harassment from their community (aOR, 7.2; 95% CI, 1.2–42.6; $P=.03$) after adjusting for current age and age at marriage. Finally, women with “severe incontinence” had higher odds of being physically abused (slapped, kicked, or beaten) (aOR, 3.4; 95% CI, 0.5–24.1) after adjusting for current age, age at marriage, and the total number of surgeries.

Comment

Principal findings

This study describes the types and severity of urinary incontinence that plague women with a history of obstetric fistula even after their fistulas have been

closed successfully. It highlights the severe impact that persistent incontinence has on these women's quality of life and their sexual and mental health.

Results in the context of what is known

The findings of this study are consistent with the findings of a similar study we conducted among fistula patients in Ethiopia.¹¹ Our findings suggest that the problem of persistent postrepair urinary incontinence is widespread among fistula patients in sub-Saharan Africa and requires urgent attention. Two observations are particularly important, as they have significant implications for fistula prevention. One is that women with

TABLE 4
Incontinence profiles in women with persistent urinary incontinence after successful fistula closure (n = 36)

| | |
|---|------------|
| Type of incontinence by subjective reporting, n (%) | |
| Stress incontinence | 24/36 (67) |
| Urgency incontinence | 17/36 (47) |
| Mixed incontinence | 17/36 (47) |
| Postvoid dribbling | 11/36 (31) |
| Leaks without any trigger | 16/36 (44) |
| Leaks all the time | 19/36 (53) |
| Cough stress test, n (%) | |
| Negative | 1/33 (3) |
| Positive | 32/33 (97) |
| Pad weight after standardized 2-h test, n (%) | |
| <4 g in 2 h | 4/28 (14) |
| >4 g in 2 h | 24/28 (86) |
| 24-h bladder diary, (mean±SD) | |
| Leaks | 20.2±20.6 |
| Voids | 13.6±11.4 |

SD, standard deviation.

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persistent urinary incontinence after fistula closure tend to acquire their fistula at a younger age. This finding has been documented previously¹⁰ and is often explained by an increased anatomic susceptibility to more severe injury because of the diminished pelvic capacity of younger adolescent girls compared with more mature women during their first delivery.¹⁸ Persistent incontinence after fistula closure is also more common among women who acquired their fistula during their first vaginal delivery. This is consistent with the report from a large chart review study of 14,928 obstetrical fistula patients at Addis Ababa Fistula Hospital in Ethiopia, which indicated that primiparas had longer labors than multiparas, developed larger urovaginal fistulas, had more rectovaginal fistulas, developed more vaginal scarring, and had more persistent incontinence after fistula closure than did multiparas. This seems to indicate the presence of a more severe injury complex in younger, primiparous patients.¹⁹ In addition, we found that most of the participants had some form

of antenatal care, yet in 44% of cases, they still planned to deliver at home. Among controls, only 11% planned to deliver at home. Ultimately, 75% of both cases and controls were delivered at the hospital. Planned home delivery likely added delays in obstetric care and potentially contributed to more severe injuries.²⁰

One surprising finding of this study was the high number of repeat fistula surgeries that cases had undergone in Uganda. In this study, 33% of the cases had 1–2 fistula surgeries, 33% had 3–4 surgeries, and 30% had ≥5 surgeries. In fistula treatment, it is well-recognized that the first operation presents the best opportunity for successful closure and that the likelihood of success diminishes with each subsequent surgery.^{7,21–23} Earlier studies have documented that a history of previous failed surgeries is a risk factor for persistent incontinence after fistula closure.^{6,7,24} In western Uganda, Kayondo et al²⁵ in 2011 found that women with previously unsuccessful fistula repair were 5 times more likely to experience residual stress

incontinence after successful closure than women with no previous attempt at repair.

Clinical implication

Our findings highlight the severe and persistent physical, social, and psychological trauma that obstetric fistula patients endure even after a “successful” fistula closure. Our findings suggest that efforts to delay both marriage and childbearing are potentially significant interventions to prevent obstetric fistulas and persistent incontinence. In addition, our findings also suggest that more effort should be devoted to promoting planned delivery at a health facility with a skilled birth attendant to reduce the added delay that likely contributes to more severe injuries. The observation that cases have higher numbers of previous fistula surgeries emphasizes the critical importance of ensuring that women with obstetric fistulas get quality care by a skilled team from the moment of their first operation.

The proper evaluation and care for women with persistent incontinence after fistula closure can be challenging in low-resource settings. Goh and Krause have argued that accurate diagnosis including the use of urodynamic studies is imperative to avoid a high rate of surgical failure.²⁶ The severity of pelvic floor and bladder injuries in this population makes these women far more complex than patients who develop postpartum incontinence after normal vaginal delivery. In the absence of a thorough diagnostic workup and urologic/urogynecologic expertise, the care of these patients can be compromised. In most low-resource settings, the care-model is restricted to surgical “closure of the hole” and does not extend to the treatment of post-closure urinary incontinence and other pelvic floor disorders. Under this “close the hole” philosophy, once the fistula is closed, the surgery is regarded as successful, whether or not the woman has actually achieved continence. As this study has shown, persistent incontinence after fistula closure has a profoundly negative impact on a woman’s mental health and

her quality of life. Conservative treatment options should be considered for patients who may not respond well to additional surgery. Castille et al²⁷ in 2015 demonstrated the efficacy of a short-term physiotherapy and education program (implemented both before and after surgery) in improving urinary continence after fistula closure. Similarly, in the Democratic Republic of Congo, researchers found a 71% improvement in functional outcomes for fistula patients who participated in a short-term physiotherapy program as part of their treatment.²⁸

Mental health services are particularly critical in the ongoing care of women with a history of obstetric fistula. In this study, we showed that one-third of the fistula patients in both groups had suicidal ideation “often” or “always” at some point since acquiring a fistula. Of those who had suicidal ideation, nearly one-third in each group reported having made plans for suicide. We did not specify the time frame of onset for suicidal ideation (before or after successful fistula closure), thus we are unable to determine if persistent incontinence poses an additional risk. In a systematic review and meta-analysis looking at the prevalence of depression in women with obstetric fistulas, researchers found a high burden of depression, ranging from 27.7% in Tanzania to 74.4% in Ethiopia.²⁹ Among the studies included in the review, one study³⁰ demonstrated reductions in depression immediately after surgery, yet, most others indicated persistent depression even after successful fistula closure because of persistent psychosocial stressors and physical symptoms. In the present study, we found that women with very severe incontinence (53% leak all the time) were more likely to experience discrimination or harassment from their community, physical abuse, and food insecurity, all of which highlight the negative impact that persistent incontinence incurs in this population.

A holistic model needs to be embedded in the existing healthcare infrastructures of low-resource countries and championed jointly by all

TABLE 5
Incontinence-related severity and quality of life measures in women with persistent urinary incontinence after successful fistula closure (n = 36)

| | |
|--|---|
| ICIQ-SF, ¹ n (%) | |
| Moderate (8–12) | 6 (17) |
| Severe (13–18) | 11 (30) |
| Very severe (19–21) | 19 (53) |
| PFISS ² | |
| Mean±SD | 3.03±1.93 |
| Median (range) | 3 (0–6) |
| ICIQ-LUTSqOL ³ | |
| Mean±SD | 62.77±12.76 |
| Median (range) | 67 (28–76) |
| Correlations | |
| Correlation between ICIQ-SF and ICIQ-LUTSqOL | .60 (.0002) |
| Correlation between ICIQ-SF and PFISS | .47 (.0063) |
| Correlation between ICIQ-LUTSqOL and PFISS | .31 (.08) |
| | Spearman rank correlation coefficient (Pvalue) |

ICIQ-LUTSqOL³, International Consultation on Incontinence Questionnaire- Lower Urinary Tract Symptoms Quality of Life questionnaire; ICIQ-SF¹, International Consultation on Incontinence Questionnaire- Short Form; PFISS², Post-Fistula Incontinence Severity Scale (Range 0–6), lowest values=least severe.

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stakeholders. In Ethiopia, for example, a partnership between Hamlin Fistula Ethiopia, Mekelle University, their NGO, and academic partners has led to the creation of one of the first formal urogynecology training programs in the country. This has expanded access to high-quality pelvic floor care to many women throughout Ethiopia.³¹ In Uganda, the newly established Terrewode Women’s Community Hospital is the first hospital dedicated to fistula treatment. This program was “built from the ground up,” starting from a deep commitment to advocacy for women victimized by fistula and the accompanying social stigmatization that often occurs. In addition to expert surgical services, this treatment program takes a holistic approach to women’s wellness, including an outreach and social reintegration program that provides mental health and social counseling services for fistula survivors.

Research implications

One strength of our study is the use of two novel low-technology tools

designed for use with low-literacy populations. The PFISS assesses women’s subjective experience of incontinence using a series of culturally appropriate illustrations showing progressively worsening levels of incontinence. When compared with the ICIQ-SF, which measures the subjective experience of incontinence using a Likert scale, there was a moderate positive correlation. There is a body of evidence that has demonstrated an effect of illiteracy on the Likert scale response performance.^{32,33} Chachamovich et al concluded that a multiple-category (5-point) response scale is not suitable for use in a non-reading population.³² In our experience, the PFISS took considerably less time to administer to study participants than the Likert scale used in the ICIQ tools. Further research with larger sample sizes should be conducted to validate the PFISS.

The paper-strip 24-hour bladder diary also proved to be a feasible, low-technology tool in this study population to overcome the limitations of

traditional bladder diaries, which require literacy. Instead of a written record, participants used white or pink strips of paper to tabulate each void (white) or urinary leak (pink). Further improvements need to be made to document the fluid intake, volumes voided, and activities that trigger leakage episodes.

The limitations of this study include lack of clinical information on the characteristics of the fistula and the index childbirth that may contribute to persistent incontinence after fistula closure. Indeed, the fistula size, degree of vaginal scarring, circumferential injury of the bladder, residual bladder size, and urethral length have been implicated as risk factors for persistent incontinence.¹⁰ Because the study participants received surgery at multiple institutions by different surgical teams, detailed clinical records were not available. Future studies done at single or multicenter institutions with standardized records and clinical practices would provide additional insights.

Conclusion

This study highlights the burden of persistent incontinence in women incorrectly deemed “cured” after the surgical closure of their obstetrical fistulas. The findings from this study should encourage stakeholders to invest in long-term, sustainable, and holistic models of care for women with childbirth injuries. Successful closure of a fistula does not mean that the problems faced by these women have been solved. There is still much to be done. ■

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Author and article information

From the Department of Obstetrics and Gynecology-Center for Global Health and Social Responsibility, University of Minnesota, Minneapolis, MN (Dr Nardos); Oregon Health & Science University-Portland State School of Public Health, Portland, OR (Ms Jacobson); Department of Obstetrics and Gynecology, Oregon Health & Science University, Portland, OR (Ms Garg); Departments of Obstetrics and Gynecology and Anthropology, Washington University, Saint Louis, MI (Dr Wall); TERREWODE, Soroti, Uganda (Ms Emasu); Terrewode Women's Fund, Eugene, OR (Dr Ruder); and Oregon State University, Corvallis, OR (Dr Ruder).

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Corresponding author: Rahel Nardos, MD, MCR. nardosr@umn.edu