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Peer reviewed

# **Factors associated with reintegration trajectory** following female genital fistula surgery in Uganda



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BACKGROUND: A female genital fistula, primarily caused by prolonged obstructed labor or after cesarean delivery in resource-limited countries, affects 500,000 to 2,000,000 women worldwide. Fistula is preventable with timely access to high-quality obstetrical care. Access to surgical repair of a female genital fistula has greatly increased over time. However, research surrounding postrepair reintegration, the process of returning to an individual's normal life, remains limited, and further efforts are needed to understand the factors shaping women's ability to rebuild their relationships and lives following repair.

**OBJECTIVE:** This study aimed to characterize the 12-month reintegration trajectory after female genital fistula repair by participant sociodemographic and clinical characteristics.

**STUDY DESIGN:** This study analyzed quantitative survey and medical record data of women (N=60) participating in a longitudinal cohort study assessing recovery after genital fistula repair in Uganda, with baseline and 4 quarterly follow-up assessments in 12 months. The primary outcome of reintegration was assessed using a 19-item postfistula repair reintegration instrument (range, 0-100) where a higher score represents better reintegration. Predictors of interest included parity and living children, quality of life, depressive symptoms at baseline, self-esteem, stigma, trauma, physical symptoms, and social support. We described participant baseline characteristics using means and proportions and estimated a series of mixed-effects linear regression models, including interactions of characteristics with time to understand how these characteristics influence reintegration trajectory in the 12 months after repair.

RESULTS: The participants' physical and psychosocial morbidities at baseline were high; more than 80% of participants reported fistula-related physical symptoms, 82% of participants described their general health as poor, and measures of self-esteem, overall social support, and overall quality of life were low. The mean reintegration score at baseline was 33 (standard deviation, 20), which increased to 78 (standard deviation, 19) at 12 months after fistula repair. The participant sociodemographic characteristics statistically associated with reintegration included any living children (B. 1.08; 95% confidence interval, -0.08 to 2.23). Moreover, psychosocial factors significantly affected reintegration with steeper trajectories for women with depressive symptoms ( $\beta$ , 0.89; 95% confidence interval, 0.02–1.75) or women experiencing internalized stigma ( $\beta$ , 0.05; 95% confidence interval, -0.00 to 0.11) and less steep for those with higher self-esteem ( $\beta$ , -0.11; 95% confidence interval, -0.24 to 0.01), overall social support  $(\beta, -0.06; 95\%)$  confidence interval, -0.12 to -0.01), and partner support  $(\beta, -0.21; 95\%)$  confidence interval, -0.35 to -0.07).

**CONCLUSION:** Understanding the prominent factors associated with differences in reintegration trajectories across the year after genital fistula surgery has the potential to inform interventions that mitigate challenges and improve women's postrepair recovery experiences.

Key words: female genital fistula, global health, obstetrics and gynecology, reintegration, reproductive psychiatry, stillbirth, Uganda, urinary incontinence, women's health

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The authors report no conflict of interest.

All participants underwent an informed consent process, including signature or thumbprint confirmation for study participation. Patient consent for publishing is not required because no personal information or detail is included.

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Original Research

## AJOG MFM at a Glance

# Why was this study conducted?

Female genital fistula is associated with significant physical and psychosocial morbidities. Optimizing recovery is paramount for improving well-being; however, factors facilitating or hindering the postfistula surgery reintegration process are not well defined.

# **Key findings**

Most participants experienced large reintegration score increases from surgery in 12 months. The presence of living children and the level of internalized stigma and depressive symptoms at baseline were positively associated with faster reintegration score increases over time. Reintegration trajectory increase was less steep for those with higher self-esteem, overall social support, and partner support at baseline, factors also associated with higher baseline reintegration score.

## What does this add to what is known?

Our findings contribute preliminary quantitative estimates of the influence of key factors on postrepair reintegration trajectory, confirming the importance of improving social support and reducing stigma to improve the fistula recovery experience.

#### Introduction

Female genital fistula in lower-resource settings is a traumatic injury resulting from prolonged obstructed labor without adequate emergency obstetrical care or iatrogenic or traumatic etiologies. 1 It is largely preventable and surgically curable.<sup>2</sup> In addition to being associated with high rates of stillbirth, the physical consequences of fistula include urinary and/or fecal incontinence along with vaginal pain, infertility, and amenorrhea.3 Moreover, a fistula is associated with psychosocial sequelae, including depression and enacted or internal stigma.1 The physical and psychosocial consequences intersect with sociocultural, economic, or awareness obstacles to care seeking and access, resulting in delays.4-9 Fistula care availability and use are increasing; a total of 68,943 fistula surgeries were reported globally between 2010 and 2021, including 1514 fistula surgeries in Uganda. 10-12

Although surgical closure success rates of fistula are high, ranging from 72% to 92%, <sup>11,13</sup> persistent postrepair urinary incontinence occurs among up to 33% of women, especially those with small bladder size, urethral damage, large fistula size, or vaginal scarring. 14-18 Other research has identified fistula-related symptom persistence even with fistula

closure, 18 suggesting that patientreported outcomes are necessary to understand the course of reintegration, the process of returning to an individual's normal life, including social, emotional, and physical recovery after fistula repair and which factors influence these trajectories.

Previous research has found that reintegration and related constructs, such as quality of life (QoL), generally increase substantially after fistula surgery, particularly for those patients with restored continence. 18-21 However, few studies have explored how patient factors, such as sociodemographic characteristics, obstetrical history, physical health status, or psychosocial health status, affect reintegration trajectory over time. Of particular interest is understanding factors that may accelerate or decelerate reintegration trajectories after fistula surgery given that they may play an important role in informing expectations for clinical care outcomes, counseling, follow-up timing, or other interventions for women after repair. Therefore, this study explored the influence of participant sociodemographic and clinical characteristics on reintegration trajectory after fistula repair.

#### **Materials and Methods**

We analyzed data from a longitudinal cohort study of 60 women accessing fistula surgery at Mulago National Referral and Teaching Hospital in Kampala, Uganda, between December 2014 and June 2015. 18

Study methods for data collection are described in detail elsewhere.<sup>22</sup> Briefly, the cohort eligibility criteria included obstetrical or iatrogenic fistula, ability to speak Luganda or English, residence in a community with cellular telephone coverage, and capability of providing informed consent. Questionnaires were administered to participants in person at baseline—the time of fistula surgery, reflecting presurgical experiences with fistula—and via mobile phone at 3, 6, 9, and 12 months after surgery. Telephones and airtime were provided to participants. Medical record abstraction at baseline captured fistula characteristics and surgical outcomes.

#### Measures

The primary outcome of reintegration, a patient-reported outcome measure, represents fistula-specific global functioning status; moreover, the primary outcome of reintegration was assessed using a validated postfistula repair reintegration instrument.<sup>17</sup> The reintegration score was calculated, summing the 19 items across 4 subfactors of mobility and social engagement, meeting family needs, comfort with relationships, and general life satisfaction, and standardized to a range of 0 to 100, where increasing score represented higher reintegration or better functional status.

Patient characteristics were selected across 4 categories of interest: sociodemographic characteristics, obstetrical history, physical health, and psychosocial health. Sociodemographic characteristics included age, relationship status, living situation, educational attainment, employment status, source of financial support, and financial status. Obstetrical history included age at first birth, age at fistula development, duration with fistula, fistula-related birth outcome, and number of living children. Physical health status included severity of urinary incontinence (International Consultation on Incontinence Questionnaire Short Form: range, 0-21),<sup>23</sup> experience of other fistularelated symptoms (ie, weakness, general or specific pain, skin irritation, vaginal discharge, and difficulty walking), general health (Stanford Self-Rated Health measure: fair or poor vs good, very good, or excellent),<sup>24</sup> and current sexual activity. Psychological health status included severity of depressive symptoms (Hopkins Symptom Checklist [HSC]: range, 1-4),<sup>25,26</sup> QoL (World Health Organization Quality of Life Brief Version [WHOQOL-BREF] overall, physical, environment, social relationships, and psychological domains: range, 0-100), 27,28 self-esteem (Rosenberg Self-Esteem Scale: range, 0 -30),  $^{28,29}$  fistula-related enacted and internalized stigma (range, 0-36), 30 trauma (Primary Care Post-Traumatic Stress Disorder [PC-PTSD] screen for trauma),<sup>31</sup> and the social support (Multidimensional Scale of Perceived Social Support, sources: overall, partner, family, and friends; range, 0-100). 32,33 A mean HSC score of >1.75 was considered positive for depressive symptomatology, consistent with research among similar populations.<sup>34–37</sup> Sociodemographic characteristics and obstetrical history were assessed at the time of fistula surgery. Physical and psychological assessments occurred quarterly except for WHOQOL-BREF and PC-PTSD screen, which were not administered at 3 or 9 months to reduce participant response burden.

# **Statistical analysis**

Sociodemographic characteristics, obstetrical history, and physical and psychosocial health measures were described using medians and interquartile ranges (IQRs) for continuous variables and proportions for categorical variables. We analyzed reintegration trajectories in the year after fistula repair using plots of subject-specific trajectories (Figure S1). We explored the influence of participant characteristics and health status at the time of fistula surgery on a 12-month reintegration trajectory by estimating a series of linear mixed-effects regression models (1 per variable) specifying random intercepts accommodating our correlated longitudinal data structure and random slopes and allowing subject-specific variation in reintegration trajectories over time. These models incorporated time and the covariate of interest and an interaction term between time and the covariate of interest, which represents the differential in time trajectory of reintegration by the covariate of interest. Given our small sample size, no adjustment variable was included in this analysis. For each variable, we compared the goodness of fit of the full model, including both main effects and the interaction term to the main effects only model through likelihood ratio tests (Table S1). The interaction coefficients measure the difference in the rate of change in reintegration between groups defined by the values of the covariate of interest. Finally, we explored the influence of physical and psychosocial health status over time on a 12-month reintegration trajectory following a similar approach (Table S2). All analyses were performed with Stata (version 16.0; StataCorp, College Station, TX). The differences were considered statistically significant at P < .05.

The study protocol was approved by the Makerere University College of Health Sciences School of Medicine Research and Ethics Committee (reference number: 2014-052) and Uganda National Council for Science and Technology (ADM 154/212/01) and the University of California, San Francisco, Human Research Protection Program, Committee on Human Research (IRB numbers: 12-09573 and 15-17467). All participants underwent an informed consent process, including signature or thumbprint confirmation.

# Results **Participant sociodemographic** characteristics and obstetrical

# history

Study participant sociodemographic and obstetrical history characteristics were reported previously.<sup>18</sup> Briefly, the median age at study entry was 28 (IQR, 21-36) (Table 1). Most participants had not completed primary school

(67%) and did not work outside the home (57%). Relationship status varied with nearly half living with a partner (37%) or married (12%). Many participants relied on their husband as their primary financial supporter (40%). The median age at first birth was 18 years (IQR, 17-20), and most participants had at least 1 living child (65%). The median age at fistula development was 23 (IQR, 18-31), although time living with an unrepaired fistula varied greatly ranging from 2 weeks to 31 years (not shown). Nearly half of the participants lived with a fistula for under 3 months (46%), whereas more than one-quarter lived with a fistula for over 5 years (28%). Many participants had developed a fistula at their first delivery (40%), and most infants were stillborn (68%).

# **Reintegration trajectories over study** follow-up

The mean reintegration score at baseline was 33 (standard deviation [SD], 20; range, 0-100) and steadily increased over time to 70 (SD, 27) at 3 months, 78 (SD, 24) at 6 months, 76 (SD, 26) at 9 months, and 78 (SD, 19) at 12 months (not shown). 18 Plots of subject-specific trajectories in reintegration scores (Figure S1) showed that subjects varied in general level and rate of change in reintegration scores, which motivated the mixed effects modeling with both random intercepts and slopes.

# **Baseline physical and psychosocial** morbidity

Baseline reports of physical and psychosocial morbidities were high among study participants (Table 2). The severity of urinary incontinence was high with a mean score of 19 (SD, 3; range, 0 -21). More than 80% of participants reported experiencing one or more other fistula-related physical symptoms, including general pain (37%), pain with urination (30%), vaginal pain (45%), vaginal discharge (32%), weakness (33%), difficulty walking (33%), and skin irritation (28%). Most participants reported poor general health (82%) and met the threshold for depression (85%). Moreover, self-esteem was low, with a Original Research ajog.org

Variable	n	%	
Sociodemographic characteristics			
Age (y), median (IQR)	28 (21-36)		
Marital status			
Married	7	11.7	
Living together	22	36.7	
Divorced or separated	16	26.7	
Widowed	3	5.0	
Single or never married	12	20.0	
Participant lives with			
Alone	2	3.3	
Husband	24	40.0	
Young children only	11	28.3	
Adult children only	4	6.7	
Parents	8	13.3	
Others	11	18.4	
Educational attainment			
None	10	16.7	
Some primary	24	40.0	
Completed primary	17	28.3	
Some secondary or more	9	15.0	
Work outside of home	26	43.3	
Primary source of financial support			
Self	17	28.3	
Husband or partner	24	40.0	
Relatives	19	31.7	
Enough money to meet needs			
Not at all	49	81.7	
A little	4	6.7	
Moderately	5	8.3	
Mostly	2	3.3	
Completely	0	0.0	
Obstetrical history			
Age at first birth, median (IQR)	18.0 (16.5–2	20.0)	
Age at fistula, median (IQR)	22.5 (18.0—31.0)		
First birth resulted in fistula	24	40.0	
Type of fistula			
WF	57	95.0	
RVF	2	3.3	
VVF + RVF	1	1.7	
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mean score of 13 (SD, 5; range, 0-30). Perceived social support varied across and within sources. The participants reported the most support from partners (mean, 71; SD, 19; range, 0-100), followed by family members (mean, 54; SD, 25; range, 0-100) and friends (mean, 29; SD, 29; range, 0-100). Nearly one-fifth of participants (17%) screened positive for trauma. Overall QoL was low with a mean of 18 (SD, 11); however, scores varied greatly by subdomain, with physical QOL having the highest mean score at 48 (SD, 24) and psychological QOL having the lowest mean score at 24 (SD, 15).

# Reintegration trajectories by baseline characteristics over 12 months following fistula repair

In addition, estimated reintegration trajectories over a 12-month study followup varied by participant baseline characteristics (Table 3). Age at fistula surgery, depressive symptoms, self-esteem, and perceived social support at the time of fistula repair had a statistically significant influence on postrepair reintegration trajectory. Reintegration trajectory was steeper for those with greater age at fistula surgery or higher depressive symptom scores at baseline, with a permonth divergence in reintegration trajectory of 0.09 (95% confidence interval [CI], 0.08-0.11) for each increasing year of age and 0.89 (95% CI, 0.02 -1.75) per 1-unit increase in the baseline level of depressive symptoms. Reintegration trajectory was less steep for those with greater self-esteem or perceived social support at baseline overall and from partners; the per-month divergence scores in reintegration trajectory were -0.11 (95% CI, -0.24 to 0.01) for each unit increase in baseline self-esteem, -0.06 (95% CI, -0.12 to -0.01) for each unit increase in overall social support, and -0.21 (95% CI, -0.35 to -0.07) for each unit increase in partner social support at baseline. Divergence in reintegration trajectory was observed to be marginal for increasing internalized stigma ( $\beta$ , 0.05; 95% CI, -0.00 to 0.11) and having any living children ( $\beta$ , 1.08; 95% CI, -0.08 to 2.23).

TABLE 1

Variable	n	%
Duration living with fistula		
<1 mo	8	13.3
1—3 mo	19	31.7
3—12 mo	9	13.3
1—2 y	3	5.0
3—5 y	5	8.3
>5 y	17	28.3
Stillbirth at fistula-related birth	41	68.3
Any children alive	39	65.0

The results from our models evaluating the relationship between changing patient characteristics over time after repair and physical and psychosocial health with reintegration trajectory over a 12-month study revealed similarly significant results across participant characteristics (Table S2). Reintegration trajectory was significantly influenced by the severity of urinary incontinence and other fistula-related physical symptoms, general health, depressive symptoms, self-esteem, enacted stigma, and physical QoL.

# Discussion **Principal findings**

Overall, reintegration scores increased over the year after surgical repair of the female genital fistula. However, the varying influence of patient characteristics at the time of fistula surgery suggests possible avenues for intervention. Baseline measures, which had the most significant effect on women's reintegration trajectory, included age at fistula repair, psychosocial health (including stigma), depression, perceived social support, and self-esteem. Moreover, physical health predictors, including general pain, any urinary incontinence, pain with urination, and vaginal pain and discharge greatly influenced reintegration over time. Individual and subdomain variations warrant further

investigation to inform targeted strategies to improve reintegration overall.

# Results in the context of what is

Women living with unrepaired female genital fistula experience high rates of psychosocial stressors because of stigmatizing behaviors driven by incontinence and the risk of secondary infertility, which often significantly decrease after a successful repair.<sup>38–40</sup> Social stigma further contributes to an inability to engage in work and earn income, limiting women's socioeconomic capital and increasing the risk that they will be perceived as a burden in their family or community. 41,42 In our study, participants who reported a higher level of perceived social support overall and from their partners, along with participants reporting a higher degree of self-esteem, had higher reintegration scores at baseline and signifisteep reintegration trajectories over time. This finding suggests that these factors mitigated the overall effect of the fistula and reintegration experience for these women and aligns with recent literature, suggesting that women lean heavily on the social support of others to meet both their fistula-related physical and psychosocial needs. 43 In contrast, the steeper postrepair reintegration trajectories seen in

women with a higher baseline of psychosocial morbidity underscore the urgency and value of timely repair. Similarly timed findings from Khisa et al44 demonstrated that social support and acceptance, marital stability, continence, and economic independence were key drivers of successful reintegration for women after repair.

The crucial role of psychosocial factors in reintegration over time suggests that routinely screening for these factors at the time of surgical repair and using them to inform targeted patient followup strategies could inform further assessment and provision of needed support to improve women's experiences. For example, the presence of persistent depressive symptoms at baseline, or slow improvement seen by a low slope trajectory, may indicate the need to refer to psychological counseling or other mental health services after repair. Understanding and incorporating indicators of reintegration are crucial given the large proportion of women who continue to experience urinary incontinence after surgical repair. In an earlier study, Khisa et al<sup>45</sup> described the importance of integrating fistula knowledge and care across the health system and prioritizing long-term follow-up to track reintegration after repair to better understand residual symptoms and long-lasting negative effects on reintegration. The need for a holistic approach to fistula care that addresses short- and long-term physical, psychosocial, and economic needs concurrently was confirmed by a 2020 scoping review.46

Similar to recent research, 18-21 we found that overall perceived physical QoL affected reintegration over time. This is consistent with repeated reports that QoL significantly improves for women after repair, although subdomains of the greatest effect seem to vary region. 18,20,21,47 Furthermore, patients reporting genitourinary symptoms, either pain with urination or vagidischarge, experienced reintegration scores over time after repair, and these symptoms contributed to chronic morbidity in women, underscoring previous findings that persistent Original Research ajog.o

<i>V</i> ariable	n	%
Physical health status		
Severity of urinary incontinence <sup>a,b</sup>		18.7 (3.4)
Other fistula-related physical symptoms	49	81.7
General pain	22	36.7
Pain with urination	18	30.0
Vaginal pain	27	45.0
Vaginal discharge	19	31.7
Weakness	20	33.3
Difficulty walking	20	33.3
Skin irritation	17	28.3
General health		
Poor	49	81.7
Fair	11	18.3
Currently sexually active	11	18.3
sychological health status		
epressive symptoms		
epressive symptoms of ≥1.75°	51	85.0
elf-esteem <sup>a,d</sup>		13.3 (4.6)
erceived social support <sup>e</sup>		
Overall <sup>a</sup>		51.1 (16.6)
Partner <sup>a</sup>		70.8 (19.4)
Family <sup>a</sup>		54.2 (25.2)
Friends <sup>a</sup>		28.7 (29.2)
istula-related stigma		
Enacted stigma <sup>a,f</sup>		6.3 (9.4)
Internalized stigma <sup>a,f</sup>		20.3 (10.8)
rauma screen positive	10	16.7
uality of life		
Overall <sup>a,g</sup>		17.5 (10.7)
Physical <sup>a,g</sup>		47.9 (24.2)
Environment <sup>a,g</sup>		41.0 (15.1)
Social relationships <sup>a,g</sup>		38.2 (22.2)
Psychological <sup>a,d,g</sup>		24.4 (15.1)

ICIQ-SF, International Consultation on Incontinence Questionnaire Short Form; WHOQOL-BREF, World Health Organization Quality of Life Brief Version.

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incontinence after repair is particularly burdensome.<sup>48</sup> We found no statistically significant difference in reintegration score over time by sexual activity, despite sexual health and fertility being identified as an important aspect of relationships in Uganda.<sup>49–51</sup> More recent findings confirm that postrepair sexual experiences and activity vary widely and are meaningfully influenced by women's individual marital and social roles<sup>52</sup>; it is possible that the nuance in this area within the current analysis was captured within our assessment of partner social support, but it remains a question for future research.

# **Clinical implications**

Globally, reintegration interventions have been implemented by various nonprofit organizations, government health organizations, or individual survivor advocacy groups and have emphasized skills' training (eg, soap making, tailoring, or animal husbandry), counseling (eg, individual or 2-week cognitive behavioral therapy), physical therapy, additional structured social support (eg, living with a host family while recovering from surgery). 46,53-55 Incorporating clinical measures of psychosocial health immediately after surgical repair and repeating throughout reintegration interventions may identify women at risk of persistent morbidity and highlight opportunities for targeted support. Furthermore, the significance of stigma on reintegration trajectories indicates a need for the expansion of tailored mental health services and resources surrounding fistula. Stigma continues to limit access to treatment and is experienced by women throughout the reintegration period, affecting social and economic opportunities for women and their families.<sup>5,56</sup> Anticipating and addressing the psychological effects of stigma and trauma clinically may equip women to better navigate these hardships and improve their reintegration.

#### **Research implications**

Our findings demonstrate the importance of continued investigation of specific factors that contribute to mental, social, and physical health issues that arise before surgical repair of the fistula and the importance of preventing fistula from occurring. Because research continues to demonstrate that postrepair challenges can negatively affect mental health and ultimately a woman's

<sup>&</sup>lt;sup>a</sup> Mean (standard deviation); <sup>b</sup> ICIQ-SF range of 0 to 21; <sup>c</sup> Hopkins Symptom Checklist score of >1.75; <sup>d</sup> Rosenberg Self-Esteem Scale range of 0 to 30; <sup>e</sup> Multidimensional scale of perceived social support range of 0 to 100; <sup>f</sup> Enacted and internalized stigma range of 0 to 36; <sup>g</sup> WHOQOL-BREF range of 0 to 100.

**TABLE 3** Influence of sociodemographic and obstetrical characteristics and physical and psychosocial health status at the time of fistula surgery on 12-month reintegration trajectory (N=60)

Model	Tin β	ne parameter <sup>a</sup> (95% CI)	Group : β	× time parameter <sup>b</sup> (95% CI)	<i>P</i> value
Sociodemographic characteristics					
Age	3.82	(2.11-5.54)	0.09	(0.08-0.11)	<.001
Married or living together	3.43	(2.62-4.22)	-0.49	(-1.62 to 0.64)	.398
Lives alone	3.25	(2.61-3.89)	-0.31	(-1.65 to 1.04)	.656
Completed primary education or more	3.32	(2.56-4.07)	-0.29	(-1.42 to 0.83)	.609
Work outside of home	3.38	(2.63-4.12)	-0.45	(-1.58 to 0.68)	.435
Primary source of financial support					.877
Self	2.89	(1.95-3.83)	0.58	(-0.82 to 1.98)	
Husband or partner	Ref	_	Ref	_	
Relatives	_	_	0.34	(-1.00 to 1.68)	
Enough money to meet needs	3.17	(2.55-3.79)	0.05	(-1.42 to 1.52)	.947
Obstetrical history					
Duration living with fistula	2.94	(2.00-3.89)	_	_	.478
<1 mo	_	_	1.51	(-0.26 to 3.27)	
1-3 mo	_	_	Ref	_	
3-12 mo	_	_	0.76	(-1.07 to 2.59)	
1-2 y	_	_	0.49	(-2.62 to 3.60)	
3-5 y	_	_	0.67	(-2.94 to 1.59)	
>5 y	_	_	0.12	(-1.51 to 1.27)	
Infant died at fistula-related birth	3.16	(2.48-3.85)	0.07	(-1.16 to 1.31)	.919
Any children alive today	2.48	(1.54-3.42)	1.08	(-0.08 to 2.23)	.072
Physical health status					
Urinary incontinence	4.70	(0.30 9.10)	-1.54	(-5.97 to 2.90)	.497
Other fistula-related physical symptoms					
General pain	3.31	(2.58-4.06)	-0.34	(-1.51 to 0.82)	.569
Pain with urination	2.92	(2.25-3.61)	0.83	(-0.39 to 2.05)	.185
Vaginal pain	3.03	(2.25-3.82)	0.33	(-0.82 to 1.48)	.572
Vaginal discharge	3.11	(2.42-3.80)	0.26	(-0.99 to 1.51)	.684
Weakness	3.10	(2.40-3.81)	0.26	(-0.97 to 1.49)	.675
Difficulty walking	3.21	(2.50-3.92)	-0.07	(-1.28 to 1.15)	.918
Skin irritation	3.13	(2.46-3.81)	0.17	(-1.15 to 1.48)	.802
General health poor	3.18	(1.75-4.60)	0.01	(-1.55 to 1.57)	.988
Currently sexually active	3.20	(2.56-3.84)	-0.08	(-1.56 to 1.40)	.918
Psychological health status					
Depressive symptoms of >1.75	2.27	(0.80-3.74)	1.08	(-0.51 to 2.68)	.186
Depressive symptoms	1.03	(-1.14 to 3.21)	0.89	(0.02-1.75)	.047
Self-esteem	4.70	(2.92-6.47)	-0.11	(-0.24 to 0.01)	<.001
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TABLE 3
Influence of sociodemographic and obstetrical characteristics and physical and psychosocial health status at the time of fistula surgery on 12-month reintegration trajectory (N=60) (continued)

Model	Time parameter <sup>a</sup>		Group × time parameter <sup>b</sup>		
	β	(95% CI)	β	(95% CI)	<i>P</i> value <sup>c</sup>
Perceived social support					
Overall	5.86	(3.31-8.40)	-0.06	(-0.12 to -0.01)	.037
Partner	7.02	(4.36-9.67)	-0.21	(-0.35 to -0.07)	.005
Family	4.62	(2.81-6.43)	-0.10	(-0.21 to 0.02)	.104
Friends	3.25	(2.12-4.38)	-0.01	(-0.14 to 0.12)	.898
Fistula-related stigma					
Enacted stigma	2.99	(2.29-3.69)	0.03	(-0.03 to 0.10)	.350
Internalized stigma	2.10	(0.85-3.35)	0.05	(-0.00 to 0.11)	.058
Trauma screen positive	3.19	(2.56-3.83)	-0.05	(-1.59 to 1.50)	.954
Quality of life					
Overall	3.94	(2.83-5.06)	-0.04	(-0.10 to 0.01)	.125
Physical	3.93	(2.65-5.21)	-0.02	(-0.04 to 0.01)	.205
Environment	4.53	(2.88-6.18)	-0.03	(-0.07 to 0.01)	.093
Social relationships	3.97	(2.74-5.19)	-0.02	(-0.05 to 0.01)	.17
Psychological	3.82	(2.70-4.94)	-0.03	(-0.06 to 0.01)	.194
Individual module were estimated for each observatoriatio					

Individual models were estimated for each characteristic.

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perceived ability to reintegrate, further understanding of the broader scope of reintegration scores is needed. Specifically, additional research is needed on how continued urinary incontinence affects women's mental health after repair. A recent study concluded that persistent physical morbidities after repair correlate with worsened psychosocial health outcomes. 18 In addition, research should seek to understand whether and how internalized stigma, perceived external stigma, or other factors that are missing from our analysis affect mental health, especially given recent literature on the negative influence of stigma on QoL, overall recovery, and reintegration among patients with a female genital fistula. 39,56,57 Related, research is needed to understand the levels and types of social support necessary to mitigate symptoms before and after surgical repair.

Given our findings on the significant effect of psychosocial health on

reintegration trajectory, efforts to assess the role of psychiatrists, psychologists, social workers, and other behavioral health professionals as part of the fistula repair surgical care team are needed. The significance of baseline measures of mental health and well-being suggests that mental health resources across the fistula care continuum would be beneficial. Given the study context, creative solutions to overcoming the limited availability of mental health providers should also be explored. Mental healthcare remains extremely limited in Uganda, with only 1.13 mental health providers per 100,000 population, limited access to trained professionals in primary care or other community settings, few facilities providing specialized care, and limited funding. 58,59 Successful reforms, including the continued decentralization of mental health services along with the training and mobilization of community-based counselors toward reducing the overreliance on

exclusively hospital-based care, may contribute to reversing this care gap. 58

#### **Strengths and limitations**

Our study robustly measured the concept of reintegration using a validated instrument and included 12 months of postsurgical follow-up with a high retention rate. In addition, we incorporated both physical and psychosocial factors in our models to provide a comprehensive evaluation of the reintegration experience for women with fistula. However, limitations to this study include a lower rate of stillbirths at fistula occurrence within our study (68.3%) compared with a metaanalysis of studies from 1990 to 2015 (90.1%), which could underestimate the relationship between psychosocial measures and reintegration trajectory.3 We employed a validated instrument for quantifying and comparing postrepair reintegration among women: however, conclusive

CI, confidence interval.

<sup>&</sup>lt;sup>a</sup> Time parameter interpretation: average per-month change in reintegration score across follow-up for the reference group; <sup>b</sup> Group × time parameter interpretation: differential in average per-month change in reintegration score across follow-up for the exposure group as compared to the reference group; <sup>c</sup> P value for the likelihood ratio test comparing additive models vs interactive models. Participant response across time: baseline (n=60), 3 months (n=59), 6 months (n=55), 9 months (n=55), and 12 months (n=58).

standards for what constitutes "successful reintegration" have not been established. Although this somewhat limits the comparability and generalizability of our findings, this study may inform a broader interpretation of reintegration score meaning. Further investigation is needed to understand the specific factors associated with persistently lower reintegration scores. In addition, the relatively small sample size of the study significantly limits external validity and suggests that further exploration with larger cohorts is needed.

#### **Conclusions**

Although various factors meaningfully affect women's reintegration after surgical repair of a female genital fistula, psychosocial factors, including depression, trauma, perceived social support, and stigma, are persistent and significant. Our study contributes to the growing body of research that suggests that programmatic and policy approaches should aim to provide short- and longterm holistic care toward improving reintegration trajectories. Both clinical and research recommendations are needed to reduce the risk of adverse outcomes, and interventions should be dynamic and flexible in design, recognizing the unique and varied experiences of women across the fistula care continuum.

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#### Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.xagr.2023.100261.

## REFERENCES

- 1. Arrowsmith S, Hamlin EC, Wall LL. Obstructed labor injury complex: obstetric fistula formation and the multifaceted morbidity of maternal birth trauma in the developing world. Obstet Gynecol Surv 1996;51:568-74.
- 2. United Nations Population Fund. Obstetric fistula & other forms of female genital fistula: guiding principles for clinical management and

- programme development. United Nations Population Fund; 2021. Available at: https://www.unfpa. org/publications/obstetric-fistula-other-formsfemale-genital-fistula, Accessed January 2, 2023.
- 3. Ahmed S, Anastasi E, Laski L. Double burden of tragedy: stillbirth and obstetric fistula. Lancet Glob Health 2016;4:e80-2.
- 4. Kazaura MR, Kamazima RS, Mangi EJ. Perceived causes of obstetric fistulae from rural southern Tanzania. Afr Health Sci 2011;11: 377-82
- 5. Baker Z, Bellows B, Bach R, Warren C. Barriers to obstetric fistula treatment in low-income countries: a systematic review. Trop Med Int Health 2017;22:938-59.
- 6. Keya KT, Sripad P, Nwala E, Warren CE. Poverty is the big thing": exploring financial, transportation, and opportunity costs associated with fistula management and repair in Nigeria and Uganda. Int J Equity Health 2018:17:70.
- 7. Gebremedhin S, Asefa A. Treatment-seeking for vaginal fistula in sub-Saharan Africa. PLoS One 2019;14:e0216763.
- 8. Ruder B, Cheyney M, Emasu AA. Too long to wait: obstetric fistula and the sociopolitical dynamics of the fourth delay in Soroti. Uganda. Qual Health Res 2018;28:721-32.
- 9. Intensifying efforts to end obstetric fistula within a decade: report of the secretary-general (A/77/229). United Nations Population Fund; 2022. Available at: https://www.unfpa.org/ resources/intensifying-efforts-end-obstetric-fistula-within-decade-report-secretary-generala77229. Accessed April 20, 2023.
- 10. Global fistula map. 2020. Available at: https://www.globalfistulahub.org/. Accessed August 26, 2020.
- 11. Loposso M, Hakim L, Ndundu J, Lufuma S, Punga A, De Ridder D. Predictors of recurrence and successful treatment following obstetric fistula surgery. Urology 2016;97:80-
- 12. Slinger G, Trautvetter L, Browning A, Rane A. Out of the shadows and 6000 reasons to celebrate: an update from FIGO's fistula surgery training initiative. Int J Gynaecol Obstet 2018;141:280-3.
- 13. Global obstetric fistula hub. Available at: https://www.globalfistulahub.org/. Accessed April 20, 2023.
- 14. Pope R, Beddow M. A review of surgical procedures to repair obstetric fistula. Int J Gynaecol Obstet 2020;148(Suppl1):22-6.
- 15. Delamou A, Delvaux T, Beavogui AH, et al. Factors associated with the failure of obstetric fistula repair in Guinea: implications for practice. Reprod Health 2016;13:135.
- **16.** Browning A. Risk factors for developing residual urinary incontinence after obstetric fistula repair. BJOG 2006;113:482-5.
- 17. Delamou A, Delvaux T, El Ayadi AM, et al. Fistula recurrence, pregnancy, and childbirth following successful closure of female genital fistula in Guinea: a longitudinal study. Lancet Glob Health 2017;5:e1152-60.

- 18. El Ayadi AM, Barageine J, Korn A, et al. Trajectories of women's physical and psychosocial health following obstetric fistula repair in Uganda: a longitudinal study. Trop Med Int Health 2019;24:53-64.
- 19. Donnelly K, Oliveras E, Tilahun Y, Belachew M, Asnake M. Quality of life of Ethiopian women after fistula repair: implications on rehabilitation and social reintegration policy and programming. Cult Health Sex 2015;17:150-
- 20. Umoiyoho AJ, Inyang-Etoh EC, Abah GM, Abasiattai AM, Akaiso OE. Quality of life following successful repair of vesicovaginal fistula in Nigeria. Rural Remote Health 2011;11:1734.
- 21. Singh V, Jhanwar A, Mehrotra S, Paul S, Sinha RJ. A comparison of quality of life before and after successful repair of genitourinary fistula: is there improvement across all the domains of WHOQOL-BREF questionnaire? Afr J Urol 2015;21:230-4.
- 22. Byamugisha J, El Ayadi A, Obore S, et al. Beyond repair - family and community reintegration after obstetric fistula surgery: study protocol. Reprod Health 2015;12:115.
- 23. Klovning A, Avery K, Sandvik H, Hunskaar S. Comparison of two questionnaires for assessing the severity of urinary incontinence: the ICIQ-UI SF versus the incontinence severity index. Neurourol Urodyn 2009;28:411-5.
- 24. Lorig K, Stewart A, Ritter P, Gonzalez V, Laurent D, Lynch J. Outcome measures for health education and other health care interventions.Sage; 1996. Available at: https://us.sagepub.com/en-us/nam/outcome-measures-forhealth-education-and-other-health-care-interventions/book5623. Accessed April 20, 2023.
- 25. Bolton P, Wilk CM, Ndogoni L. Assessment of depression prevalence in rural Uganda using symptom and function criteria. Soc Psychiatry Psychiatr Epidemiol 2004;39:442-7.
- 26. Derogatis LR, Lipman RS, Rickels K, Uhlenhuth EH, Covi L. The Hopkins Symptom Checklist (HSCL): a self-report symptom inventory. Behav Sci 1974;19:1-15.
- 27. Martin F, Russell S, Seeley J. The WHO-QOL BREF guestionnaire in Luganda: validation with a sample including people living with HIV in Uganda. Norwich, England: School of International Development, University of East Anglia; 2013.
- 28. Webster J, Nicholas C, Velacott C, Cridland N, Fawcett L. Validation of the WHOQOL-BREF among women following childbirth. Aust NZJ Obstet Gynaecol 2010;50:132-7.
- 29. Rosenberg M. Society and the adolescent self-image. 2015. Available at: https://press. princeton.edu/books/hardcover/97806916494 43/society-and-the-adolescent-self-image. Accessed April 20, 2023.
- **30.** El Ayadi AM, Barageine JK, Neilands TB, et al. Validation of an adapted instrument to measure female genital fistula-related stigma. Glob Public Health 2021;16:1057-67.
- 31. Prins A, Bovin MJ, Kimerling R, et al. The primary Care PTSD Screen for DSM-5 (PC-

- PTSD-5).US Department of Veterans Affairs; 2015. Available at: https://www.ptsd.va.gov/ professional/assessment/screens/pc-ptsd.asp. Accessed January 6, 2014.
- 32. Zimet GD, Powell SS, Farley GK, Werkman S, Berkoff KA. Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. J Pers Assess 1990;55:610-7.
- 33. Nakigudde J, Musisi S, Ehnvall A, Airaksinen E, Agren H. Adaptation of the multidimensional scale of perceived social support in a Ugandan setting. Afr Health Sci 2009;9 (Suppl1):S35-41.
- 34. Bolton P, Bass J, Neugebauer R, et al. Group interpersonal psychotherapy for depression in rural Uganda: a randomized controlled trial. JAMA 2003;289:3117-24.
- 35. Kaida A, Matthews LT, Ashaba S, et al. Depression during pregnancy and the postpartum among HIV-infected women on antiretroviral therapy in Uganda. J Acquir Immune Defic Syndr 2014;67(Suppl4):S179-87.
- **36.** Psaros C, Haberer JE, Boum 2nd Y, et al. The factor structure and presentation of depression among HIV-positive adults in Uganda. AIDS Behav 2015;19:27-33.
- 37. Ashaba S, Kakuhikire B, Vořechovská D, et al. Reliability, validity, and factor structure of the Hopkins Symptom Checklist-25: population-based study of persons living with HIV in Rural Uganda. AIDS Behav 2018;22:1467-74.
- 38. Belayihun B, Mavhandu-Mudzusi AH. Effects of surgical repair of obstetric fistula on severity of depression and anxiety in Ethiopia. BMC Psychiatry 2019;19:58.
- **39.** Changole J, Thorsen VC, Kafulafula U. I am a person but I am not a person": experiences of women living with obstetric fistula in the central region of Malawi. BMC Pregnancy Childbirth 2017:17:433.
- 40. Yeakey MP, Chipeta E, Taulo F, Tsui AO. The lived experience of Malawian women with obstetric fistula. Cult Health Sex 2009;11:499-513.

- 41. Ahmed S, Holtz SA. Social and economic consequences of obstetric fistula: life changed forever? Int J Gynaecol Obstet 2007;99 (Suppl1):S10-5.
- 42. Jarvis K, Richter S, Vallianatos H. Exploring the needs and challenges of women reintegrating after obstetric fistula repair in northern Ghana. Midwifery 2017;50:55-61.
- 43. Hotchkiss E, Nalubwama H, Miller S, et al. Social support among women with genital fistula in Uganda. Cult Health Sex 2022;0:1-16.
- 44. Khisa AM, Nyamongo IK, Omoni GM, Spitzer RF. A grounded theory of regaining normalcy and reintegration of women with obstetric fistula in Kenya. Reprod Health 2019:16:29.
- 45. Khisa W, Wakasiaka S, McGowan L, Campbell M, Lavender T. Understanding the lived experience of women before and after fistula repair: a qualitative study in Kenya. BJOG 2017;124:503-10.
- 46. El Ayadi AM, Painter CE, Delamou A, et al. Rehabilitation and reintegration programming adjunct to female genital fistula surgery: a systematic scoping review. Int J Gynaecol Obstet 2020;148(Suppl1):42-58.
- 47. El-Gazzaz G, Hull TL, Mignanelli E, Hammel J, Gurland B, Zutshi M. Obstetric and cryptoglandular rectovaginal fistulas: long-term surgical outcome; quality of life; and sexual function. J Gastrointest Surg 2010;14:1758-63.
- 48. Nardos R, Phoutrides EK, Jacobson L, et al. Characteristics of persistent urinary incontinence after successful fistula closure in Ethiopian women. Int Urogynecol J 2020;31:2277-83.
- 49. Anzaku SA, Lengmang SJ, Mikah S, Shephard SN, Edem BE. Sexual activity among Nigerian women following successful obstetric fistula repair. Int J Gynaecol Obstet 2017;137: 67-71.
- 50. Pope R, Ganesh P, Chalamanda C, Nundwe W, Wilkinson J. Sexual function before and after vesicovaginal fistula repair. J Sex Med 2018;15:1125-32.

- 51. Emasu A, Ruder B, Wall LL, Matovu A, Alia G, Barageine JK. Reintegration needs of young women following genitourinary fistula surgery in Uganda. Int Urogynecol J 2019;30:1101-10.
- 52. El Ayadi AM, Nalubwama H, Miller S, et al. Women's sexual activity and experiences following female genital fistula surgery. J Sex Med 2023;20:633-44.
- 53. Khisa AM. An exploratory study of reintegraof following women obstetric fistula surgery in West Pokot. SAGE Open; 2015. p. 1-8. Available at: https://journals.sagepub. com/doi/10.1177/2158244015621112.
- 54. Shallon A, Ojengbede OA, Mugisha JF, Odukogbe ATA. Social reintegration and rehabilitation of obstetric fistula patients before and after repair in Sub-Saharan Africa: a systematic review. Nepal J Obstet Gynaecol 2018;13:5-
- 55. Oluwasola T, Bello O. Clinical and psychosocial outcomes of obstetrics fistulae in sub-Saharan Africa: a review of literature. Semantic Scholar; 2020. Available at: https://www. semanticscholar.org/paper/Clinical-and-Psychosocial-Outcomes-of-Obstetrics-in-Oluwasola-Bello/c70ba3f37acd515cbf0038b95b 707158d7c396db. Accessed April 20, 2023.
- 56. El Ayadi AM, Barageine JK, Miller S, et al. Women's experiences of fistula-related stigma in Uganda: a conceptual framework to inform stigma-reduction interventions. Cult Health Sex 2020:22:352-67.
- 57. Bangser M. Obstetric fistula and stigma. Lancet 2006;367:535-6.
- 58. Kigozi F, Ssebunnya J, Kizza D, Cooper S, Ndyanabangi S. Mental Health and Poverty Project. An overview of Uganda's mental health care system: results from an assessment using the world health organization's assessment instrument for mental health systems (WHO-AIMS). Int J Ment Health Syst 2010;4:1.
- 59. Kaggwa MM, Harms S, Mamun MA. Mental health care in Uganda. Lancet Psychiatry 2022;9:766-7.