



Profiles and experiences of women undergoing genital fistula repair: Findings from five countries

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This article presents data from 1354 women from five countries who participated in a prospective cohort study conducted between 2007 and 2010. Women undergoing surgery for fistula repair were interviewed at the time of admission, discharge, and at a 3-month follow-up visit. While women's experiences differed across countries, a similar picture emerges across countries: women married young, most were married at the time of admission, had little education, and for many, the fistula occurred after the first pregnancy. Median age at the time of fistula occurrence was 20.0 years (interquartile range 17.3–26.8). Half of the women attended some antenatal care (ANC); among those who attended ANC, less than 50% recalled being told about signs of pregnancy complications. At follow-up, most women (even those who were not dry) reported improvements in many aspects of social life, however, reported improvements varied by repair outcome. Prevention and treatment programmes need to recognise the supportive role that husbands, partners, and families play as women prepare for safe delivery. Effective treatment and support programmes are needed for women who remain incontinent after surgery.

Keywords: genital fistula; patient characteristics; developing countries; quality of life; socio-cultural factors

Introduction

Obstetric fistula, a result of unattended obstructed labour and limited access to emergency obstetric care, is one of the most shattering maternal morbidities; obstructed labour is a leading cause of maternal deaths in developing countries (Khan, Wojdyla, Say, Gülmezoglu, & Van Look, 2006; Neilson, Lavendar, Quenby,

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& Wray, 2003). Women with fistula suffer from constant leaking of urine and/or faeces. Less commonly, fistulas may occur because of sexual violence, surgical injury (during caesarean or hysterectomy surgery), radiation therapy, or malignant disease. Some evidence suggests that fistulas from caesareans are increasing in developing countries where emergency obstetrical services are weak (Onsrud, Sjoveian, & Mukwege, 2011).

Although there are no accurate global estimates of numbers of obstetric fistulas, Stanton, Holtz, and Ahmed (2007) found that the most commonly cited estimates are two million worldwide with 50,000–100,000 new cases annually. The Demographic and Health Surveys is attempting to better assess country-level lifetime prevalence (Johnson & Peterman, 2008) and recent surveys show self-reported fistula symptoms as 0.4% in Nigeria (National Population Commission [NPC] and ICF Macro, 2009), 2.0% in Uganda (Uganda Bureau of Statistics [UBOS] and ICF International, 2012), and 4.7% in Malawi (National Statistical Office [NSO] and ORC Macro, 2005).

Published accounts have found that many women and their families fail to recognise danger signs that necessitate skilled attendance at delivery or experience delays in seeking care due to lack of transportation or funds for transport; some experience delays once they reach the facility due to lack of providers, supplies, or equipment (Bangser et al., 2010; Holme, Breen, & MacArthur, 2007; Mselle, Kohi, Mvungi, Evjen-Olsen, & Moland, 2011a; Turan, Johnson, & Polan, 2007).

Much has been published about social and economic hardships women with fistula endure (Ahmed & Holtz, 2007). Popular media portray women who suffer with fistula as being very young, newly married, and abandoned by their families (Kristof, 2009; *The Oprah Winfrey Show*, 2005). A growing number of published studies focus on characteristics of women with obstetric fistula, including women's experiences living with fistula; these studies paint different profiles than the popular media (Bangser et al., 2010; *Fistula Care*, 2012; Mselle, Moland, Evjen-Olsen, Mvungi, & Kohi, 2011b; Pope, Bangser, & Requejo, 2011).

Zheng and Anderson (2009) and Roush (2009) reviewed evidence from low-resource countries, primarily in sub-Saharan Africa and found that while many women with fistula are divorced/separated, there is evidence that some husbands and family members are supportive of women who develop fistula. Zheng and Anderson (2009) conclude that fistula affects women across all age groups and that fistula develops among women with higher parities. Roush (2009) found that common sequelae for women with fistula are loss of role in their community and family, isolation, and economic hardship.

There is a dearth of published longitudinal studies examining women's social and reintegration experiences after fistula repair surgery. Four studies – one from Eritrea (Turan et al., 2007), two from Ethiopia (Browning & Member, 2008; Nielsen et al., 2009), and one from Tanzania (Pope et al., 2011) – have assessed aspects of women's reintegration post-surgery. Each found that most women's social interactions improved after fistula surgery; Nielsen et al. (2009) found that even women with some continuing incontinence at follow-up reported improvements in social interactions. Pope, Bangser, and Requejo (2011) found women who had a closed fistula with no incontinence had higher quality of life than those with continuing incontinence post-surgery. We aimed to fill gaps in the evidence by presenting results from a multi-country study which examined women's experiences leading to fistula

formation, and the quality of their lives living with fistula, and three months after surgery.

Methods

These analyses are a secondary analysis of data collected during a study evaluating factors that predict fistula repair surgery outcomes (Barone et al., 2012). The study sample consisted of women seeking fistula repair between September 2007 and September 2010 at 11 facilities in five countries: Bangladesh ($n=3$), Guinea ($n=1$), Niger ($n=2$), Nigeria ($n=3$), and Uganda ($n=2$). Study sites were purposively selected from among 19 fistula repair facilities in seven countries supported by Fistula Care in 2007 and included six public and five private and faith-based institutions located in urban ($n=5$) and rural ($n=6$) settings. Sites were selected based on their interest and capacity to conduct the study and may not be representative of fistula patients nor fistula repair facilities in each country, though at the time of the study, there were a limited number of facilities in each country providing routine fistula repair surgery (vs. periodic outreach efforts). Women were eligible for the study if they freely consented to participate, signed an informed consent form, had a urinary fistula or rectovaginal fistula, and agreed to attend one follow-up visit three months after repair. The protocol was reviewed and approved as required by institutional and government guidelines in each country.

Facility staff conducted structured interviews with participants at the time of admission to the study, at discharge, and at the three-month follow-up visit. Interviews were conducted in local languages, using standardised questionnaires; some questions allowed for multiple responses (prompted or unprompted). In some instances, data were missing from the questionnaires; variables for which 10% or greater of cases were missing are noted.

In the study, we examined women's experiences and characteristics before and after fistula repair. We studied how fistula affected daily living and assessed if quality of life had improved after repair surgery.

Finally, at follow-up, we examined women's family and social situations by outcome of their fistula surgery – closed and dry versus not closed or closed with remaining incontinence. Fistula closure was determined at the follow-up visit by pelvic examination with a dye test in women who reported urine leakage. If no pelvic examination or dye test was conducted, fistula closure was determined through the providers' response to the question, 'Does the client have continuous and uncontrolled leakage of urine?'

In terms of country-level analyses, patient characteristics and experiences are described using frequencies for categorical variables and medians and interquartile ranges (IQR) for continuous variables. No tests of significance by country were conducted; proportions by country are shown to provide in-country programme managers and policy makers with information which could assist with programme design and to generate hypotheses for future research. Differences in the effects of living with fistula, pre- and post-fistula development (i.e. at the time of admission for surgery), were assessed as well as differences between time of admission (i.e. pre-surgery) and follow-up using McNemar paired analysis within each country; these analyses were conducted using STATA 10. Differences in patient social and family circumstances by surgery outcome were tested using generalised estimating

equations, accounting for clustering of patient outcomes within facilities, using SAS version 9.1.

Data presented are for 1354 women who underwent fistula repair surgery: 140 from Bangladesh, 251 from Guinea, 171 from Niger, 422 from Nigeria, and 370 from Uganda. Data on participants' family and social situations post-repair are presented for 1300 women who returned for three-month follow-up.

Results

Respondent characteristics

Women seeking fistula repair heard about the services from a range of sources (unprompted multiple responses). Overall, radio was the most common (37.3%), followed by health professionals (33.9%), former fistula patients (20.4%), relatives (13.5%), and outreach workers (7.1%). The most frequently mentioned source of information varied by country: in Bangladesh, 47.9% said they heard from an outreach worker; in Guinea and Niger, it was a health professional (39.8% and 60.8%, respectively); and in Nigeria and Uganda, it was the radio (57.5% and 43.0%, respectively).

Most women arrived at hospital accompanied by their mother (30.8%) or husband (26.8%). Women in Bangladesh (33.6%), Guinea (27.9%), and Nigeria (36.2%) were more likely to say they were accompanied by their husband compared to women from Niger (13.5%) and Uganda (17.3%). Overall, 13.5% of the women (primarily from Uganda) said they came alone.

The overall median travel time to the treatment facility was five hours (IQR 2–9). Women in Guinea had the longest journey (median 24 hours; IQR 4–48); women in Nigeria, the shortest (median 2 hours; IQR 1–4).

Table 1 describes patient characteristics across countries. The median age at the time of admission was 25.0 years (IQR 20.0–35.0). There appeared to be some differences across countries: women from Bangladesh and Guinea were older (36.0 and 30.0 years, respectively) and those from Nigeria were younger (20.0 years).

Median age at fistula occurrence was 20.3 years (IQR 17.3–26.8; data were missing in 30.7% of cases, mostly from Bangladesh and Niger). Women in Nigeria appear to be younger on average than women from the other countries. The overall median age at first marriage was 15.0 years (IQR 14.0–18.0); women from Uganda appeared to be older (18.0 years) than those from other countries (15.0 years). Median parity was 2.0 (IQR 1.0–5.0). Median parity was one in Nigeria, two in Uganda, and three in Bangladesh, Guinea, and Niger. Just over one-third of women had no living children; notably over 50% of Nigerian women had no living children. Women with no children were more likely to be divorced than those with children (38.0% vs. 20.0%, respectively).

The proportions of women achieving primary or higher education ranged across countries from 39.3% and 43.5% in Bangladesh and Uganda, respectively to 11.2%, 6.4%, and 6.2% in Guinea, Niger, and Nigeria, respectively. The large majority of women across countries were rural residents (85.8%).

Few women lived in homes with flush toilets (3.9%), electricity (20.0%), or piped water (22.7%). Sixty-nine percent of women lived in a home with a radio, 36.7% with a cell phone, and 15.3% with a television.

Table 1. Characteristics of women having fistula repair surgery, by country.

	Total (n = 1354)	Bangladesh (n = 140)	Guinea (n = 251)	Niger (n = 171)	Nigeria (n = 422)	Uganda (n = 370)
Median age at fistula repair (IQR)	25.0 (20.0–35.0)	36.0 (30.0–45.0)	30.0 (22.0–38.0)	26.0 (20.0–35.0)	20.0 (18.0–26.0)	25.0 (20.0–32.0)
Median age at fistula occurrence (IQR)	20.3 (17.3–26.8)	27.7 (21.7–37.0)	23.0 (17.7–28.9)	24.7 (18.8–30.1)	18.7 (16.0–24.8)	20.6 (17.9–26.3)
Median age at first marriage (IQR)	15.0 (14.0–18.0)	15.0 (12.0–17.5)	15.0 (14.0–16.0)	15.0 (14.7–17.0)	15.0 (13.0–16.0)	18.0 (17.0–20.0)
Median parity (IQR)	2.0 (1.0–5.0)	3.0 (1.0–5.0)	3.0 (1.0–6.0)	3.0 (1.0–5.3)	1.0 (1.0–4.0)	2.0 (1.0–5.0)
Women with no living children (%)	38.1	36.0	37.8	26.5	56.5	25.5
Primary or higher education (%)	20.8	39.3	11.2	6.4	6.2	43.5
Rural residence (%)	85.8	95.0	88.4	81.9	78.0	91.1
Household construction						
Piped water (%)	22.7	53.2	0.4	12.4	38.9	12.8
Electricity (%)	20.0	33.6	1.6	7.1	44.6	5.2
Flush/pour flush toilet (%)	3.9	20.7	0.0	0.6	4.5	1.1
Household possessions						
Radio (%)	69.4	21.4	23.1	92.4	88.6	86.5
Cell phone (%)	36.7	38.6	2.4	67.7	45.7	34.7
Television (%)	15.3	21.4	2.0	7.7	34.6	3.5
Refrigerator (%)	3.9	1.4	0.8	1.2	10.2	0.8
Landline (%)	1.9	5.0	0.0	0.6	2.6	1.9
Median fistula duration (years) (IQR)	1.0 (0.3–3.1)	1.8 (0.5–9.9)	2.6 (0.7–9.5)	0.3 (0.3–0.9)	0.8 (0.3–2.0)	0.8 (0.3–3.8)

IQR = interquartile range.

Almost all women (95.3%) had a vesicovaginal fistula and most (97.0%) reported that leaking began after delivery. Interestingly, in Bangladesh, 10.9% of women reported their leaking began following a medical procedure unrelated to pregnancy. Women had been living with fistula for a median of 1.0 year (IQR 0.3–3.1; data missing for 30% of the cases, mostly from Bangladesh and Niger); though women from sites in Bangladesh and Guinea appeared to have been living with fistula longer (1.8 and 2.6 years, respectively).

Women's experiences with ANC, labour, and delivery for the pregnancy which caused the fistula

Half the women reported that they attended at least one antenatal care (ANC) visit (Table 2). It is notable that 90.7% of women in Uganda reported that they attended at least one visit and that only 10.9% of women from Nigeria reported they attended ANC. The median number of reported ANC visits was 3.0 (IQR 2.0–4.0). Among women who reported attending ANC, 41.3% said they learned about the importance of having a birth plan and 42.1% said they had been told about signs of pregnancy complications.

Overall, 69.9% of women reported they delivered at a health facility; 29.5% delivered at home. A high proportion of women from Niger and Uganda reported they delivered in a health facility (84.2%, 91.3%, respectively). Among women who reported that they delivered at a facility, 79.1% laboured at home for more than 12 hours before seeking care. The reasons for delay in seeking care fell into two categories: structural (e.g. mode and cost of transportation, distance to a facility) and sociocultural/attitudinal (e.g. not customary, husband/family would not allow). Women in Bangladesh and Guinea were more likely to say that their husband or other family members did not allow them to go to a facility.

About three-quarters (73.7%) of women who said they delivered at home were assisted by a traditional birth attendant (TBA); 10.5%, by a doctor, nurse/midwife, or auxiliary midwife; 14.2%, by a friend or relative; and 1.6%, reported no assistance with delivery. In Bangladesh, women reported different experiences: 25.5%, reported a doctor or nurse/midwife assisted with delivery; 8.5%, a TBA; and the remaining two-thirds, a relative. Women who delivered at home were more likely to give sociocultural reasons for doing so, while women who eventually sought care were more likely to say that they delayed seeking care because of structural reasons.

Counselling and other services post-surgery

All study sites provided some counselling and support for women during their two to four week hospitalisation (Table 3). Nearly, all women reported being counselled about fertility potential and the importance of next delivery in a health facility (see Table 3). Some women received training (e.g. numeracy/literacy) or participated in income generating activities as part of rehabilitation.

Obstetric fistula and daily life

We gathered information about the effects of fistula on women's lives (Tables 4 and 5). At admission, we asked women about their marital status, living arrangements,

Table 2. Antenatal care, labour, and delivery experiences with causal pregnancy by country.

	Total (n = 1354)	Bangladesh (n = 140)	Guinea (n = 251)	Niger (n = 171)	Nigeria (n = 422)	Uganda (n = 370)
Received ANC (%)	50.0	25.4	60.2	60.6	10.9	90.7
Median number of ANC visits (IQR)	3.0 (2.0–4.0)	2.0 (2.0–3.0)	3.0 (2.0–3.0)	3.0 (3.0–4.0)	5.0 (2.0–6.0)	3.0 (3.0–4.0)
Among those attending ANC, % told about:						
Birth plan (%)	41.3	35.5	16.2	11.2	43.2	62.0
Signs of pregnancy complications (%)	42.1	27.6	16.7	15.3	56.4	61.3
Labour at home > 12 hours before seeking care (%)	79.1	100.0	94.4	73.9	73.9	73.4
Reasons for delay in seeking care among women who laboured > 12 hrs ^a						
Structural delays						
No transport (%)	27.1	15.4	53.1	3.9	15.2	32.9
Transport too expensive (%)	22.8	15.4	35.2	0.0	6.8	37.2
Facility too far away (%)	20.4	12.3	35.2	5.9	22.0	20.1
Care too expensive (%)	12.7	43.1	6.3	0.0	21.2	8.5
Poor service quality (%)	1.7	4.6	3.1	0.0	3.0	0.0
Facility not open (%)	1.1	1.5	1.6	0.0	2.3	0.4
Sociocultural delays						
Husband/family did not allow (%)	25.3	35.4	67.2	11.8	13.6	12.0
Not necessary (%)	21.5	50.8	13.3	26.5	19.7	16.7
Not customary (%)	17.7	16.9	50.0	6.9	23.3	1.7

^aMultiple responses; percentages exceed 100%.

Table 3. Counselling and other support services provided during hospitalisation by country.

	Total	Bangladesh	Guinea	Niger	Nigeria	Uganda
Characteristic	(<i>n</i> = 1354)	(<i>n</i> = 140)	(<i>n</i> = 251)	(<i>n</i> = 171)	(<i>n</i> = 422)	(<i>n</i> = 370)
Counselling about:						
Planning for next delivery	92.9	76.1	94.8	98.7	89.2	99.7
Need for pelvic muscle exercises	90.1	71.7	99.2	43.9	99.0	100.0
Family planning	89.7	70.4	94.8	96.8	86.8	93.7
Fertility potential	80.6	80.1	95.2	99.3	90.9	51.4
Emotional/psychological counselling	89.0	16.2	98.4	96.8	96.9	97.3
Attended support groups	43.3	12.5	86.5	5.1	43.0	41.8
Participated in income-generating activities	12.0	5.9	0.0	8.9	32.5	0.5
Received any training/education	46.3	43.1	0.8	10.8	85.1	49.9
	<i>n</i> = 603	<i>n</i> = 57	<i>n</i> = 2	<i>n</i> = 17	<i>n</i> = 346	<i>n</i> = 181
Literacy/numeracy training ^a	23.8	10.5	0.0	29.4	38.1	0.6
Vocational skills training ^a	49.9	57.9	0.0	35.3	75.7	0.0

^aAmong those who said they received any training.

primary source of income, and ability to meet basic needs before and after fistula developed. We also gathered this same information at three-month follow-up. Women were significantly more likely not to be married after the fistula developed than they were beforehand ($p < 0.001$); marital status changed little at follow-up (Table 4). Just over one-quarter of women (26.7%) reported that they were divorced at admission. Rates ranged from 21.1% (Nigeria) to 32.9% (Guinea; data not shown). Nearly, all divorced women (94.8%) said that fistula contributed to their divorce. Greater proportions of women from Bangladesh and Guinea, who were the oldest women in this cohort, were widowed.

There was also a significant shift in women's living arrangements. Over 90% of married women reported that they were living with their husbands before fistula developed; however, this dropped to 69.8% at admission ($p < 0.001$) and increased at follow-up to 71.1% ($p < 0.001$; see Table 5). Significantly larger proportions of women said they were living with parents ($p < 0.01$) at admission than before the fistula developed. Overall, very few women said they lived alone before the fistula, although the proportion increased significantly by the time of admission ($p < 0.001$) and declined significantly by follow-up ($p < 0.01$). In Guinea and Uganda, significantly more married women reported they were living with their husband at follow-up compared to admission ($p < 0.001$). Husbands were the primary source of income at all three points in time; however, proportions shifted considerably: 69.9% of women reported their husband was their primary source of income before fistula developed; 51.4%, at admission ($p < 0.001$); and 54.0%, at follow-up. Slightly more

Table 4. Effects of fistula on women's lives: comparison of experiences before fistula developed (Pre) and at the time of admission (Admiss.), by country.

	Total		Bangladesh		Guinea		Niger		Nigeria		Uganda	
	Pre	Admiss	Pre	Admiss	Pre	Admiss	Pre	Admiss	Pre	Admiss	Pre	Admiss
	<i>n</i> = 1329	<i>n</i> = 138	<i>n</i> = 138	<i>n</i> = 249	<i>n</i> = 170	<i>n</i> = 417	<i>n</i> = 355					
Marital Status: Married	92.6	66.4***	87.7	60.9***	95.6	57.0***	97.1	71.2***	95.0	76.5***	87.6	61.1***
	<i>n</i> = 885	<i>n</i> = 84	<i>n</i> = 141	<i>n</i> = 142	<i>n</i> = 120	<i>n</i> = 323	<i>n</i> = 217					
Living with ^a : Husband ^b	92.1	69.8***	98.8	92.9*	80.9	78.0	88.3	32.5***	94.7	65.3***	94.9	82.9***
	<i>n</i> = 1351	<i>n</i> = 140	<i>n</i> = 250	<i>n</i> = 142	<i>n</i> = 421	<i>n</i> = 370						
Parents	14.5	36.8***	10.7	20.0***	12.8	23.2***	9.4	65.9***	22.8	46.8***	10.0	27.6***
Other relatives	9.7	16.2***	9.3	8.6	6.4	10.4	18.2	31.8***	12.6	18.8***	4.9	13.0***
In-laws	9.8	5.8***	10.0	2.9***	2.4	3.6	22.4	7.1***	15.7	10.0***	2.2	3.2***
No one	1.0	3.9***	0.0	5.7**	2.4	9.6***	0.0	0.6	0.5	1.0	1.6	4.3***
	<i>n</i> = 1351	<i>n</i> = 139	<i>n</i> = 250	<i>n</i> = 170	<i>n</i> = 422	<i>n</i> = 370						
Husband primary source income	69.9	51.4***	95.7	52.5***	68.4	44.8***	69.4	44.1***	69.7	61.8***	61.9	46.8***
	<i>n</i> = 1343	<i>n</i> = 145	<i>n</i> = 250	<i>n</i> = 169	<i>n</i> = 417	<i>n</i> = 367						
Ability to meet basic needs, Easily/somewhat	87.7	78.5***	80.7	71.4**	60.0	31.2***	97.0	87.6***	96.2	97.4	95.4	87.7***

^aMultiple responses; percentages exceed 100%; ^bAmong women reporting to be married.
p* < 0.05; *p* < 0.01; ****p* < 0.001.

Table 5. Effects of fistula on women's lives: comparison of experiences at the time of admission (Admiss) and three month follow-up (FU), by country.

	Total		Bangladesh		Guinea		Niger		Nigeria		Uganda	
	Admiss	3 mo FU	Admiss	3 mo FU	Admiss	3 mo FU	Admiss	3 mo FU	Admiss	3 mo FU	Admiss	3 mo FU
	<i>n</i> = 1278	<i>n</i> = 126	<i>n</i> = 249	<i>n</i> = 140	<i>n</i> = 411	<i>n</i> = 352						
Marital Status: Married	66.1	66.8	61.1	67.5	57.0	65.9**	70.0	70.0	76.2	73.0	61.1	58.8***
	<i>n</i> = 870	<i>n</i> = 98	<i>n</i> = 250	<i>n</i> = 141	<i>n</i> = 412	<i>n</i> = 368						
Living with ^a : Husband ^b	63.2	71.1***	79.6	83.7	44.4	58.8***	24.1	29.1	51.5	40.3***	48.9	50.0***
	<i>n</i> = 1298	<i>n</i> = 127	<i>n</i> = 250	<i>n</i> = 141	<i>n</i> = 412	<i>n</i> = 368						
Parents	36.4	38.4	21.3	19.7	23.2	20.0	65.2	56.7*	46.8	58.7***	27.7	27.4***
Other relatives	16.1	17.1	8.7	4.7**	10.4	7.2*	34.0	31.9	18.7	23.8*	12.8	14.9***
In-laws	5.9	5.1	3.1	0.0	3.6	.8***	8.5	8.5	10.0	11.2	3.0	1.6***
No one	4.1	2.9**	6.3	7.9	9.6	4.4***	0.7	3.5	1.0	0.7	4.3	2.4*
	<i>n</i> = 1294	<i>n</i> = 125	<i>n</i> = 251	<i>n</i> = 141	<i>n</i> = 411	<i>n</i> = 366						
Husband primary source of income	51.7	54.0	52.8	51.2	45.0	51.4*	44.7	47.5	62.0	62.0	47.0	50.3***
	<i>n</i> = 1278	<i>n</i> = 124	<i>n</i> = 249	<i>n</i> = 141	<i>n</i> = 407	<i>n</i> = 357						
Ability to meet basic needs: Easily/somewhat	78.2	84.4***	72.6	73.4	31.3	57.8***	87.2	85.8	97.5	97.1	87.4	91.9***

Note: ^aMultiple responses; percentages exceed 100%; ^bAmong women reporting to be married.
p* < 0.05; *p* < 0.01; ****p* < 0.001.

women from all countries except Bangladesh reported their husband as the primary source of income at follow-up compared to admission (only significant in Guinea ($p < 0.05$) and Uganda ($p < 0.001$)). A large majority of women (87.7%) said they could easily or somewhat easily meet their basic needs before fistula; this dropped to 78.5% at admission ($p < 0.001$) and rose to 84.4% at follow-up ($p < .001$). The largest proportion of women who could not meet their basic needs across the three time periods were women from Guinea; these women were relying mostly on families for financial support.

Living with fistula interfered with women's daily lives (Table 6), including the ability to attend community gatherings (85.3%), have sexual relations (85.2%), attend religious gatherings (83.6%), earn money (80.0%), work (72.1%), and eat with others (68.7%). Women who had lived with fistula for over a year were more likely to say that their condition interfered with their ability to work and earn money.

At three-month follow-up, a large majority of women reported improvements in some aspects of their lives, the most notable change being the ability to eat with others (89.3%). Women who lived with fistula for more than one year reported greater improvements in their ability to work, earn money, and attend religious and community gatherings compared to women who lived with fistula for less than one year (data not shown).

Overall, 65.9% of women who returned for follow-up had a closed fistula and were dry; 34.1% of the women were not dry, that is, the fistula was not closed or the fistula was closed but they had some incontinence remaining. Changes in women's social circumstances at follow-up varied by repair outcome (Table 7). Married women who were dry were more likely to report that they were currently living with their husband (76.0%) compared to those who were not dry (60.9%). While women overall reported improvements in daily life three months post-repair, those who were not dry were significantly less likely to report improvements than women who were dry.

Discussion

This study is one of the largest collections of data with profiles and experiences of women with fistula. It is one of the few published studies that include prospective data about women's lives post-surgery across multiple sites and countries. The study suggests some differences in women's experiences by country: women in Bangladesh and Guinea were older at the time of surgery suggesting lack of access or knowledge about treatment. Women in Nigeria were the youngest at the time of surgery and with the lowest parity; they also lived closest to the treatment facility. Women in Uganda, who had higher levels of education, were more likely to attend ANC, had higher levels of knowledge about birth preparedness and were least likely to cite sociocultural reasons for delays in seeking delivery care. While there were differences, overall a similar picture emerged across countries: these women married young, most were married at the time of admission for repair surgery, levels of education were low, and for many, the fistula did not occur with a first pregnancy. These data confirm findings from other studies which show that fistula occurs in women of all reproductive ages (Bangser et al., 2010; Zheng & Anderson, 2009).

The common assumption that most women living with fistula are divorced or abandoned did not hold true in this study population. While the percentage of women who reported that they were divorced/separated varied among countries,

Table 6. Obstetric fistula and social interactions before and after surgery by country (%).

	Total (n = 1354)	Bangladesh (n = 140)	Guinea (n = 251)	Niger (n = 171)	Nigeria (n = 422)	Uganda (n = 370)
Before surgery, leaking from fistula interfered with: ^a						
Attendance at community gatherings	85.3	83.6	99.2	84.2	73.7	90.2
Having sexual relations	85.2	69.9	92.8	76.6	86.8	87.8
Attendance at religious gatherings	83.6	85.0	99.2	83.6	69.1	88.9
Ability to earn money	80.0	83.3	98.8	85.4	58.2	87.3
Ability to work	72.1	90.0	100.0	77.2	36.3	85.0
Ability to eat with others	68.7	86.3	87.6	64.3	52.9	69.0
Improvements since surgery ^{a,b}	(n = 1300)	(n = 127)	(n = 251)	(n = 141)	(n = 413)	(n = 368)
Eats with others	89.3	69.8	88.0	92.2	86.4	99.2
Able to work	80.7	74.8	83.3	83.0	65.5	97.0
Attends religious gatherings	74.5	62.2	79.3	45.0	69.1	92.6
Attends community gatherings	70.4	65.4	79.0	42.9	64.4	83.6
Able to earn money	62.0	50.8	82.9	14.2	58.9	73.5

^aMultiple responses; percentages exceed 100%.

^bAt follow-up women were not asked if sexual relations had improved, but were asked if they had resumed sexual intercourse. Overall 1.7% reported they had engaged in sexual intercourse.

Table 7. Patient social circumstances by repair outcome at three month follow-up (%).

	Status of fistula closure (<i>n</i> = 1253)	
	Closed and dry (<i>n</i> = 826)	Not closed or closed with remaining incontinence (<i>n</i> = 427)
Married/living as married	68.6	61.4***
Living with ^a		
Husband ^b	76.0	60.9
Parents	36.7	44.0
Other relatives	15.0	22.7
Adult children	10.6	15.9
Friends	6.5	7.7***
In-laws	4.9	5.6
Alone	1.5	5.6***
Husband as primary source of income	57.5	48.1***
Can easily/somewhat meet basic needs	89.6	74.6***
Improvements since surgery ^a		
Eats with others	94.7	79.0*
Able to work	87.7	66.3
Attends religious gatherings	85.7	54.4*
Attends community gatherings	82.3	48.1**
Able to earn money	74.2	37.9***

^aMultiple responses; percentages exceed 100%. ^bAs reported by married women only.
p* < 0.05; *p* < 0.01; ****p* < 0.001.

nearly two-thirds reported that they were married at admission, and 70% of married women were living with their husband. Other studies have found similarly high proportions of women who were married at the time of fistula surgery or follow-up (Mselle et al., 2011b; Nielsen et al., 2009; Roush, 2009; Women's Dignity Project and EngenderHealth, 2006; Zheng & Anderson, 2009). At follow-up, more married women were living with their husband than at admission, except in Bangladesh and Nigeria. In Nigeria, where women were youngest and had the lowest parity, more women were living with relatives than with their husband; although we did not gather data on this, perhaps, they returned to their natal homes to recover from surgery. The reasons for the changes in living arrangements for the Bangladeshi cohort are also unknown.

Among married women, about one-quarter reported they lived with family members other than their husband. This may be a signal of abandonment by the husband but not by other family members.

In reports from sub-Saharan Africa, duration of living with fistula ranges from less than one to six or more years (Holme et al., 2007; Kayondo et al., 2011; Mselle et al., 2011b; Women's Dignity Project and EngenderHealth, 2006). The relatively short length of time our study participants were living with fistula could be related to the availability of and their knowledge about repair services in their home regions. In

a recent study in Tanzania, researchers compared women who had been repaired several years before the interview with a group of women awaiting surgery; they found the average duration of living with fistula for the group awaiting surgery was shorter (1.2 years) compared to the group who had undergone repair years earlier (seven years; Pope et al., 2011). Fistula repair services had been available at all but one of the study sites for at least five years before the start of this study; these sites air radio messages and conduct other activities to raise awareness about fistula treatment through community outreach (K. Beattie, personal communication, May 21, 2012). These efforts may be increasing awareness, and women may be going to facilities for care sooner rather than later. Women from Guinea had been living with fistula for nearly three years and perhaps had least access to services, given that it took them on average more than one day to reach the repair facility. In Guinea, Nigeria, and Niger, there are reports of women crossing national borders to seek services; this may account for the longer time travelled to the repair facility by the Guinean women. We did not collect information about country of residence. This is an area which requires more exploration.

The World Health Organization (WHO) recommends pregnant women attend at least four ANC visits (Villar et al., 2001). As in other studies (Bangser et al., 2010; Holme et al., 2007; Kayondo et al., 2011; Women's Dignity Project and Engender-Health, 2006), many women in this study reported they attended some ANC care during the causative pregnancy; however, there were differences among countries and most women reported attending fewer than four ANC visits.

While several countries have made important progress in reducing maternal mortality (WHO, 2012), this study points to the remaining challenge for preventive maternal health programmes to better address safe birth planning. For every woman who dies of pregnancy-related causes, an estimated 20 women experience an acute or chronic morbidity, often with tragic consequences, such as fistula (Hardee, Gay, & Blanc, 2012). While use of ANC is increasing, there is room for improvement in many countries (Wang, Alva, Wang, & Fort, 2011). Less than half the women in this cohort who attended ANC recalled being informed about birth plans and signs of pregnancy complications. Personal and community resources were possibly inadequate, given that most women who delivered at a health facility laboured at home for more than 12 hours. The data suggest that both access to ANC and improved information are required to promote timely skilled delivery. Better awareness and preparation would help to minimise the first two delays in women's access to emergency obstetric care: knowing when to seek care and getting to a health facility for care (Thaddeus & Maine, 1994).

Most women experienced isolation perhaps because of the reactions of others or their own discomfort with their condition. Many women were unable to eat with others or attend community or religious events. At follow-up, most women reported that many aspects of their lives had improved. While there were differences between women who were dry and those who were not dry, even women who were not dry reported improvements in many parts of their lives. Effective treatment and support programmes are needed for women who remain incontinent after surgery. Reintegration requires a multisectoral approach. The health system alone will not be able to address all aspects of reintegration. Reintegration begins with case identification, psychosocial counselling, and support to undergo treatment. The health system has a role to play in rehabilitation, nutrition, physical therapy,

discharge guidance, clinical follow-up, and continued psychosocial counselling. As the data show, most women received some counselling during hospitalisation as part of reintegration. Community-based groups engaged in addressing the needs of vulnerable women are well placed to address stigma and to identify educational, vocational, and income-generation opportunities for women who have received fistula repair. During reintegration, family support can be crucial.

This study had several limitations. Women who received fistula surgery at one of the study sites may not be representative of all women with fistula, however, this data set represents a broad sample of women from a range of countries and facilities, using the same data collection tool increasing generalisability. Fistula is a rare occurrence and it may be difficult to ever obtain nationally representative profiles of women in each country who have this condition. To our knowledge, this manuscript represents the first published description of experiences of women from Guinea. At the time of this study, most countries had only a few facilities where surgical repair services were routinely available.

The data collected during interviews with women are all self-reported and thus subject to inherent inaccuracies and reporting biases. Some people have difficulty in recalling the timing of past events (e.g. age at marriage, duration of labour, when and how the fistula occurred); in this study, data for some events were contradictory (e.g. age at fistula, current age relative to the number of years living with fistula). Data were missing for age at fistula development and duration of living with fistula. Both of these variables were created using the date when the leaking began. In Bangladesh and Niger, data on date of occurrence when leaking began were missing for more than 30% of the cases; this was a result of women not being able to recall the date when their leaking began. Staff at participating facilities conducted the interviews; it is possible that women provided socially acceptable responses to these providers. Interviews were structured and did not allow for in-depth follow-up about women's experiences; in-depth follow-up questions would have allowed for better understanding of the nuances of women's experiences. In addition, a longer follow-up period would allow for better assessments of health and changes in social life. Despite its limitations, this research is one of the few published studies with a large cohort that examines women's lives post-surgery.

Conclusion

This study reinforces findings from recently published literature reviews: fistula affects women across all age groups, not just young women; fistula does develop among women with higher parities; not all husbands and families abandon women with fistula, and only a very small minority live alone.

This is the first multi-country study describing experiences among women with fistula who seek repair services. Based on these women's experiences, it is important to ensure that prevention, which includes family planning and safe motherhood messages, reach all women and girls of reproductive age, and that prevention and treatment programmes recognise the important role that husbands, partners, and families play in helping women to prepare for safe delivery, obtain repair services, and care for themselves after repair surgery.

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