Title

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Journal

The Journal of Sexual Medicine, 20(5)

ISSN

1743-6095

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Publication Date

2023-04-27

DOI

10.1093/jsxmed/qdad010

Peer reviewed

The Journal of Sexual Medicine, 2023, **20**, 633–644
https://doi.org/10.1093/jsxmed/qdad010
Advance access publication date 9 March 2023
Original Research

Women's sexual activity and experiences following female genital fistula surgery

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Abstract

Background: Surgical repair has been found to have a transformative impact on the lives of women affected by female genital fistula, however, various physical, social, and economic challenges may persist post-repair preventing complete reengagement in relationships and communities. Nuanced investigation of these experiences is needed to inform programming that aligns with women's reintegration needs.
Aim: We investigated sexual activity resumption, experiences, and concerns of Ugandan women during the year following genital fistula repair surgery.
Methods: Women were recruited from Mulago Hospital between December 2014 and June 2015. We collected data at baseline and four times post-surgery about socio-demographic characteristics and physical/psychosocial status; and assessed sexual interest and satisfaction twice. We performed in-depth interviews with a subset of participants. We analyzed quantitative findings descriptively, coded and analyzed qualitative data thematically, and integrated mixed-methods findings in interpretation.
Outcomes: Sexual activity, pain with sex, sexual interest/disinterest, and sexual satisfaction/dissatisfaction were measured quantitatively whereas sexual readiness, fears, and challenges following surgical repair of female genital fistula were assessed qualitatively.
Results: Among the 60 participants, 18% were sexually active at baseline, which decreased to 7% post-surgery, and increased to 55% at one year after repair. Dyspareunia was reported by 27% at baseline and 10% at one year, few described leakage during sex or vaginal dryness. Qualitative findings showed wide variance of sexual experiences. Some reported sexual readiness quickly after surgery and some were not ready after one year. For all, fears included fistula recurrence and unwanted pregnancy.
Clinical Implications: In addition to physical repair, ongoing psychosocial support is needed for comprehensive reintegration and the restoration of desired sexuality.
Strengths & Limitations: Our mixed-methods findings add nuance and depth to the understanding of women's postoperative sexual experiences; however, our study would have been strengthened by the inclusion of clinical data and a more detailed sexual dysfunction assessment.
Conclusion: Post-repair sexual experiences vary widely and intersect meaningfully with marital and social roles following fistula and repair, necessitating attention to physical and psychosocial domains of sexuality among this population.

Keywords: female sexual dysfunction; sexuality; pelvic floor dysfunction; female genital fistula; Uganda; mixed methods.

Introduction

Female genital fistula remains a major public health problem with as many as 2 million women estimated to be living with the condition and 50 000 to 100 000 annual incident cases globally.[1,2] Largely caused by prolonged obstructed labor, fistula presents as uncontrollable urinary or fecal incontinence, and women with fistula experience significant physical, psychological, and social consequences.[3,4] Surgical fistula repair is largely successful, with up to 90% of fistula repairs resulting in fistula closure and incontinence resolution.[5-8] Prior research confirms the transformative impact of fistula surgery on the lives of affected women; however, it also demonstrates that various physical, social, and economic challenges may persist postrepair, resulting in some difficulty reengaging back into relationships and communities.[9-15] These findings suggest the need for detailed assessment of the different components embedded within the recovery, rehabilitation, and reintegration process to facilitate development of services tailored to women's needs.[16]

Fulfilment of social roles was cited as the most important factor for women's rehabilitation from fistula within a systematic review of qualitative studies from sub-Saharan Africa.[16] This includes shifting relationships with husbands or partners and resuming sexual activity. While no consistent guideline exists regarding the minimum amount of time that women should wait before resuming sexual activity following

Received: July 7, 2022. **Revised:** December 23, 2022. **Accepted:** January 9, 2023

fistula repair, providers recommend that women wait until fully recovered from surgery to reduce risk of fistula repair breakdown.[17] For example, the World Health Organization and the EngenderHealth FistulaCare and FistulaCarePlus programs recommend 3 to 6 months of abstinence from sexual intercourse following surgical repair.[1,17] Other literature on general patient education following pelvic reconstructive surgery suggests that a case-by-case approach that trusts women's instincts and personal motivations may be appropriate.[18,19] However, clinical evidence to better inform this guideline is needed. The complex intersection of varied physical, psychological, and social factors associated with fistula and its consequences may complicate women's readiness to resume sexual activity and their experiences if and when they do. The limited literature on sexual experiences following fistula repair suggests that some women experience sexual dysfunction following fistula repair, such as dyspareunia, loss of libido, and fear of intercourse, all of which interfere with resuming roles and relationships.[10,15,20-22] Yet, women who have undergone fistula repair may have unmet fertility desires and hope to have children after fistula repair,[11,12,14] particularly in contexts where fertility norms are high and childless women may face infertility-related stigma.[23]

Improving our understanding of women's experiences of resuming sexual activity after genital fistula repair may have important implications for guiding programming to meet women's reintegration needs through supporting a return to intimate relationships and reproduction. We therefore sought to understand Ugandan women's resumption of sexual activity, their sexual experiences, and their concerns during the year following fistula surgery. We quantitatively explored partnerships, sexual activity, sexual interest and pleasure, pain during sex, and satisfaction with sex life. We qualitatively inquired about interest, readiness, and concerns related to sexual experiences postrepair.

Methods

Our analysis was situated within a sequential explanatory mixed methods study, a quantitative followed by a qualitative component, which sought to understand trajectories of recovery and reintegration following genital fistula surgery among women at Mulago Hospital in Kampala, Uganda.[9,24] Mulago Hospital is the national referral and teaching hospital for Makerere University College of Health Sciences. Fistula repair is provided by the urogynecology division as a routine surgical service and supplemented by annual fistula repair camps. Upon discharge, patients are provided with sexual and reproductive health instructions to delay penetrative sexual intercourse for at least 3 months and to deliver future children via cesarean section. Similar to other patient care plans, there is an array of observed patient behavior, ranging from nonadherence to strict adherence.

Quantitative component

We recruited a longitudinal cohort of 60 women at fistula surgery. Women were eligible for participation upon completion of initial examination and clearance for genital fistula surgery if they spoke Luganda or English, resided in a community with cellular telephone coverage, and were capable of providing informed consent. Participants were recruited from December 2014 to June 2015. Data were collected in person at hospitalization for fistula surgery and over the telephone at 3, 6, 9, and 12 months postsurgery. Measures included sociodemographic characteristics and assessment of physical and psychosocial status. At each data collection point, we assessed whether participants were in a relationship, if they were sexually active, and if they experienced any pain with sexual intercourse. We also captured participants' levels of satisfaction with their sex lives (5-point response scale ranging from *very satisfied* to *very dissatisfied*) and whether they had experienced any loss of sexual interest or sexual pleasure (4-item response scale ranging from *extremely* to *not at all*) at baseline and months 6 and 12.[25-27]

Qualitative component

We invited a selection of the longitudinal cohort for in-depth interview following the conclusion of the 12-month follow-up to qualitatively explore experiences of reintegration following fistula surgery. We purposively selected participants to ensure representation of a range of physical and psychosocial recovery experiences. Women were invited to participate via telephone call. In the interview, we sought to understand each woman's perspective and experiences with sexual intercourse after fistula surgery, including her level of interest and readiness, physical and psychological concerns, and decision-making processes.

We also asked women about their fertility desires and plans. Thirty women completed an interview with an experienced female Ugandan qualitative researcher with public health training and involvement in fistula research for 10 years (H.N.). Interviews were held in a private location and lasted 1 to 1.5 hours. The interviews were audio recorded with permission and then translated into English for analysis by an experienced translator. Field notes were made after interview. Transcripts were not returned to study participants for comment or correction after the interview. Thematic saturation was not evaluated for the focal topic of this study, although it was obtained for our primary analytic focus: reintegration.

Analysis

Univariate analyses were performed to describe (1) the sociodemographic characteristics of participants at baseline and (2) the distributions of the sexual experience variables for our full cohort across study follow-up. Using Stata (version 14; StataCorp), we calculated means and standard deviations for continuous variables and proportions for categorical variables. Transcripts from in-depth interviews were coded by 2 authors (H.N. and A.M.E.) using inductive and deductive codes within Atlas.ti 7 Windows software and analyzed to understand women's sexual behavior, experiences, and concerns following recovery from genital fistula surgery. Coding disagreements were resolved by discussion. Coded data were analyzed thematically to describe the different dimensions and commonalities of each theme and to assess for patterns and linkages between themes. Participant checking was not implemented to obtain feedback on the findings.

Ethical approval

The study protocol was approved by the Research and Ethics Committee (REF 2014-052; School of Medicine, College of Health Sciences, Makerere University), the Uganda National Council on Science and Technology (ADM 154/212/01), and the Committee on Human Research (IRB 12-09573 and 15-17467; Human Research Protection Program, University of California, San Francisco). All individuals eligible for the research underwent an informed consent process; those

Table 1. Characteristics of longitudinal cohort participants and nested qualitative participants at study enrollment.

	Longitudinal (n = 60)		Nested qualitative (n = 30)	
	No.	%	No.	%
Age, y[a]	28 (21-36)		32 (27-38)	
Marital history				
Ever married	48	80.0	26	86.7
Age at marriage, y[a]	18 (17-20)		18.5 (17-21)	
Marital status				
Married	7	12	4	13.3
Living together	22	37	11	37
Divorced/separated	16	27	11	37
Widowed	3	5	0	0
Single/never married	12	20	4	13
Participant household				
Participant lives with				
Alone	2	3.3	3	6.7
Husband	24	40.0	11	36.7
Young children only	11	28.3	6	20.0
Adult children only	4	6.7	3	10.0
Parents	8	13.3	2	6.7
Others	11	18.4	5	16.6
Socioeconomic status				
Educational attainment				
None	10	16.7	5	16.7
Some primary	24	40.0	10	33.3
Completed primary	17	28.3	9	30.0
Some secondary or more	9	15.0	6	20.0
Work outside of home	26	43.3	12	40.0
Primary source of financial support				
Self	17	28.3	10	33.3
Husband/partner	24	40.0	13	43.3
Relatives	19	31.7	7	23.3
Household assets				
Piped water	9	15.0	6	20.0
Radio	35	58.3	19	63.3
Flush toilet	4	6.7	3	10.0
Electricity	26	43.3	39	65.0
Mobile phone	39	65.0	17	56.7
Land	28	46.7	11	36.7
Sexually active at 12 mo postsurgery	29	50.0	16	53.3

[a]Median (IQR).

unable to provide signatures for informed consent provided thumbprint confirmation.

Results

Participant characteristics

The median age at enrollment was 28 (IQR, 21-36) and 31.5 (IQR, 27-38) years for the longitudinal cohort and nested qualitative cohort, respectively (Table 1). Approximately half of participants reported being married or living together (48% and 50%). Participants largely lived with their husbands (40% and 37%), young children only (28% and 20%), or other relatives/friends (18% and 17%). Half of participants had completed primary education (53% and 50%). Many households had radio (58% and 63%), electricity (43% and 65%), mobile phone (65% and 57%), and land ownership (47% and 37%). Approximately half of participants in both cohorts were currently sexually active at 12 months following surgery (50% and 53%). The majority indicated being counseled on safely resuming sexual activity during their fistula repair hospitalization (97%); however, detailed information was not often provided. Participants in the longitudinal cohort and nested qualitative cohort were generally similar in respect to sociodemographic characteristics, including marital status and sexual activity.

Sexual experiences and concerns across study follow-up

Three primary themes—readiness, fears, and challenges—emerged from quantitative and qualitative findings surrounding sexual experiences and concerns across the cohort (Figure 1). Intimate partnership status was consistent across study follow-up, with approximately half of participants partnered (Figure 2; Table S1). Nearly 20% reported being sexually active at the time of fistula surgery (18%); following surgery, sexual activity was indicated by 7% at 3 months and increased to 55% at 12 months. Among sexually active participants, pain during sexual intercourse was present for 27% at baseline and decreased to 10% by 12 months.

Satisfaction with sex life was low at baseline, prior to surgical repair, with most women being very dissatisfied (60%) or dissatisfied (22%) and only 18% being satisfied or very satisfied. Satisfaction with sex life improved substantially across the 12-month follow-up, with 43% of women being satisfied or very satisfied at 12 months. Loss of sexual interest or pleasure was reported by 82% of women at baseline, 60% of whom described this as extreme. Significantly fewer participants indicated loss of sexual interest or pleasure by 12 months postsurgery (36%). Overall, sexual dissatisfaction appeared to be stronger among women who had lived with

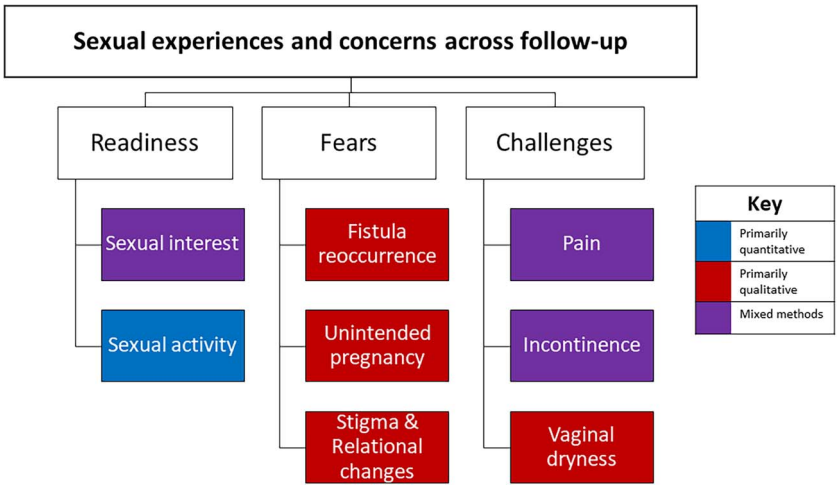

Figure 1. Thematic findings about postrepair sexual experiences and concern by type of data analyzed. Flowchart of thematic sexual experiences and concerns (readiness, fears, and challenges) of study participants following fistula repair. Findings are color coded by type of data analyzed: primarily quantitative, primarily qualitative, or mixed methods.

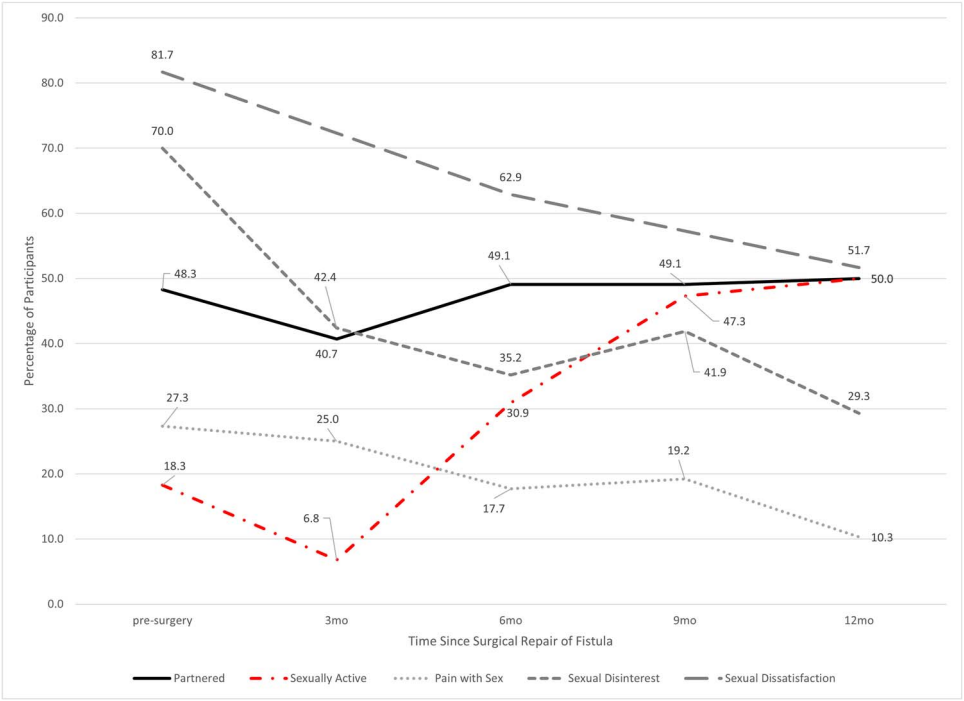

Figure 2. Partnership and sexual experiences following genital fistula repair, Uganda. The percentage of participants reporting various outcomes (partnered, sexually active, pain with sex, sexual disinterest, and sexual dissatisfaction) across time from presurgical repair of genital fistula to 12 months postrepair.

fistula longer: while one-quarter of women who had lived with fistula for ≤1 month reported dissatisfaction, more than three-quarters who had lived with it for ≥5 years reported dissatisfaction (Table 2).

Readiness for sexual intercourse

Our quantitative analysis revealed that 55% of our study participants had resumed sexual intercourse in the 12 months following fistula surgery, and this was similar in our nested qualitative sample (60%). A higher proportion of women who were sexually active with fistula prior to surgery reported resuming sexual intercourse by 12 months (73%) as compared with those who reported being sexually inactive prior to surgery (45%). During the in-depth interview, participants discussed their perceptions of readiness for resuming sexual intercourse following fistula repair, and narratives varied widely. While 1 participant was instructed to wait 6 weeks, the few others who specified a length of time were counseled to abstain from sex for 3 or 6 months following surgical repair. Most women shared that they were ready for sexual intercourse again about 4 to 6 months after surgical repair, although this ranged from as early as 1 month postsurgery for 1 participant to about 10 months, with some women sharing that they were still not feeling ready by the time of interview.

Consistent with our quantitative data, some women described a lack of interest in sex in our qualitative data. Several of these women linked their lack of desire directly to their fistula and repair experience, yet others explained that

Table 2. Sexual activity and experiences by fistula characteristics at 6 and 12 months following surgery.

	Sexually active				Pain with sex				Loss of sexual interest/pleasure				Dissatisfied/very dissatisfied with sex life			
	6 mo		12 mo		6 mo		12 mo		6 mo		12 mo		6 mo		12 mo	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Type of fistula																
VVF (n = 57)	18	33.3	28	50.9	3	16.7	3	10.7	18	33.3	16	29.1	32	60.4	29	52.7
RVF (n = 1)	0	0.0	1	100.0	0	0.0	0	0.0	2	100.0	0	0.0	1	100.0	0	0.0
VVF/RVF (n = 2)	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	50.0	1	100.0	1	50.0
Presumed fistula etiology	n = 34		n = 34		n = 12		n = 16		n = 34		n = 34		n = 34		n = 34	
Obstetric (n = 16)	6	40.0	8	53.3	0	0.0	1	12.5	4	26.7	4	26.7	10	66.7	7	46.7
Iatrogenic (n = 19)	6	31.6	8	42.1	1	16.7	1	12.5	7	36.8	7	36.8	11	57.9	13	68.4
No info (n = 25)	6	26.1	13	54.2	2	33.3	1	7.7	9	39.1	6	25.0	14	63.6	10	41.7
VVF classification	n = 49		n = 50		n = 15		n = 24		n = 49		n = 50		n = 48		n = 50	
I (n = 11)	3	27.3	7	63.6	1	33.3	1	14.3	4	36.4	3	27.3	7	63.6	2	18.2
IIAa (n = 18)	4	23.5	6	35.3	1	25.0	1	16.7	7	41.2	3	17.7	11	66.7	10	58.8
IIAb (n = 7)	2	33.3	2	33.3	0	0.0	0	0.0	2	33.3	1	16.7	4	66.7	3	50.0
IIBa (n = 3)	2	66.7	3	100.0	0	0.0	1	33.3	0	0.0	0	0.0	0	0.0	1	33.3
IIBb (n = 5)	1	25.0	2	40.0	0	0.0	0	0.0	3	75.0	5	100.0	4	100.0	5	100.0
III (n = 1)	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	100.0	1	100.0
No info (n = 7)	3	42.9	4	57.1	1	33.3	0	0.0	2	28.6	3	42.9	5	71.4	5	71.4
Scarring	n = 45		n = 44		n = 15		n = 22		n = 45		n = 44		n = 44		n = 44	
Yes (n = 15)	2	13.3	4	26.7	1	50.0	2	50.0	10	66.7	5	33.3	14	93.3	10	66.7
No (n = 19)	9	47.4	13	72.2	1	11.1	0	0.0	4	21.1	5	27.8	8	42.1	4	22.2
No info (n = 11)	4	36.4	5	45.5	1	25.0	1	20.0	2	18.2	4	36.4	7	70.0	9	81.8
Time lived with fistula	n = 57		n = 58		n = 18		n = 29		n = 57		n = 58		n = 56		n = 58	
<1 mo (n = 8)	4	57.1	6	75.0	0	0.0	0	0.0	0	0.0	1	12.5	3	42.9	2	25.0
1-3 mo (n = 20)	6	31.6	12	60.0	0	0.0	0	0.0	6	31.6	3	15.0	10	52.6	9	45.0
3-12 mo (n = 8)	1	12.5	3	42.9	0	0.0	1	33.3	4	50.0	2	28.6	6	75.0	2	28.6
1-2 y (n = 2)	2	100.0	2	100.0	0	0.0	0	0.0	0	0.0	1	50.0	1	50.0	1	50.0
3-5 y (n = 5)	1	25.0	1	25.0	1	100.0	0	0.0	2	50.0	2	50.0	4	100.0	3	75.0
>5 y (n = 17)	4	23.5	5	29.4	2	50.0	2	40.0	8	47.1	8	47.1	11	68.8	13	76.5
Sexually active presurgery																
Yes (n = 11)	5	45.5	8	72.7	1	20.0	2	25.0	5	45.4	3	27.3	7	63.6	7	63.6
No (n = 49)	13	28.3	21	44.7	2	15.4	1	4.8	15	32.6	14	29.8	28	62.2	23	48.9

Abbreviations: RVF, rectovaginal fistula; VVF, vesicovaginal fistula.

this sentiment was unrelated to their perceptions of physical recovery:

> I am not even interested [in sex] because whenever I think about my condition, I lose interest. . . . Even when I heal completely, it will take me a long time. . . . Since I have been sick, I would have to spend a long time, which has been instructed by the doctors, or I would just make a personal decision to give it a pause. (16 years old, single, not sexually active, left ureteric fistula, successful surgery, no current urinary incontinence)

> My sex appetite changed. . . . Right now my partner might want to have intercourse with me but I would feel uninterested. [Since I had the operation . . . my partner] has nothing much to say about it; he says, "We shall live with [this situation] since we have nothing to do now." (36 years old, living with partner, sexually active, vesicovaginal fistula [VVF] I, successful surgery, no current urinary incontinence)

> I was feeling fine just that I lost the appetite of being with a man [having sex]. I don't feel any pains, it is just that it affected me psychologically; I no longer want to be with a man. In fact, I feel like abusing [my partner]. He also [has noticed my lack of interest in sex], and he wonders how we will survive with it, he first forces me to be with him. . . . I have nothing that I fear but I just don't feel like being with him. I don't have any fears regarding what may happen because currently I am on family planning. (20 years old, living with partner, sexually active, VVF IIBa, successful surgery, no current urinary incontinence)

One woman described how she initially felt a lack of interest in sex following the surgery, yet desire had started returning more recently:

> The doctors had told me to take 6 months but those 6 months passed and we moved on until the year ended [*laughs*] minus trying it out. . . . In the beginning, I didn't have any "feelings" for some time but I regained them gradually. [It is about 2 months ago] is when I started regaining my feelings. . . . I am not saying that I get aroused every time, but it happens on about 2 days in a month. (39 years old, living with partner, sexually active, right ureteric fistula, successful surgery, no current urinary incontinence)

Fears around postsurgical sexual intercourse

Women described substantial fears related to resuming vaginal sex following repair for various reasons, primarily concerns regarding fistula recurrence or becoming pregnant when they expressly did not want to conceive; this was consistent across women who had resumed sexual intercourse and those who had not.

Fear of fistula recurrence

Most qualitative participants shared that they were hesitant to resume sexual intercourse following fistula repair out of fear that their fistula symptoms would return. Several women described how their fears of sexual intercourse resulting in fistula recurrence had been quite strong in the beginning but abated as they started having intercourse and did not experience any subsequent leaking of urine or other fistula-related symptoms. For some, the resolution of fear occurred with the first time that they had intercourse after surgery without consequence, but others remained fearful for several months before they began feeling comfortable:

> I was always so afraid of [intercourse]; I always thought, "What if he taps [my bladder!]" [*Laughs*] . . . I said to myself, "What if God had blessed me to heal the first time but then the man injures it!" However, when I did it the first time and didn't get a problem, I continued up to now. I don't have any problem. (26 years old, living with partner, sexually active, VVF IIAa, successful surgery, no current urinary incontinence)

> I was just scared that maybe it [fistula] could break again. [That fear] was there for a long time. Actually I was just scared that I would return to the same issue. So I would [have sex] but 50/50 . . . for like 2 good months. . . . I realized that what I was scared of wasn't happening. So I knew that it was okay to do it. (28 years old, divorced/separated, not sexually active, fistula type not available, successful surgery, urinary incontinence once per day)

Several women discussed how their fears of fistula recurrence heavily influenced their decisions to delay sexual intercourse beyond the counseling that many received instructing them to avoid intercourse for 3 months postsurgery. These women described the difficult decision-making process they went through before feeling comfortable with resuming, while others continued to abstain due to substantial fears and distrust that it will be safe:

> It took me many months [to have sex again after the repair]. . . . I think I resumed intercourse in November. We were repaired in January, so I think I was about to make a full year. Of course I had some fear but like you know that [sex] is a natural act, I convinced myself after all they had instructed us to take 3 months minus intercourse and yet I had even surpassed them. So when I got this man, . . . I did it but I had fear in my heart; I thought about how it would be! I was scared. . . . I was so scared. (28 years old, single, sexually active, VVF type I, successful surgery, no current urinary incontinence)

> I was afraid because I thought that it might happen again [leaking]. I was so scared. Well since I was scared and yet the person with whom I was wasn't, he said, "But the period is overdue; they instructed us to wait for 3 months but we are about hitting 6 months! So what's up?" then I was like "Arggh" and then we agreed. (24 years old, divorced/separated, sexually active, VVF IIAb/rectovaginal fistula, successful surgery, no current urinary or fecal incontinence)

> The decision to have intercourse again is not easy because I might have intercourse and things come out bad. . . . You never know what the devil plans; you can resume intercourse and you suddenly get loose again. (23 years old, divorced/separated, not sexually active, VVF type IIAa, successful surgery, no current urinary incontinence)

Fear of unintended pregnancy

Fears of unintended pregnancy featured strongly in women's narratives of decision making around resuming sexual intercourse. For many, these fears were intricately linked to how they perceived their levels of healing from fistula and

the anticipated impact that a pregnancy would have on their bodies. Others were motivated by the desire to avoid further surgery, including cesarean section, which would be required for a subsequent delivery.

> On that first time [having intercourse after repair] I feared because I thought that I would get pregnant and yet I was restrained from it. The second time I refused because I thought that I would get pregnant again. I could see that I had healed but I thought that I wasn't fully healed, so I was scared about it. . . . I chose to have that [contraceptive] injection because I was afraid that [my partner] would force himself on me, something which I didn't want. (23 years old, living with partner, not sexually active, fistula type not available, leaking at hospital discharge, no current urinary incontinence)

> Each time I think about [the fistula], I feel it is too much and then what worries me most is giving birth again. . . . I am so much worried about getting pregnant and it even scares me most because that would call for another operation because I never have normal births. And then I still have to go back for an operation of the bladder for another time. (40 years old, married, sexually active, VVF type IIBa, leaking at hospital discharge and anticipating a subsequent fistula surgery, current urinary incontinence 1 time per day)

Several of the qualitative participants were concerned about resuming sexual intercourse for fear of being at risk of acquiring HIV. One participant shared that she was concerned about her husband's promiscuity but uncertain of his HIV status, while another spoke more generally about the risk of contracting HIV. Another participant described overcoming her fear of HIV acquisition through going together with her partner for couples HIV testing prior to resuming intercourse.

Despite these narratives, some women shared that they had experienced no fears about resuming intercourse. One woman described receiving counseling from a local nonprofit organization advising that she should feel confident reinitiating intercourse when she wished. She summarized the encouragement that she received from a social reintegration workshop:

> There's no worry [about having intercourse again] because I feel my body is normal. . . . Even if I get pregnant, I know I will give birth by caesarean section. . . . I have nothing much to worry now and when we were in the workshop, they said that there's no effect it has on your body. It even helps one on recovering because the more you have intercourse, the faster your chances of healing quickly. (28 years old, divorced/separated, not sexually active, VVF type IIAb, leaking on hospital discharge, current urinary incontinence 1 time per day)

Of note, this patient's perspective deviates from the recommendations provided upon discharge, which instruct patients to abstain from penetrative sexual intercourse for at least 3 months.

Other reasons for abstaining from sexual intercourse

Among the women who had not resumed intercourse by 12 months postsurgery, other reasons for abstaining included current physical status and fear of stigmatization, concerns around relationships, and lack of partner interest due to trauma from the woman's fistula experience. One woman whose fistula had not completely been healed by surgery, despite having undergone multiple operations, shared that her persistent incontinence was the reason for her not wanting to have a sexual partner: "Because of urine; since I have urine, I might sleep with someone and he wakes up in a flood of urine. That's my only fear" (43 years old, divorced/separated, not sexually active, VVF type I, leaking at hospital discharge, current urinary incontinence all the time).

Another woman's surgical repair was so extensive that sexual intercourse had become completely impossible:

> There are times when [my husband] feels like having intercourse but we can't because I was sewn. . . . [We have not had intercourse since my repair]; there's no way how we could. . . . My husband [gave it a try] but it all failed. I am all sealed. There's only a small hole for easing myself. He tried like 2 times thinking that I was lying to him. (49 years old, married, not sexually active, VVF type IIAb, leaking at hospital discharge due to urethral incontinence, current urinary incontinence all the time)

Several women shared their general dissatisfaction with men based on their experience in prior relationships—with one indicating that she did not want to take on the additional work that a relationship would bring, given that she had little to benefit from a relationship, and with another sharing that she would rather be in no relationship than one with a poor-quality partner:

> I lost interest in men due to [my husband's] mistreatment. (39 years old, living together, sexually active, VVF type IIAa, not leaking at hospital discharge, no current urinary incontinence)

> Since my repair, I have not been with a man again. My heart doesn't like it. When I look at men, I always see that they have the same thinking. I have my children so why would I be looking for a man that will make me work even harder and when the time for harvesting reaches, he stops my child from eating yet we have a big expanse of land? Let the people that are still young remarry otherwise for my case, there's nothing else that I still need. (48 years old, divorced/separated, not sexually active, VVF type IIAa, not leaking on hospital discharge, no current urinary incontinence)

> These city men are tricky, all they need is just being with you and they leave you afterwards, I don't want people to play around with me. [The men in the village] are a total loss and I don't feel like anything. I can stay alone and I am okay with it. . . . I don't want to be moving around from one person to another, it is better when I know that I am having my man, he understands me and I understand him as well. So if I see that someone is just going to play around with me, then it is better I forego such. (30 years old, divorced/separated, not sexually active, VVF type IIBb, leaking on hospital discharge, current urinary incontinence once per week or less)

Finally, one woman described her husband's traumatic response to her surgery and his fears that she has not healed

as having resulted in his inability to have sex despite her own readiness:

> There is a huge change [to my relationship with my husband compared to before the repair] because he completely failed to regain his manpower. He says that whenever he is not with me he gets aroused but whenever he is with me, he loses all his manpower the moment he tries thinking about [sex]. He always tells me that his mind always relives the moment he saw me leaving the [surgical] theater. . . . By the time I came out, I was semiconscious, so he really saw a dead body. . . . He told me, "Honestly speaking, whenever we are about to have sex, I relive the moment I saw you immediately after leaving the theater room. My mind relives that image and then I really feel like you are still going through pain!" He also said, "I pray and fast for God to help me get rid of that image but I don't know." He had never had a sick person and neither did he know that a person can be in this condition and still recover and get fine, so that greatly affected him. (39 years old, living with partner, sexually active, right ureteric fistula, successful surgery, no current urinary incontinence)

Challenges with sexual intercourse

While many women resumed intercourse with few reported problems, some narrated a variety of negative experiences with intercourse due to issues that affected them physically: dyspareunia, leakage of urine during sexual intercourse, pain from vaginal stitches from the fistula repair, and vaginal dryness.

Dyspareunia was the most commonly reported difficulty that women had with resuming sexual intercourse. For most, the pain occurred only when they had first resumed sex after surgery; however, a few women described persisting pain:

> Yeah, [I felt pain on intercourse]. It went on for about 6 months, although I think it was worsened by the fear that I had. (19 years old, living together, sexually active, VVF type I, successful surgery, no current urinary incontinence)

> [The first time I had sex after surgery] it was hard because that place had narrowed. Whenever I sat in the basin I would not insert there my finger, so it was like it was about to get blocked. Actually it was painful. (28 years old, divorced/separated, not sexually active, No Info on fistula type, successful surgery, urinary incontinence once per week or less)

> When we had covered 3 months, there was a time when he told me, "Let's give it a try. Don't you know that your friends are already trying with their husbands!" but I told him, "That is out, unless you want me to leave and start sleeping at my mother's home!" then he gave up. . . . [The first time we resumed], I was worried about [leaking again]. . . . I didn't have any pain [then, but] the pain started after some time, it is so far 2 months. . . . Whenever we have sex I feel a lot of pain to the extent that I don't want to have sex with him again and when I go to urinate I would feel a lot of pain and a strong irritation. . . . It's been long; about 2 months. So, I end up hating my man. (37 years old, living with partner, sexually active, VVF type IIAa, successful surgery, no current urinary incontinence)

Two respondents shared that although they no longer regularly experience urinary incontinence, it has occurred during sexual intercourse. This has resulted in mixed reactions from their partners, with one understanding and the other responding quite negatively:

> I feel the urge to pee and then have intercourse with my man, it can leak. Otherwise if I don't feel any urge to pee I don't have any problem. . . . I first go and pee [before having intercourse]. He doesn't notice it but I do. Sometimes it would leak in very large amounts. (26 years old, living with partner, sexually active, VVF type IIAa, successful surgery, no current urinary incontinence)

> I didn't heal. It's not that I leak like every now and then but when I have intercourse that's when I leak. . . . It happens each time we have intercourse. . . . [I tried easing myself before intercourse] but it didn't yield any results. [My husband] only hurls insults at me. . . . I told him why he doesn't be patient with me because I was having a problem and he refused. . . . He says that he hates me. . . . He said that if I get my own money, I should [pay for my own treatment]. . . . He tells [people] that whenever we are having intercourse, I leak. . . . When I have completely healed [I have hopes of having intercourse again], though if I am still having this problem, I don't have hopes of having intercourse. (30 years old, living together, sexually active, VVF type IIAa, successful surgery, current urinary incontinence once per week or less)

Two other respondents described disruption to their sexual lives due to the persistent presence of stitches from the fistula repair in their vagina, which have caused pain for themselves and/or their partners during intercourse:

> I have one problem. I still have stitches and [my partner] is affected most and at times when he thinks about them, he even loses appetite there . . . because each time we are together, the stitches cut him. Actually, when we have to be together, it is all about endurance because they cut him and at times they don't cut him. I also feel them when I am showering, they pierce my fingers. . . . At times, he may be having the appetite [for sex] but then he recalls that there are policemen and he foregoes it. [The doctors] said that if they take me back to the theatre, they would remove them. (40 years old, married, sexually active, VVF type IIBa, leaking at hospital discharge, current urinary incontinence once per day)

Of note, absorbable synthetic sutures are routinely used for surgical repair of fistula with an absorption timeline of 60 days.

> The last time when I was repaired, I think they stitched me and the stitches really scared me. They were plastic in nature and they were really piercing and hurting. I had even decided to get back to hospital but that day as I was showering, the stitches came out. . . . They were scary and they would really scratch. . . . I am okay now and [my husband] was complaining that they were piercing him a lot as well. (30 years old, divorced/separated, not sexually active, VVF type IIBb, leaking at hospital discharge, current urinary incontinence once per week or less)

Finally, one woman reported vaginal dryness following surgery that initially made it difficult to have sex, which subsequently resolved:

> I didn't find any problem [having sex], but [my husband] felt bad; that thing was really hurting. . . . He found me so stiff! It is [abdominal pain] which was paining me, and . . . I wouldn't be able to release [sexual fluids]. (42 years old, living with partner, sexually active, uterovesical fistula, successful surgery, no current urinary incontinence)

Discussion

Our findings from this mixed methods assessment of women's sexual activity and experiences over the year following genital fistula repair surgery in Uganda suggest that patient-reported fistula-related sexual dysfunction is common but improves for most women across time following repair. Women's resumption of sexual activity and dysfunction after surgery are nuanced by fistula type, time lived with fistula, postoperative scarring, relationship status, and partner support, among other variables (Table 2). Most women cited dissatisfaction with their sexual lives and significant loss of sexual interest or pleasure at the time of fistula surgery. By 12 months postsurgery, pain and loss of pleasure had decreased, though approximately half of our study participants continued to report dissatisfaction. Similar to previous studies, women in our study who had lived with fistula for a shorter amount of time expressed readiness to be with their husbands sooner.[3,14] Women's narratives of postrepair sexual experiences, which included a lack of interest in sex and fears about resuming intercourse largely due to concerns regarding fistula recurrence and unwanted pregnancy, aligned with prior findings while highlighting additional worries related to continued urinary incontinence, anticipated stigma, and/or relationship concerns.[20]

Increased dissatisfaction and decreased interest in sex are largely consistent with prior literature on this topic due to the challenges that physical fistula symptoms and their management have on intimacy and the stigma associated with this condition. Regardless of whether they were sexually active prior to surgery, most women reported loss of sexual interest/pleasure at 12 months postsurgery. While literature on pleasure remains sparse, our findings deviate slightly from some studies suggesting a more universal interest in reengaging in sexual intercourse as a result of strong social norms linking womanhood, martial satisfaction, and childbearing.[3] Women with fistula who have maintained intimate relationships describe spending large amounts of time and energy managing urine leakage and mitigating associated smells to maintain relationships with their spouses, often feeling isolated and lonely despite their efforts.[21] However, of the 55% of women who resumed sexual activity at 12 months postsurgery, >40% indicated being satisfied or very satisfied with their sex lives. This finding diverges from prior data from focus groups with women at earlier and mixed states of treatment, which suggested that most participants abstained from sex altogether.[21] In our study, the proportion of participants who were dissatisfied or very dissatisfied with their sex lives decreased by 20% by 12 months postsurgery. This underscores postsurgical benefits for those who achieve successful repair. Interestingly, we also found that a slightly higher proportion of women who were sexually active prior to surgery reported dissatisfaction at 12 months (64%) when compared with those who were sexually inactive presurgery (49%). This topic should be investigated further as it may inform individualized patient counseling. Additionally, narratives surrounding postsurgical satisfaction in our study included different emotions and experiences, such as fear and pain, regardless of prior sexually activity. Efforts are needed to destigmatize and support couple communication throughout the continuum of female genital fistula and repair.

The timeline of resumption of sexual activity and experiences varied among the study participants and was not without challenges, including dissatisfaction, vaginal dryness, painful stiches, relationship strains predating the fistula and repair, and the impact of witnessed trauma on partners' readiness. Many respondents reported having resumed sexual activity within the first year following repair; however, the feelings of dissatisfaction with their sex lives, to the extent of some noting extreme loss of interest in having sex, mirrored what has been published elsewhere.[15,28] The loss of libido identified here and in other studies could be linked to fistula-related psychological trauma or internalized stigma that lingered even after obstetric fistula surgery.[29,30] For example, in Malawi, women reported limiting their relationships, as they were convinced that they could not have normal sex lives after sustaining a fistula for fear of interfering with the postsurgical healing process.[15] Vaginal dryness and painful stitches during sexual intercourse after fistula repair appear to have been mentioned only within one other study[15]; however, experiences of dyspareunia and urine leakage during sexual intercourse seem to be more common consequences.[11,15] Pope et al stated that 12.2% of women in Malawi experienced problems with intercourse after surgery, with 50% citing incontinence during intercourse and the remaining 50% citing pain during intercourse.[15] Our findings suggest that the less prominent realities, such as dryness and stiches, still negatively affect sexual experiences and warrant further investigation. It is possible that patients incorrectly perceive remaining sutures as bands of scar tissue, highlighting an additional opportunity for patient counseling. Dyspareunia due to vaginal dryness was addressed in a study in Switzerland, which suggested that the application of a local estrogen cream following fistula repair surgery among postmenopausal patients may have improved sexual function.[31] Generally, vaginal estrogen therapy has improved sexual activity among women experiencing dryness and/or pain; these and other treatment or coping strategies should be further researched to address and improve women's sexual experiences postrepair. Finally, some women in our study had not resumed sexual activity by the end of follow-up, and several attributed lost interest to their perceptions of a low-quality partner or relationship. While for some, interest waned as a result of their partners' responses to fistula or repair, others alluded to accepting that their partners or relationships had not been what they had hoped even before these experiences. While future childbearing was not in our analysis, prior studies found that women who hope to have more children were more likely to resume sex.[12] Taken together, these findings emphasize the need to strengthen and tailor sexuality counseling to support women in achieving the healthy relationships that they sought and to help prepare women and their partners for sexual life and reproduction after fistula repair.

Women in our study further described various fears as inhibiting sexual intercourse after fistula repair: fears of fistula

breakdown, pregnancy, or acquiring a sexually transmitted infection made some women avoid sexual activity or engage in it with hesitation or concern. These findings are similar to other studies reporting uncertainty and worry about the ability to bear children and the possibility of fistula repair breakdown on subsequent pregnancies.[11,13,15] However, this study appears to be among the minority of studies in which the fear of fistula breakdown seemed to be more frequently associated with having sexual intercourse, as opposed to pregnancy or performing demanding physical tasks.[20] This may be partially attributable to the postoperative counseling provided by [Anonymized] Hospital staff regarding future childbearing. After fistula repair, all patients are counseled to plan for future pregnancies by involving hospital-based prenatal care, seeking early admission to a facility in preparation for birth, and delivering via caesarean section. This may also be a result of continued stigmatization and resulting underprioritization of exploring sexual interest and activity, highlighting opportunities to increase programming and research to increase awareness and ensure holistic reintegration for women postrepair. Prior studies have reported that rehabilitative practices surrounding fistula repair lack consistency and would benefit greatly from patient-centered care pathways that address specific postoperative complaints.[32] Our findings similarly support the call for increased investment in holistic rehabilitation to improve long-term health and social outcomes.[32] Our findings underscore the need for continued investigation and improvement of functional outcomes alongside anatomic repair, as cited in other literature.[33]

Another key finding related to decision making about resuming sex postrepair involved the increased risk of acquiring a sexually transmitted disease. It is believed that early resumption of sexual intercourse after giving birth encourages the men to "stay more at home" and not have extramarital affairs, thereby reducing the risk of sexually transmitted infections such as HIV/AIDS.[34] Unfortunately, the development of most genital fistula at childbirth makes this less realistic considering the fact that to facilitate healing after obstetric surgery, women are encouraged to abstain from sexual intercourse for a period of 3 to 6 months, as found in our study and prior literature.[12] Studies have already shown that this period of abstinence does not resonate well with some men who feel distanced from their wives, leading to misunderstandings in the homes,[35] extramarital affairs, or divorces.[11,30] These experiences have been reported more commonly by women who lived with a fistula for a longer time before accessing repair surgery, underscoring the importance of increased awareness of and access to these services.[14] It is also not surprising that women in this study and others reported fear of acquiring HIV/AIDS if they resumed sexual intercourse after surgery, including one analyzing postrepair experiences that identified this among nearly 20% of participants.[15] This prompted some women to remain abstinent until they got tested with their partners before resuming sex. Postoperative-focused literature has suggested that supporting women who wish to resume sex without prescribing a specific period of abstinence increases patient autonomy and quality of life.[18] These findings highlight the need to trust and support women in achieving their goals on their timelines, again suggesting the benefit of holistic, patient-centered counseling and rehabilitation services.

Qualitative findings among women in our study specifically suggested that they would have benefited from increased and improved pre- and postrepair counseling, as several women described being surprised by unexpected consequences from sutures and scarring in addition to narrowing of the vaginal opening as a result of surgery, which is consistent with other studies.[28] Prior studies have suggested that many women expect that surgery will cure their incontinence as well as any sexual dysfunction.[15] Improved patient-provider communication regarding surgical expectations, decisions, and outcomes may facilitate more accurate beliefs that result in more realistic expectations and fewer unpleasant surprises.[15] Related research on the sexual experiences of women after radical cystectomy found that improved expectations were an important component of rehabilitation that often relied on provider initiation of the topic, given the patient's limited knowledge and the stigmatization surrounding discourse about sex and pleasure.[36] Couples in our study and prior literature spoke often about the loss of interest in the marriage and sex life as a result of female genital fistula and repair.[21] The timing and repetition of counseling may be another consideration toward improving the patient's experience. Another study investigating couple's experiences following vulvar surgery recommended that couple-based preoperative consultation include topics surrounding sexuality.[37] Sexual experiences and concerns should be discussed beyond the patient's surgical hospitalization and routinely at the 6-week follow-up visit and at subsequent visits throughout the first year following repair. It is critical for couples to understand not only when they can expect to more safely reengage in sex but also what it might be like for each partner given each woman's specific condition, history, and surgical experience.

Strengths and limitations

Our study adds nuance and depth to the understanding of women's postoperative sexual experiences with the inclusion of the nested interviewed cohort. These findings can guide the development of future surgical counseling guidelines as well as postoperative rehabilitation efforts. While our study focused on women's self-reported experiences, which represent important patient-reported outcomes, findings would have been strengthened with collection of clinical data and use of a longer validated sexual dysfunction measure. Additionally, the analysis would have benefited from additional questions about the specifics of postoperative counseling, if any, received by women and their partners. Finally, complete high-quality medical record data were not available for every participant, which limited our analysis and ability to evaluate differences within and between specific subsets of the population.

Conclusions

These findings suggest that sexual readiness and satisfaction vary widely and that dysfunction after genital fistula repair is a real and serious problem that may prevent women's resumption of their desired marital and social roles. Resumption of sexual life for a woman who has undergone genital fistula surgery, if wanted, should go beyond repairing her fistula to include psychosocial support and rectification of problems that constrain sexual activity after fistula repair. In alignment with prior literature, our findings demonstrate that genital fistula manifests physical symptoms as well as significant sociocultural repercussions.[14] Adequately supporting women postrepair will likely entail addressing the intersecting stigma of sexuality and genital fistula at personal, relational, and

social levels. Reintegration support for women following fistula repair should incorporate services that target restoration of women's sexuality and sexual life, including incorporating male education regarding what to expect and how men can best support their partners.[14,15] These reimagined reintegration packages should occur parallel to ongoing efforts to demystify the nature of genital fistula and the availability of successful repair.

Supplementary material

Supplementary material is available at *The Journal of Sexual Medicine* online.

Acknowledgments

We thank our study participants for sharing their time and experiences with us. We appreciate the Bixby Early Career Investigators Works in Progress group for review and discussion of manuscript revisions.

Funding

Primary data collection was funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development of the US National Institutes of Health (R21HD075008), the Fistula Foundation, and the US Agency for International Development via the Fistula Care Plus Project, administered by EngenderHealth. Support for qualitative interviews and continuing analytical work was funded by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (R00HD086232).

Conflicts of interest: None declared.

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