"Hoping for a Normal Life Again": Reintegration After Fistula Repair in Rural Tanzania

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Abstract

Objective: To explore women's expectations, worries, and hopes related to returning to their family and community after fistula repair.

Methods: We used a concurrent mixed methods design with a hospital survey and qualitative interviews. One hundred fifty-one women completed a questionnaire, eight were interviewed in hospital after fistula repair, and one woman was followed up at home for six months during the reintegration phase.

Results: Women were concerned about where they could live and about not being accepted by their husbands and in-laws. While 51% feared that their husbands would not accept them despite full recovery, 53% said their parents would accept them. In the qualitative study women wished to live with their parents, whereas almost one half (49.7%) of the women in the quantitative study, who had lived with fistula for a shorter time, wished to live with their husbands. All women hoped to have children in the future, although many women, especially those with no children, were worried about whether they could bear children in the future. Despite fears related to economic survival and social acceptance, women were optimistic about regaining a normal social life.

Conclusion: Women's expectations of going home after fistula repair are linked to their history of living with obstetric fistula. For women who have lived with a fistula for many years, reintegration involves re-establishing an identity that is clean and respected. To facilitate this transition, fistula repair needs to be accompanied by psychological and social rehabilitation and assistance in returning to reproductive capabilities.

Key Words: Social reintegration, obstetric fistula, women's experiences, fistula repair

Competing Interests: None declared.

Received on February 16, 2012

Accepted on February 23, 2012

Résumé

Objectif : Explorer les attentes, les craintes et les espoirs des femmes en ce qui a trait à leur retour dans leur famille et leur communauté à la suite de la réparation d'une fistule.

Méthodes : Nous avons utilisé un devis de méthodes mixtes concomitantes, conjointement avec un sondage hospitalier et des entrevues qualitatives. Cent cinquante et une femmes ont rempli un questionnaire, huit femmes ont été interviewées à l'hôpital à la suite d'une réparation de fistule et une femme a fait l'objet d'un suivi à la maison pendant six mois au cours de la phase de réinsertion.

Résultats : Les femmes exprimaient des préoccupations au sujet de l'endroit où elles pourraient vivre et de la possibilité de ne pas être acceptées par leur mari et la famille de ce dernier. Cinquante et un pour cent des femmes craignaient que leur mari ne les accepte pas malgré une récupération totale; toutefois, 53 % des femmes ont affirmé que leurs parents les accepteraient. Dans le cadre de l'étude qualitative, les femmes souhaitaient vivre avec leurs parents, tandis que dans le cadre de l'étude quantitative, près de la moitié (49,7 %) des femmes (qui présentaient une fistule depuis moins de temps) souhaitaient vivre avec leur mari. Toutes les femmes espéraient avoir des enfants à l'avenir; cependant, bon nombre de femmes, particulièrement celles qui n'avaient pas d'enfants, s'inquiétaient de ne pas pouvoir connaître de grossesses à l'avenir. Malgré des craintes liées à la survie économique et à l'acceptation sociale, les femmes demeuraient optimistes quant à leur capacité de reprendre une vie sociale normale.

Conclusion : Les attentes des femmes quant à leur retour à la maison à la suite de la réparation d'une fistule sont liées à la façon dont elles ont vécu la présence d'une fistule obstétricale. Pour ce qui est des femmes qui ont vécu avec une fistule pendant de nombreuses années, la réinsertion met en jeu le rétablissement d'une identité qui est propre et respectée. Pour faciliter cette transition, la réparation de fistule se doit d'être accompagnée d'une réhabilitation psychologique et sociale, ainsi que d'une aide quant au retour des capacités génésiques.

J Obstet Gynaecol Can 2012;34(10):927–938

INTRODUCTION

Healing, recovering, and reintegrating into the family and community after suffering the consequences of obstetric fistula involves a number of challenges for women, even after successful treatment. Reintegration is broadly defined as the process of helping women affected by obstetric fistula return to the life they lived before they developed a fistula. This includes how women adjust and reconnect to employment, families, communities, and social life in order to restore their lost dignity and respect and to increase their self-esteem.[1]

Obstetric fistula results from prolonged unrelieved obstructed labour.[2,3] Obstructed labour occurs in approximately 5% of all pregnancies and accounts for an estimated 5% of maternal deaths in resource-poor countries.[2] Obstetric fistula affects at least two million women and girls annually, the majority of whom live in Africa and Asia.[4,5] In Tanzania, estimates indicate that between 2500 and 3000 new cases of obstetric fistula occur each year.[6,7]

Following development of an obstetric fistula, women leak urine and/or feces uncontrollably through the vagina. The condition is associated with leakage, odour, and social exclusion. Women often feel unfit to live with the rest of their family members and isolate themselves or are isolated by their families and communities. In many cases, women with a fistula are divorced by their husbands.[8,9] Social exclusion and lack of recognition experienced by women during the time they suffer from the fistula (varying from a few months to many years) leads to a diminished sense of self-worth.[1,10,11] Because of their physical impairment and the stigma and myths associated with the condition,[8,12,13] many such women end up living apart and without economic support from their husbands.[8]

Surgical fistula repair that stops or reduces leaking[14] usually improves the affected women's quality of life.[8] The efforts of a range of women's health organizations, advocates, and donors to address problems associated with obstetric fistula, starting in approximately 2003, have been successful in raising awareness and increasing the availability of fistula repair services for women in many countries. Today, surgical fistula repair is offered at no or low cost in many African countries,[15] with success rates as high as 90%,[16,17] but awareness of the services in rural areas is limited. In Tanzania in 2007 there were approximately 30 doctors trained in fistula repair and approximately 1000 repairs performed.[18,19]

While many women who have a successful repair succeed in returning home,[13] others have nowhere to go even after they are completely healed.[20] Some women remain in hospital or stay near the hospital where they received treatment.[21,22] Some remain in towns and resort to survival strategies such as begging or prostitution.[20] Women who go back to their communities may still not enjoy family and community life as fully as they did before they developed a fistula.[23]

Although an increasing number of women undergo surgical fistula repair, little is known about how women see their life prospects after repair and how they perceive being reintegrated into their community. Studies have assessed treatment efficacy, quality of life, urinary and reproductive health,[14,24] fertility, including child-bearing outcomes,[25] experiences of incontinence, and gynaecological and social problems.[9] Only one study on reintegration of women after fistula repair, examining the relationship between surgical outcomes and perceived quality of life, has been conducted in Tanzania.[23] The study we report here sought, through qualitative and quantitative approaches, to provide information about women's expectations of life after fistula repair and to explore their hopes and worries related to reintegration into family and community life. Specifically, the study investigated women's concerns about child-bearing, married life, social interaction, and economic survival. The purpose of the study was to give women suffering the social and physical consequences of obstetric fistula a voice and to alert the political community to the need for comprehensive reintegration and rehabilitation programs addressing the psychological and social needs of this marginalized group of women.

This study used the "reintegration needs" model of women affected by obstetric fistula developed in 2006 by the Data, Indicators and Research Group of the International Obstetric Fistula Working Group.[26] The model was developed to understand women's expectations and experiences of reintegration after surgical treatment of obstetric fistula. This model suggests that following fistula repair, women expect to regain their physical and mental health, and their social and economic well-being.

ABBREVIATIONS

BMC	Bugando Medical Centre
CCBRT	Comprehensive Community Based Rehabilitation in Tanzania Hospital
NGO	non-governmental organization

MATERIALS AND METHODS

We carried out a mixed methods study between October 2008 and February 2010. This methodology was selected because the reintegration issues of women after fistula repair had not been well explored and would benefit from insights likely to be missed when only a single research method is used.[27] While quantitative methods were used to identify patterns in the way women perceived reintegrating into their communities after fistula repair, the qualitative method explored in depth the women's hopes, dreams, fears, and worries about the future. The qualitative and quantitative studies were performed concurrently using different samples. The qualitative data were emphasized over the quantitative in the analysis. The qualitative study was carried out at the Comprehensive Community Based Rehabilitation in Tanzania hospital in Dar es Salaam and the Mpwapwa District in the Dodoma region. The quantitative study was carried out at both CCBRT hospital and the Bugando Medical Centre. The BMC is located in Mwanza city in the Mwanza Region of western Tanzania. CCBRT and BMC hospitals were selected because they are the major service points for fistula surgery in Tanzania. Both hospitals have special wards for fistula patients, and CCBRT has in addition a hostel where fistula patients live while waiting for fistula surgery.

Data Collection Methods

The qualitative study

The qualitative study involved one-time interviews with women admitted to the CCBRT fistula ward about their experiences of birth care, life before repair, and expectations of life after repair. We report here on the last. A senior nurse midwife approached all women admitted to the ward during the study period and asked about their willingness to participate in the study. Eight women met the inclusion criteria (admitted to hospital after fistula repair, ability to speak Kiswahili, and willing to participate in the study) and provided written consent to participate in the study. Women were informed about their right to participate (or not) in the study and their right to withdraw from the study at any time, and a convenient time for an interview was subsequently arranged. Specific permission to use an audio-recorder during the interview was obtained from each informant. Further, it was made clear that the information they provided, whether orally or in writing, would be treated with strict confidentiality and would be used for research purposes only. Eight individual semi-structured interviews[28] were conducted in Kiswahili by the first author, a Tanzanian nurse with a background in social sciences and health promotion, and a fluent Kiswahili speaker. An interview guide included topics and questions on women's social and demographic background and on their expectations for their lives following fistula repair. Interviews were conducted in a separate room in the hospital, out of sight and hearing of other patients and staff in the fistula ward. All interviews were audio-recorded, and notes were taken. Recruitment was stopped after the data achieved saturation,[29] at which point answers from women seemed to repeat information gained earlier and little new information was forthcoming.

In addition to these hospital-based interviews, three informants were recruited as follow-up cases: two women from Dar es Salaam, and one from Dodoma region. The number of follow-up cases was set low because of cost, time, and difficulties involved in travel and tracing the women. The initial interview took place in the hospital before surgery, and the follow-up interview was held five days after surgery but before discharge from hospital. Although care was taken to note physical addresses and relatives' telephone numbers, two of the three women were lost to follow-up after being discharged. One had moved to her parent's home in the Lindi region, and another had relocated to a different residence and could not be reached by telephone. One informant was followed up at home for six months after surgery in her home village in the Mpwapwa district after discharge from the CCBRT hospital. The first author made four home visits to Asha (fictive name) and her family in a period of six months after her surgery and spent one night with them. Notes on her life experiences following fistula repair were written throughout the visits.

The quantitative study

All women with an obstetric fistula and admitted to the fistula wards during the data collection period (from July 2009 to February 2010) were invited to participate; only those who consented were recruited. No women who met the inclusion criteria refused to participate. One hundred fifty-one women affected by obstetric fistula completed the close-ended questionnaire. The questionnaire had been developed in a wider collaborative research group on fistula studies, Gender, Generation and Social Mobilisation: Challenges of Reproductive Health and Rights Among Vulnerable Groups in Ethiopia, Sudan and Tanzania, funded by the Norwegian Programme for Development, Research and Higher Education (GeSoMo-NUFU) and was used concurrently in Tanzania, Sudan, and Ethiopia to collect comparable data from women with obstetric fistula who had undergone or were about to undergo fistula surgery. The questionnaire, which contained five questions focused on women's expectations of reintegration, was translated from English to Kiswahili

Table 1. Characteristics of women interviewed in the qualitative study

Fictive name	Age	Years in School	Marital status	Parity	Living children	Duration with fistula	Residence
Rehema	35	7	Single	3	0	18 years	Kisongo, Kilwa
Sofia	20	7	Divorced	1	1	6 months	Mlandizi, Pwani
Agnes	32	7	Divorced	1	0	19 years	Ifakara, Morogoro
Jenifer	40	7	Married	8	5	1 year	Mbugani, Manyoni
Ashura	43	7	Separated	4	1	20 years	Kitinku, Manyoni
Halima	25	7	Divorced	3	2	8 months	Iringa, Tanzania
Wema	28	7	Divorced	2	1	12 years	Mvumi, Dodoma
Milka	18	0	Single	3	2	3 months	Mkoka, Kongwa

and pilot tested at Muhimbili National Hospital before the main study. Two trained research assistants (both senior nurses with experience in health research), one in each hospital, facilitated the data collection exercise. In order to test the setting, the first author administered five questionnaires in each selected facility.

Data Analysis

The qualitative study

Data analysis began after the first interview and was connected to the data collection process. Each interview was audited several times before the next interview was conducted, enabling continuous development of the interview guide. All eight interviews were transcribed verbatim in Kiswahili, and then translated from Kiswahili to English by a linguistic instructor from the Dar es Salaam University College of Education. Two English transcripts were translated back[30] into Kiswahili at a later date to check the quality of translation. Thematic analysis[31] was employed and included familiarization with the material, identification of the codes, searching for themes, revision of the themes, and interpretation. Phrases and sentences related to the women's expectations after surgical fistula repair were coded in the margin of the transcript sheets. Codes that were similar or connected to each other were organized to form themes. To strengthen content validity, the research team scrutinized the organization of the codes and agreed on the formulation of themes. The narrative and observation notes from the follow-up visits to Asha's home were organized according to themes emerging from the hospital-based interview data of women's expectations of the reintegration process.

The quantitative study

In addition to basic sociodemographic variables, the following five questions in the quantitative questionnaire were designed for this aspect of the study on perceptions and expectations of the process of reintegration:

1. With whom are you planning to stay after the surgery is complete?
2. Who do you think will accept you when you get home?
3. Do you wish to have children in future?
4. Would you like to marry again?
5. How do you see yourself making a living?

We used SPSS v.15 for Windows (IBM Corp., Armonk NY) for data analysis. Descriptive analyses, frequencies, and proportions were used to summarize the data. Cross-tabulation and chi-square statistics were used to assess the statistical significance of associations between variables. Quantitative method was used to determine the proportions of women's perception of reintegration following fistula treatment, thus broadening our understanding of women's expectations after fistula repair.

The Muhimbili University of Health and Allied Health Sciences Research and Ethical Review Board provided ethics approval, and permission to conduct the study was obtained from both CCBRT and BMC hospitals. Written consent was obtained from each participant in the qualitative study, whereas oral consent was deemed sufficient for those included in the quantitative study. All names used are fictitious.

RESULTS

Of the 151 women with obstetric fistula in the quantitative study, 39% were aged 21 to 30, and 14% were under 18. Most women (97%) were either illiterate or had completed only primary education; 18% were divorced, and 65% were still living with their husbands during the study. Fifty seven percent (n = 86) had lived with obstetric fistula for less than a year, whereas 25% (n = 37) had done so for three years or more.

The sociodemographic characteristics of the study participants in the qualitative study are summarized in Table 1. Of these nine women (aged from 18 to 43), five were either divorced or not living with their husbands at the time of data collection.

Women's Expectations of Life After Fistula Surgery

Asha's story

Asha was 33 years old at the time of the study and living in the Dodoma region. Following prolonged obstructed labour in her first pregnancy at age 21, she developed both a vesico-vaginal fistula and a recto-vaginal fistula. Her baby was stillborn, and she sustained unilateral nerve damage resulting in leg paralysis and a limp. Her husband divorced her and Asha moved back with her parents. She lived with these physically and socially disabling conditions for 10 years before accessing surgery. She had three procedures over three years to complete surgical repair of both vesico-vaginal fistula and recto-vaginal fistula. When she was discharged from hospital after her third fistula repair, she returned to her natal village to stay with her younger sister and her sister's two children in their inherited two-roomed thatched mud-house. People in the neighbourhood were surprised to find that Asha had been cured, that she was no longer surrounded by odour, and that she could walk again. Despite a persisting limp and minor leakage of urine, Asha was pleased with the outcome of the surgery and had strong hopes that she would become completely dry and be able to live the life expected of a woman.

Other women's expectations

In other women, the themes that were identified through analysis of their expectations of life following surgical fistula repair were uncertainty about being accepted as a wife, the need to have children, hope for a social life, and worries about survival. These are discussed below.

1. Uncertainty about being accepted as a wife

Following fistula surgery, women usually remain in hospital for up to several months for care and recovery before they are discharged "to go home." But where home would be was not obvious. When women in the quantitative survey were asked where they expected to stay after fistula repair, approximately one half (49.7%) said they would return to their husbands (Table 2). Among these women, 55% had lived with fistula for less than one year. Women who were primigravid or had low parity more often planned to live with their husbands after fistula repair ($P = 0.002$) (Table 3).

The women in the qualitative study had lived with a fistula for much longer, and their expectations of life after repair were shaped by their experiences of living with a fistula before treatment. For many, returning to live with their husband and in the village where they had previously lived was not possible (as illustrated by Asha' story). Their experience of losing the respect, support, and love of their husband surfaced in their reflections about marriage:

> "I know after I am healed I will be respected again, but for that man [her husband], I don't think I will go back to him because my heart is hurt." (Ashura)

> "Truly, if I am healed, I will never go back to him, it's enough. . . . I was good to him before I got this problem, now because of this problem, I am like rubbish to him." (Halima)

Table 2. Expectations of women on reintegration after fistula repair

Expectations	N = 151 n (%)
With whom are you planning to stay after surgery?	
Husband/partner	75 (49.7)
Own parents	46 (30.5)
Parents-in-law	3 (2.0)
Relatives	25 (16.6)
Others	2 (2.2)
In the future do you hope to give birth again?	
Yes	83 (55.0)
No	46 (30.5)
Don't know	17 (11.3)
Not possible	4 (2.7)
Missing	1 (0.7)
In the future would you like to marry again?	
Yes	57 (37.7)
No	43 (28.5)
Don't know	13 (8.6)
Missing	38 (25.2)
Who do you think will accept you (checked more than once)	
Husband/partner	76 (51.3)
Own parents	80 (53.0)
Parents-in-law	25 (16.6)
Children	36 (23.8)
Other relatives	56 (37.1)
Neighbours/friends	15 (10.6)
Community/church	32 (21.2)
Missing	1 (0.7)
How do you see yourself make a living?	
Having own job/income	120 (79.5)
Help from family/relatives	25 (16.6)
Help from NGO or other organization	3 (2.0)
Other	3 (2.0)

Table 3. Determinants of who women plan to stay with after fistula repair

	Husbands		Parents		In-laws		Relatives	
N = 151	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)
Age, years								
15 to 24	30 (44.8)	37 (55.2)	24 (35.8)	43 (64.2)	2 (3.0)	65 (97.0)	10 (14.9)	57 (85.1)
25 to 34	26 (50.0)	26 (50.0)	16 (30.8)	36 (69.2)	0 (0)	52 (100.0)	9 (17.3)	43 (82.7)
35 to 44	15 (65.2)	8 (34.8)	5 (21.7)	18 (78.3)	1 (4.3)	22 (95.7)	3 (13.0)	20 (87.0)
≥ 45	2 (22.2)	7 (77.8)	1 (11.1)	8 (88.9)	0 (0.0)	9 (100.0)	3 (33.3)	6 (66.7)
Education level								
None	23 (47.9)	25 (52.1)	10 (20.8)	38 (79.2)	0 (0.0)	48 (100.0)	11 (22.9)	37 (77.1)
Primary	48 (48.5)	51 (51.5)	34 (34.3)	65 (65.7)	3 (3.0)	96 (97.0)	14 (14.1)	85 (85.9)
≥ Secondary	2 (50.0)	2 (50.0)	2 (50.0)	2 (50.0)	0 (0.0)	4 (100.0)	0 (0.0)	4 (100.0)
Pregnancy fistula occurred	(P = 0.002)							
1st	29 (34.5)	55 (65.5)	36 (42.9)	48 (57.1)	2 (2.4)	82 (97.6)	14 (16.7)	70 (83.3)
2nd	9 (50.0)	9 (50.0)	4 (22.2)	14 (77.8)	0 (0.0)	18 (100.0)	5 (27.8)	13 (72.2)
3rd	8 (61.5)	5 (38.5)	2 (15.4)	11 (84.6)	0 (0.0)	13 (100.0)	1 (7.7)	12 (92.3)
4th	11 (78.6)	3 (21.4)	1 (7.1)	13 (92.9)	0 (0.0)	14 (100.0)	2 (14.3)	12 (85.7)
≥ 5th	15 (71.4)	6 (28.6)	3 (14.3)	18 (85.7)	1 (4.8)	20 (95.2)	3 (14.3)	18 (85.7)
Duration with fistula, years								
< 1	57 (53.8)	49 (46.2)	32 (30.2)	74 (69.8)	3 (2.8)	103 (97.2)	16 (15.1)	90 (84.9)
1 to 5	4 (44.4)	5 (55.6)	5 (55.6)	4 (44.4)	0 (0.0)	9 (100.0)	0 (0.0)	9 (100.0)
≥ 6	12 (33.3)	24 (66.7)	9 (25.0)	27 (75.0)	0 (0.0)	36 (100.0)	9 (25.0)	27 (75.0)

> Even women who had children with their husband before they developed a fistula had negative feelings about going back to live with their husband after repair:"If I am cured, I will never live with him. He has gotten himself another wife. . . . I will go and live with my child and my grandmother." (Wema)

Although many women in the quantitative study expected to go home and stay with their husband, more than one half (51.3%) felt that their husband would not accept them regardless of their being fully recovered (Table 2). Women's expectations of being accepted by their husband and children were inversely associated with parity ($P < 0.001$). Moreover, living with fistula for a shorter duration was significantly associated with being accepted by their husbands ($P = 0.002$) (Table 4). Nevertheless, women said that when they returned to their communities after surgery their parents (53%) and relatives (37%) would accept them (Table 2). Among those who felt that their parents would accept them, 48% were married, 55% were primigravid, and 64% had lived with a fistula for six years or more. These findings are in line with the qualitative findings, in which women claimed that after they had recovered and were healed, they would live with their parents or settle with relatives instead of going back to live with their husband:

> "Once I am cured, I am planning to go and live at my father's home or stay here, because my mother stays right here in the city [Dar es Salaam]." (Rehema)

> ". . . from the hospital I will first go to my brother at Mburahati, Dar es Salaam; from there I will go to my husband's house at Mlandizi and pick up my things, and thereafter, I will leave and head home to my parents." (Sofia)

Some women, especially those who were already divorced from their husband, could not see a point in returning to their marital home, and they said they would rather live and seek work in the towns:

> ". . . from here [CCBRT hospital], I will go to Sinza [Dar es Salaam] and find a job because a friend told me that if I am completely healed, she will find me a job." (Halima)

2. The need to have children

While staying in the village with her sister, Asha received marriage proposals, but she refused them, remembering the problems she had gone through as a result of the fistula and her husband's mistreatment. Asha did not think

Table 4. Determinants of who women believe will accept them when they return home after fistula repair

	Husbands		Parents		In-laws		Children	
N = 151	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)
Age, years								
15 to 24	31 (47.0)	35 (53.0)	39 (58.2)	28 (41.8)	13 (19.4)	54 (80.6)	9 (13.4)	58 (86.6)
25 to 34	27 (51.9)	25 (48.1)	28 (53.8)	24 (46.2)	7 (13.5)	45 (86.5)	15 (28.8)	37 (71.2)
35 to 44	15 (65.2)	8 (34.8)	10 (43.5)	13 (56.5)	4 (18.2)	18 (81.8)	8 (34.8)	15 (62.2)
≥ 45	2 (22.2)	7 (77.8)	3 (33.3)	6 (66.7)	1 (11.1)	8 (88.9)	4 (44.4)	5 (55.6)
Education								
None	22 (45.8)	26 (54.2)	18 (37.5)	30 (62.5)	9 (19.1)	38 (80.9)	13 (27.1)	35 (72.9)
Primary	51 (52.0)	47 (48.0)	60 (60.6)	39 (39.4)	16 (16.2)	83 (83.8)	22 (22.2)	77 (77.8)
≥ Secondary	2 (50.0)	2 (50.0)	2 (50.0)	2 (50.0)	0 (0.0)	4 (100.0)	1 (25.0)	3 (75.0)
Pregnancy fistula occurred	($P < 0.001$)						($P < 0.001$)	
1st	28 (33.7)	55 (66.3)	55 (65.5)	29 (34.5)	13 (15.5)	71 (84.5)	9 (10.7)	75 (89.3)
2nd	10 (55.6)	8 (44.4)	10 (55.6)	8 (44.4)	2 (11.1)	16 (88.9)	4 (22.2)	14 (77.8)
3rd	9 (69.2)	4 (30.8)	4 (30.8)	9 (69.2)	3 (23.1)	10 (76.9)	6 (46.2)	7 (53.8)
4th	12 (85.7)	2 (14.3)	2 (14.3)	12 (85.7)	2 (14.3)	12 (85.7)	6 (42.9)	8 (57.1)
≥ 5th	15 (71.4)	6 (28.6)	9 (42.9)	12 (57.1)	4 (20.0)	16 (80.0)	10 (47.6)	11 (52.4)
Duration with fistula, years	($P = 0.002$)							
< 1	58 (54.7)	48 (45.3)	55 (51.9)	51 (48.1)	20 (18.9)	86 (81.1)	25 (23.6)	81 (76.4)
1 to 5	4 (50.0)	4 (50.0)	6 (66.7)	3 (33.3)	3 (33.3)	6 (66.7)	2 (22.2)	7 (77.8)
≥ 6	13 (36.1)	23 (63.9)	19 (52.8)	17 (47.2)	2 (5.7)	33 (94.3)	9 (25.0)	27 (75.0)

she wanted to get married again, but she hoped very much to have a baby.

Some other women, particularly those who had also experienced the loss of their baby during labour, expressed a desire to have children. Of 151 women in the quantitative study, more than one half (55%) expressed a desire to give birth in the future. Most of these women (81%) had lived with a fistula for less than one year, and many (69%) were primigravid. The findings suggest that young age, low parity, and a shorter time living with a fistula are positively associated with a woman's desire to become a mother in the future ($P < 0.005$) (Table 5). These results complemented the narratives of some women in the qualitative interviews:

> "I will go home and rest and wait until the period of abstinence passes—according to the instructions that is four months. Thereafter, I will see if I can get pregnant again." (Sofia)

The experience of rejection and the suffering and negative experiences associated with living with fistula made some other women think that it would be a long time before they would want to have children:

> "I will never forget the pain I got from this problem [pause]. I will wait for a long time before I have children. I just leave everything to God." (Milka)

Others, who already had children and were healed, were quite determined neither to get pregnant again nor to find someone to marry:

> "I will never marry. One child I have is enough . . . after all, who will marry me?" (Wema)

Women who had bad obstetric histories seemed to retain little hope of having a child in the future:

> "I will not deliver again . . . yes, one is enough. I have had four deliveries. All were bad luck. So I don't think it will happen." (Ashura)

3. Hoping for a social life

The majority of women living with obstetric fistula (89%) expected that their friends would not accept them even after successful fistula repair. Some of the women in the qualitative study said that they would never want to have close friends again because of finding that their friends did not support them at the time they needed them most:

Table 5. Determinants of women's expectations to give birth again after fistula repair

N = 150	Yes n (%)	No n (%)	Don't know n (%)	Not possible n (%)	*P*
Age, years					< 0.001
15 to 24	58 (69.9)	5 (10.9)	4 (23.5)	0 (0.0)	
25 to 34	22 (26.5)	22 (47.8)	8 (47.1)	0 (0.0)	
5 to 44	3 (3.6)	13 (28.3)	5 (29.4)	2 (50.0)	
≥ 45	0 (0.0)	6 (13.0)	0 (0.0)	2 (50.0)	
Education level					0.72
None	24 (28.8)	13 (28.3)	8 (47.1)	2 (50.0)	
Primary	56 (67.5)	32 (69.6)	9 (52.9)	2 (50.0)	
≥ Secondary	3 (3.6)	1 (2.2)	0 (0.0)	0 (0.0)	
Marital status					0.05
Married	53 (63.9)	33 (71.7)	10 (58.8)	2 (50.0)	
Single	20 (24.1)	3 (6.5)	1 (5.9)	0 (0.0)	
Divorced	9 (10.8)	10 (21.7)	6 (35.3)	2 (50.0)	
Widowed	1 (1.2)	0 (0.0)	0 (0.0)	0 (0.0)	
Pregnancy in which fistula occurred					0.003
1st	58 (69.0)	14 (16.7)	9 (10.7)	3 (3.6)	
2nd	10 (55.6)	6 (33.3)	2 (11.1)	0 (0.0)	
3rd	6 (46.2)	6 (46.2)	1 (7.7)	0 (0.0)	
4th	7 (50.0)	5 (35.7)	2 (14.3)	0 (0.0)	
≥ 5th	2 (10.0)	14 (70.0)	3 (15.0)	1 (5.0)	
Duration with fistula, years					0.005
< 1	67 (80.7)	28 (60.9)	11 (64.7)	0 (0.0)	
1 to 5	5 (6.0)	2 (4.3)	1 (5.9)	1 (25.0)	
≥ 6	11 (13.3)	16 (34.8)	5 (29.4)	3 (75.0)	

> "I will never have friends because they discriminated against me when I needed them most." (Wema)

Asha, by contrast, was pleased with her current social situation. She was able to interact freely with her friends and neighbours in the community in which she lived. During visits, the researcher observed Asha's friends plaiting her hair and chatting and laughing with her. Asha declared that what made her most happy was having her friends back. Some of them had deserted her because of her odour, but she could now sit together with friends as before, and take part in the social life of the community, including religious ceremonies:

> ". . . I am no longer obsessed with the changing of clothes; no worries of soiling or smell, and all other embarrassments are all gone."

Some other women were also optimistic about regaining a normal social life after complete healing:

> "I will be very happy to be with my friends again. With my friends we will chat for a long time, and laugh as usual, because for now even laughing is not possible." (Jenifer)

> ". . . because I will be cured, I will feel good and normal doing my activities as usual. If my friends visit, I will speak without fear, I will be free from fear and sit comfortably without tightening my legs and being restless with fear." (Ashura)

4. Worrying about survival

Asha and her sister owned three acres of farmland, and they both went to the *shamba* (farm) to work every day. Because Asha was still leaking urine and had no access to water for washing, she could not stay for long. The urine burnt her skin, but as Asha emphasized, the work was necessary for survival and for social acceptance: "If you don't work and get money, nobody can support you for everything. You will become a burden to others and you will be less valued."

Because of her limp, Asha joined Chama cha Walemavu Mpwapwa, the Mpwapwa society for the disabled. The

organization gave all its members a health insurance card, paid members' medical bills, and boosted them economically through the support of income-generating activities. Despite her work in the *shamba* and support from Chama cha Walemavu Mpwapwa (Mpwapwa Society for the Disabled), Asha was unable to sustain herself economically, and she depended on her sister, who supplemented her income through the sale of local brew in the village.

Most of the women (80%) believed that, if cured, they would be able to make a living by themselves, and very few (4%) thought that they would seek support from NGOs or other organizations (Table 2). Among those who expected to make a living by themselves, 59% (n = 70) wanted to be mothers in the future, and 55% (n = 50) wished to marry again. The results also indicated that there was a significant association between women's expectations of making a living by themselves and their wish to have children ($P < 0.001$) or marry ($P = 0.002$) in the future.

The hope and expectation of having work and becoming self-sustaining after surgery also came through strongly in the qualitative interviews:

> "I will be able to do many activities, for example, farming. At present, my farming is ineffectual and I supplement this with petty business, and pottery to earn a living. I will continue with this." (Jenifer)

Taking up the work they did before they were affected by fistula was a goal for many:

> "If I am healed, I will continue with my earlier business of selling charcoal." (Wema)

Having work and being able to provide for themselves was seen as a way to restore their value as women and potential wives:

> "When I am healed, I will be very happy. First, I will find a job and work hard because if I have money, my value will be restored and I can be married again." (Halima)

DISCUSSION

How the women in our study expected to reintegrate into society after successful fistula repair seemed to be linked to a complex of factors associated with their experiences of living with fistula and suffering the physical and social consequences of the condition before surgery, their reproductive history, and their ability to work and be economically independent. Their hopes and concerns about the future were related to social acceptance in their family and their community, to economic survival, and to their ability to give birth and become mothers.

Our study findings point to a close association between having an independent income and regaining dignity as a woman in the community. In line with the findings of another study conducted in Tanzania,[23] the common expectation of women in this study was to go back to their households, to resume farming responsibilities, and to earn a living as they had before the fistula experience. As noted by others,[23] women who reintegrate into their communities after fistula repair demonstrate a positive connection between being able to work again on the farm and their reintegration process. Women acquire respect, especially from their husbands, if they are able to make financial contributions to the family.[11]

But despite full recovery, many women are unable to sustain themselves after they return home because they have been left out of economic activities for many years. Economic difficulties may compromise their quality of life[23] and the degree to which they reintegrate. Those who are most adversely affected are women who are not completely healed and who have trouble engaging fully in farming or other work due to complications such as urinary stress incontinence.[23,32,33]

At present, there are a number of international and local non-governmental organizations and community-based initiatives that assist in the rehabilitation and reintegration of women into their families and communities after fistula surgery.[34,35] These organizations focus on building capacity in literacy and income-generating activities.[36] For instance, recognizing economic challenges that women affected by obstetric fistula face even after they are fully recovered, a hospital in Nigeria provides women with skills in embroidery and tie-dyeing[37] to help them become financially independent. However, the assistance provided by some of the NGOs is not enough to free these women from their dependency.

As illustrated in this study, being able to bear a child was prominent in women's hopes and expectations of life after fistula repair. Although many women felt that they would not like to marry again, nearly all wished to regain their reproductive capacity and to have children. Central to the experience of developing the fistula was the loss of the child. As documented in other studies, many women affected by obstetric fistula have given birth to stillborn babies and have been left childless.[34,38,39] In the Tanzanian culture, being a mother is salient to one's

identification as a woman. The value of women is, as in many other African societies, connected to having children,[13,40] which brings respect, honour, and a sense of pride.[40] The loss of a child or having no children means a loss of social status. Not realizing motherhood means not realizing womanhood and the position and status granted to women as mothers and reproducers of the lineage. In this study, women who had children before they developed a fistula expected less rejection from their husband and in-laws after fistula repair than women who had not had a living child.

After complete treatment and cure of fistula, women can become pregnant and have children; the chance of achieving a successful pregnancy ranges from 19% to 29%,[41,42] and studies conducted in Tanzania[23] and Malawi[25] found that some women have successfully delivered live babies following fistula repair. However, women who have had fistula surgery can also experience the possible consequences of obstetric fistula, including infertility, miscarriage, and perinatal mortality.[25] As part of the reintegration process after fistula repair, women need help restoring their reproductive capabilities. In subsequent pregnancies, these women would require close follow-up during the antenatal period, appropriate nursing care, and delivery by Caesarean section.[43] They must be advised about the importance of early and regular pregnancy monitoring and of the importance of Caesarean section.[42]

At the core of women's expectations of life after fistula repair was the hope of regaining their identity as a woman. For women who have lived with obstetric fistula for many years, reintegrating into the community involves a redefinition of self and a transition from being identified as filthy, dependent, and unworthy to being identified as clean, feminine, and active in family and community life. This transition involves a change not only in how others perceive them, but also in how the women perceive themselves. An illness carries meaning both on the concrete level of symptoms and on the higher level of the cultural significance attached to that particular disorder, which is often stigmatized.[44] A chronic illness may be so central in a life course that it becomes "inseparable from life history"[44] and therefore becomes part of a woman's identity. In the life course of women who have suffered the consequences of obstetric fistula for many years, the humility of leaking and smelling and the experience of social exclusion shape their perception of self as unworthy.[1] Hence, the suffering of a woman affected by fistula and the meanings that she and others attach to it become an embodied part of her sense of self.[45]

The majority of women in this study did not expect to go back to live with their husband or to marry again after fistula repair. Even women who expressed a deep hope that they would be accepted as a wife after surgery were very uncertain. Some women did not wish to return to their home communities. This finding is consistent with other studies.[20,46] It has also been documented that even when women manage to reintegrate into their communities after surgery, they continue to feel socially isolated.[9] Women's educational status was found not to influence women's perceptions of their reintegration into the community, probably because educational status was very low across the study sites. Almost all of the women (97%) were illiterate or had attained only primary education.

Reintegration of former fistula sufferers into family and community life after surgery has focused primarily on their needs. The "reintegration needs" model developed by Data, Indicators and Research Group of the International Obstetric in 2006[26] maps the physical and mental health needs and the needs for social and economic well-being of women after obstetric fistula surgery. The findings in this study strongly support the need to address reintegration issues in this comprehensive manner, but we argue that in order to address this problem adequately, the perspective of needs should be complemented with a perspective of how suffering becomes embodied and how stigma produces a spoilt identity.[47] After repair, a major challenge is to transform a "spoilt identity" as filthy and unworthy to an identity that corresponds with the cultural expectations of being a woman.

The mixed method of analysis for our study was chosen in order to capture both the patterns and the unique individual perceptions of social reintegration after fistula repair. The convenience strategy used in sample selection for the quantitative part was appropriate for this study. It helped us obtain an adequate number of participants within the data collection period in a context where the nature of the fistula problem, and the stigma attached to it, prevented many women from seeking treatment. There are many obstacles in conducting community follow-up research, including costs and drop-outs, but there is still a need to follow up the women affected by obstetric fistula to assess their living conditions after fistula repair. One case study was followed for six months and gave us an insight into how the expectations of women affected by obstetric fistula were met when they return to their original places of residence. We believe that these findings are relevant in many other settings of sub-Saharan Africa with socioeconomic conditions similar to those of Tanzania.

CONCLUSION

Women who have had surgical repair of an obstetric fistula expect to improve their physical, mental, social, and economic well-being, but for women who have lived with fistula for many years the transition to a normal life can be challenging in terms of re-establishing an identity as a woman, having a live-born child, securing an income, and restoring dignity. In order to facilitate this transition, surgical repair needs to be accompanied by psychological and social rehabilitation. A holistic approach involving different participants at different levels is required and should take into consideration women's sexual and reproductive needs as well as strategies for their economic empowerment.

ACKNOWLEDGEMENTS

We would like to thank the Gender, Generation and Social Mobilization (GeSoMo)-NUFU Project, University of Bergen, Norway, for initiating the study as part of a larger inter-country study and for financial support. We are greatly indebted to participants who contributed important information to this study. We thank the CCBRT and BMC hospitals' leadership and the staff working in the fistula wards. Thank you Stephen Noel and Devota Samuel of the AFNET project for organizing and assisting in community data collection. This research was conducted as part of a PhD study at the Muhimbili University of Health and Allied Sciences (MUHAS).

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