The quality of life of Ethiopian women after fistula repair: Implications on rehabilitation and social reintegration policy and programming

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Short Title: The quality of life of Ethiopian women after fistula repair

Abstract
Despite growing recognition of the importance of linking obstetric fistula prevention and treatment strategies with rehabilitation and social reintegration programs, little research and programming have been oriented toward this goal. This mixed-methods study aimed to examine the experiences of 51 Ethiopian women after fistula repair surgery to identify priority post-repair interventions that could maximise their quality of life. The study showed that the majority of women felt a dramatic sensation of relief and happiness following repair, yet some continued to experience mental anguish, stigma, and physical problems regardless of the success of the procedure. All women suffered intense fear of developing another fistula, most commonly from sex or childbirth. Despite this, the majority of women planned to have sex and children, while a smaller cohort avoided these behaviors, thus subjecting them to isolation, marital conflict, and/or economic vulnerability. Our findings suggest that obstetric fistula programs should integrate post-repair counseling about fistula and risk factors for recurrence, community-based follow-up care, linkages to income-generation opportunities, engagement of fistula survivors for community outreach, and process and outcome metrics for evaluating reintegration efforts to ensure women regain healthy, productive lives.

Key words: obstetric fistula; rehabilitation; social reintegration; reproductive health; Ethiopia

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Introduction

Fistula, which affects 2 to 3.5 million women and girls in developing countries, is characterized by a hole between the bladder and vagina and/or rectum that forms typically after prolonged, obstructed labor (De Ridder, Badlani, and Browning 2009; Wall 2006). The resulting potent odor from uncontrollable urinary and/or fecal incontinence subjects women to extreme isolation and stigmatization from their families and communities (Wall 2002). It is common for these women to be abandoned by their husbands, relegated to separate eating and sleeping areas, excluded from social events and religious practice, and to struggle to engage in income-generating activities (De Ridder, Badlani, and Browning 2009; Ahmed and Holtz 2007; Muleta, et al. 2008). Furthermore, the vast majority (85%) of women lose their babies during the birth that leads to their fistula, which can jeopardize their social value and marital relations (Ahmed and Holtz 2007). These factors predispose fistula victims to low self-esteem, stress, depression, anxiety, fear, loss of libido and sexual pleasure, and even suicide (Weston, et al. 2011).

The success of obstetric fistula treatment has largely been defined in terms of the surgical closure rate, which can be achieved in up to 90% percent of cases (Arrowsmith, Ruminjo, and Landry 2010). However, the psychological trauma and other physical sequelae (e.g., stress incontinence, infertility, amenorrhea, and foot-drop) often persist after treatment and undermine women’s quality of life (Yeakey, et al. 2011; Hassim and Lucas 1974; Ahmed and Holtz 2007; Roenneburg, Genadry, and Wheeless 2006; Waaldijk 2004; United Nations General Assembly 2012). In recognition of the multidimensional pathology that obstetric fistula patients experience, ‘Obstructed Labor Injury Complex’ advocates for treatment services to look beyond the hole that causes incontinence and address ongoing mental, sociocultural, and physical health problems (Arrowsmith, Hamlin, and Wall 1996). Indeed, in a small study of Kenyan women, all participants experienced long-term psychological trauma, reduced sense of self-worth, and distress over their ability to conceive children after their treatment (Khisa and Nyamongo 2012). Moreover, Pope, Bangser, and Requejo (2011) showed that 4.5 years after treatment, Tanzanian women felt their ability to return to work, principally in agriculture, and having family support were critical to their recovery. The paradigm for understanding women’s experiences with and perceptions of their recovery must account for aspects of wellbeing other than the surgical procedure.

The need to integrate prevention and surgical treatment strategies for obstetric fistula with rehabilitation and social reintegration programs is increasingly recognized (Muleta, et al. 2008). The United Nations Population Fund recommends ‘education, counseling, life skills training, and financial and social support services to help women reconnect with their families and communities, strengthen their economic self-sufficiency, and rebuild their self-esteem after years of isolation and stigma’ (UNFPA and Engender Health 2003). Yet, according to a needs assessment of obstetric fistula practitioners and patients in nine African countries, these services and community follow-up were nearly non-existent (UNFPA and Engender Health 2003). Part of this implementation failure lies in the lack of evidence about which interventions to prioritize in the face of limited financial and human resources.

There is a small but growing body of research on women’s experience following fistula repair surgery to help clarify their rehabilitation needs (Ahmed and Holtz 2007). To date, few studies have focused on Ethiopia, home to 26,000-40,000 women with obstetric fistula (Fantu, Segni, and Alemseged 2010; Thankam and Marguerite 2009; Muleta, Rasmussen, and Kiserud 2010). With only eight physicians, nurses, and midwives per 10,000 population, and only ten facilities offering fistula repair services, less than 2,000 women receive treatment each year of
the 9,000 who develop it (Direct Relief International 2012; African Health Workforce Observatory 2010). A mixed methods study of over 1,900 households in Ethiopia found that of the 55 women with fistula only 14 had been treated, many of whom complained of persisting health problems and nearly half said they continued to experience depression without redress (Muleta, et al. 2008). Two other studies in Ethiopia found that, following repair, simple social activities, namely visiting friends, travelling by bus or going to the market, and restoration of sexual relations and fertility were the major drivers of perceived improvements in wellbeing (Browning and Menber 2008; Neilson, et al. 2003). This study aimed to examine the post-repair experience and perceptions of Ethiopian women to ensure they regain healthy, productive lives.

Methods

Study Design

A mixed-methods research study was conducted to examine the experiences and perceptions of Ethiopian women after they develop fistula and obtain repair services with support from Pathfinder International’s Integrated Family Health Program (IFHP). Pathfinder International is a nonprofit organization that works in developing countries to improve access to and uptake of quality reproductive health, family planning (FP), and maternal, newborn, and child health (MNCH) services. One component of IFHP, a USAID-funded FP/MNCH program, identifies women with fistula and facilitates referral by providing accommodation and transportation to and from hospitals in four regions of Ethiopia. This analysis of the qualitative data focuses specifically on the post-repair period.

Ethics approval for the study was obtained from each of the four regional health bureaus. IFHP staff were trained to invite women who received fistula treatment with support from IFHP to participate in the study. All women who were invited participated. Staff were trained to recruit a diverse group of women in terms of age, parity, and socioeconomic status. This selection methodology resulted in a purposive sample of 51 women. The sample size was based on the objective of achieving thematic saturation.

A team of four trained interviewers native to Ethiopia conducted in-depth interviews in local languages using a semi-structured questionnaire in June 2011. Before implementing the interviews, interviewers participated in a three-day training that addressed research ethics and procedures and qualitative interview techniques. Interviews were completed at Yirgalem Hamlin fistula center and Welayita Sodo Africa Humanitarian Action Office in Southern Nations Nationalities and Peoples (SNNP) region, at Abebech Gobena Children Aid Center, IFHP West Arsi Zone Health Office, and IFHP East Hararghe Zone Health Office in Oromia region, at IFHP Amhara Regional Health Office and North Gondor Zonal Health Department in Amhara region, and in office spaces organized by the IFHP Tigray Regional Health Office in Kofla and Adwa woredas in Tigray region. Interviewers read an information sheet to each participant to obtain their informed consent and ask for permission to tape record the interview. On average, 3-6 interviews were conducted per day, each lasting approximately 1.5 hours. Interviewers audiotaped and took notes on each interview, then transcribed them verbatim.

Analysis

Each interviewer used narrative thematic techniques from grounded theory to analyze the data and develop a taxonomy of domains. For these domains, subthemes were developed and representative quotes chosen. The analysis methodology was largely inductive, but particular interest in patterns surrounding family planning followed a more theoretical thematic analytical
approach (Virginia and Victoria 2006). The interviewers drafted reports on the preliminary findings, translated them into English, and shared them with members of the research team based in Addis Ababa and at Pathfinder’s headquarters in the United States. After review by the study team, key themes and outliers were identified and the interviewers were asked to extract all relevant information from the transcripts and to translate that into English. Another member of the research team synthesized these reports, and used axial coding to expand upon and revise the thematic framework. During this stage in the analysis, the local team was consulted to provide feedback and clarification.

Results
The 51 participants were between 17 and 68 years of age with an average age of 35 years (median 30 years) (Table 1). Most women were uneducated (n=38, 75%). While the majority were married at the time of the pregnancy that led to the fistula, five women had never been married, four of whom became pregnant following a rape. By the time they had their repair, 35% of women were divorced or separated. Thirty five percent of women were still married, and the five women who had never been married remained so. Just over half of women (n=27) had no children, and a quarter had either 1-2 children (n=12) or 3-5 children (n=11).

All women developed fistula following obstructed labor. It was unclear whether or not the four rape victims’ sexual assaults affected their fistula development. Only eight infants (15.7%) survived the birth that led to fistula. This was the first pregnancy for 34 women (66.7%). Women suffered an average of 9.8 years before receiving repair (range: 2 weeks to 42 years).

Physical health recovery and gaps
Forty-two women (82%) no longer suffered from urine or fecal leakage following their repair surgery. The majority of women felt a dramatic improvement in their health after fistula repair. Some women complained of minor ongoing problems including headache, swelling and pain in their breasts, pain during urination, cardiac problems, stomach pain, especially while traveling long distances, and, less frequently, a sensation of warmth on all or some parts of their bodies and pain from labor intensive work or baking injera. One woman believed that she developed epilepsy during her ‘lonely life with fistula’. Although women attributed these health issues to their fistula, they may not be related. On the other hand, a few women reported problems known to be related to fistula; one woman reported amenorrhea, two reported foot-drop, and two women said they wanted to have a child but were struggling with infertility.

Nine women, some from each region, reported that although they could control fecal leakage, they still could not control their urine flow. Most of these women acknowledged that they experienced improvement in their health, but continued to suffer from ongoing problems.

My health has improved. I am interacting with people. But I am still not free. I could not get out of bed before fistula repair, I can now. But my urine still leaks… I can do nothing independently and I cannot go the market. (Oromia, 18 years old, Muslim, divorced)

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3 Injera is a yeast-risen flatbread that is a staple food in Ethiopia.
One young woman was concerned that her persistent leakage and amenorrhea would undermine her chances of having a baby and getting married, but she was waiting to hear from the hospital about when to return.

Mental health relief and ongoing desperation

Women experienced a powerful sensation of relief, happiness, and hope after their successful surgical repair, as many did not know that this procedure was possible. They had a deep sense of gratitude for not being different from other women. Many no longer felt discrimination, and instead felt back to normal—‘like rising from the dead’—and ‘finally felt like a human being’. Simple, daily affairs, such as being able to visit relatives and neighbors, wear white clothes, drink coffee, and attend the market transformed many women’s sense of self and outlook on life.

Women’s mental health status was particularly influenced by their ability to reengage in their community and family life, in sharp contrast to the extreme social isolation and abuse most experienced during the time they had a fistula. Most women were eager to and felt capable of reintegrating into their community and participating in social gatherings and religious ceremonies. The majority of women in Tigray and SNNP regions said they spend their time thanking God and attending church and many in Oromia were happy to be able to attend Mosque to pray, which they were unable to do before their repair.

Before [my repair], I hid myself from the community, but now I can do whatever I want anytime. (Amhara, 22 years old, Muslim, married)

Before my repair, I was not going to different social events like funerals and invitations. After the repair, I go where I want. I believe I am not different from anyone. I am the same as any woman. I can sit as I want. Nothing is there to make me feel worried. (Oromia, 45 years old, Orthodox, divorced)

However it was evident that even with complete repair some women continued to experience residual distress and anxiety. For example, one woman shared that when she participated in community events she did not feel equal to other women because those who knew about her history still discriminated against her. Specifically, when other women were invited for meetings and trainings, she was not included because everybody thought she was incapable of participating. Others felt inadequate because they were limited physically, which had implications on their ability to participate in public works programs or certain cultural events, and thus exacerbated their low self-esteem. Moreover, a few women were subject to outright discrimination despite no longer leaking urine or feces.

When I pass along the road, young people say ‘bad smelling woman’ because they hear adults talk about me negatively. I feel not as normal as other woman, so I can’t sit confidently even if I have no leakage because others don’t want to sit next to me. (Tigray, 30 years old, Orthodox, divorced)

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4 White clothes are worn at formal events so they have cultural importance in Ethiopia.
The nine women whose incontinence persisted continued to live in anguish. They believed people in their village still disliked them, which they attributed to a lack of education and understanding among their communities about the circumstances that lead to fistula.

It is all the same after treatment. I get demoralized. I have no communication with my husband. My friends do visit me. My parents are the only close people to me, but they do not understand my fistula. It is only God and me who know my case. (Oromia, 18 years old, Muslim, divorced)

It was common for these women to deprive themselves of food or drinks at social gatherings and community events because they feared that they would leak urine. Without access to follow-up services, a few women’s persistent fistula made them feel such desperation that they contemplated suicide.

After my physician said they have done all what they can do, I do not think I will be cured. Because of this there is no change in my living condition after repair, so I do not like being alone and rather wish to die sooner. (SNNP, 28 years old, Protestant, married)

Fear of fistula recurrence
Nearly all women experienced intense fear that they would experience a relapse. The majority of women believed they had an elevated risk of developing another fistula from having sex, a subsequent pregnancy, or doing physical tasks. Thus, many women avoided sexual activity, marriage or remarriage, or demanding work.

I do not want [sex], is it not the cause of my problems? I want to live healthy and I do not want to get in trouble after all. Do not speak about sexual relations; it is the cause of all problems. What does a husband do other than causing fistula? Fearful! (Oromia, 23 year old, Orthodox, divorced)

Those who were not in a position where they could negotiate these decisions lived in perpetual fear of developing the condition again. Two women went so far as to avoid cultural activities that involved intense physical movement, such as funeral rites where women jump and clash themselves on the ground, and riding in cars for fear that ‘the fistula might be untied from the car’s movement’. Several women expressed they ‘don’t feel free during sex’ and some were afraid that their husbands would not send them to the hospital for their next birth.

Marital status
At the time of repair, the marriages of 17 women had already fallen apart due to the fistula. Several married women who felt that their husbands were placing unreasonable demands on them to farm or have sex were considering leaving their marriages as well. It was less common for women to initiate separation, yet a handful of women had already or were in the process of asking their husbands for a divorce. Only two women received ownership of their rightful portion of property following separation, which typically left them landless.

Women who had been abandoned by their husbands commonly harbored negative perceptions of men and were not interested in remarrying.
My husband remarried within one week after I developed fistula. After my fistula was repaired, I totally do not want to get engaged in a relationship with a male partner. Today’s males are good for nothing. They are not there with their partners during difficult times. I do not think about this. (Oromia, 22 years old, Orthodox, divorced)

In contrast, 18 women said their husbands continued to be supportive and assumed more responsibility over the household to support their recovery.

My husband could not go with friends as his clothes smelled like urine because he spent much of his time with me. Now we are happy. My husband came to the fistula care center when they warned us not to do heavy work and then after he does not allow me to do such tasks and does it himself. (Oromia, 30 years old, Muslim, married)

Those who were interested in remarrying planned to do so only after they fully recovered, even though they feared remarrying might lead to another fistula. Older women were more focused on raising their children or grandchildren or earning money than pursuing a relationship.

Perspectives on childbearing and sex
Among women of reproductive age, there was a strong trend toward wanting to have children after full recovery. This was especially true of women who did not have any children or did not have a son, as significant cultural value is placed on bearing children, especially boys. A thirty-year old woman in Tigray said she really wanted another child to please her husband since she had only given birth to a girl. She explained that husbands in her community expect their wives to give birth to a baby boy as soon as possible, otherwise they go to another woman. So, she is determined to have a baby boy so that she can ‘stop giving birth and take care of her health’.

Women perceived fertility, both before and after fistula repair, as a major factor in sustaining their marriage.

I want to have two more children, if God allows, because in Sidama culture having children makes women respected. (SNNP, 28 years old, Protestant, married)

Women were very motivated to follow their doctor’s advice to avoid intercourse for three months to one year following their repair surgery or until they had fully healed. However, the desperation to have a boy drove one woman to continue to have sex with her husband even after she noticed her urine leakage was worsening. Many husbands felt entitled to have sex when they wanted to, which was frustrating for women who were disinterested in sex, and terrifying for those who feared that it would cause another fistula. One woman preferred to sleep on the ground with her children so that she could avoid sex with her husband altogether. However, her husband told her it was her duty to have sex with him because she was his wife and he was feeding her; this was a major source of conflict for the couple. Another woman agreed to have sex with her husband shortly after her repair if he arranged for her to go to the hospital if she developed another fistula. In general, women were very conscientious about the need to carefully plan to have their next birth at a healthcare facility, and most intended on delivering at the fistula hospital where they had received treatment.
In other cases, husbands respected their wives’ wishes, and they had positive sexual relations. A woman in Tigray explained that because her husband had been trained as a volunteer community health worker, he had learned about what causes fistula, so he did not pressure her to have sex with him.

After the repair, I didn’t have sex with my husband for one year. Now our sex life is back to normal. (Amhara, 18 years old, Orthodox, married)

Four of the respondents had children after their repair, which some felt was the happiest event in their lives following fistula repair because it brought them respect. In contrast, two women were struggling with infertility, and at a loss of understanding why they could not become pregnant. This created significant stress because they worried their husbands would leave them. One of these women visited local health workers for advice but had not received satisfactory guidance.

Generally, if women were older or already had two or more children—including at least one son—they were more focused on caring for their existing children and recovering their health than increasing their family size. For these women, the fear of having another fistula from complicated labor combined with their age and/or satisfaction with their family outweighed their desire to have subsequent children.

In order to prevent or space pregnancy, several women used or thought about family planning services, specifically Depo-Provera, Implanon and in one instance, Norplant. Several women had used contraception following their repair to allow themselves time to recover physically before having another child, whereas others planned to adopt a method after having a baby. A few women had stopped using contraception because they were interested in having children or suffered side effects. Most learned about contraception from doctors at the fistula hospitals or from Health Extension Workers at the nearby health post. However, three women who wanted information about family planning had not received appropriate guidance from health workers or could not afford to go to the clinic for contraception.

I [have sex] with care. [Doctors] told me to come back for birth control injection after three months, but I did not go due to lack of transportation. (Oromia, 30 years old, Muslim, married)

Returning to work
After fistula repair, all women tried to avoid fetching water and farming, if possible. Most married women said their husbands tried to compensate for their inability to do physically demanding work, which they had told their husbands was an important part of their recovery process. However, because Ethiopia has an agricultural economy, many women continued to cultivate and sell produce with varying success. Some unmarried women depended on their children to perform farming activities or had their mothers or brothers support them financially.

Typically, women felt responsible for household chores or petty trade. Some women were able to return to the job they had before fistula, but women whose fistulas were not completely healed after repair faced more severe limitations.

I cannot make coffee or bake injera, and during holidays when my brother and his wife go to neighbours, I just sit in the house. (Oromia, 25 years, Muslim, divorced)
Moreover, one woman shared that she felt challenged re-engaging in economic activities after her repair since she had been isolated from economic activities in the community for so long. Some women no longer had the strength or stamina to perform the work they were responsible for before the fistula. Many, particularly those who were unmarried, lamented not being capable of doing more physically taxing work because they could no longer rely on the higher income from such work. One woman in Tigray said she gets jealous of women who earn 20-30 Birr ($1.20-1.80 USD) from daily labor, an impossibility for her since she cannot carry stones and heavy loads. This loss of income exacerbated their economic hardship and threatened their already tenuous livelihood. Financial constraints paired with low self-efficacy and a lack of hospital outreach stifled receipt of necessary care.

It is not as before, but still my urine is leaking and I do not know when my urine leaks. I did not go back for reexamination because my mother has no money to take me. (Oromia, 17 years, Muslim, separated)

Despite the widespread poverty, there was a strong, shared desire among women to become self-sufficient and improve their lives by contributing to their household income. Although women were highly motivated to expand their income-generating activities, they were limited by a dearth of start-up capital or credit. To resolve this issue, many requested a credit service to allow fistula survivors to borrow money to improve their lives. For instance, a woman in Tigray shared that she plans to do better business if she can get credit of 2,000-2,400 Birr ($118-137 USD). Another woman in SNNP wanted to buy and sell coffee and breed cattle in the long-term, but worried she would not have the capital for either.

**Communication gap with fistula care providers**

After the repair surgery, most women felt comfortable asking questions without fear or shame. Yet, four women in Oromia and one in Tigray faced a language barrier with their physician that may have prevented them from sharing important information, such as continuing leakage.

I could not ask what I wanted due to [Amharic] language difficulty. When I left the fistula center to my home, my urine was leaking and there is still no change. (Oromia, 22 years old, Orthodox, divorced)

Another woman regretted that she did not ask her doctor whether there were any risks to giving birth to a child soon after her repair.

Participants had variable recollections of what was included in their post-repair counseling. Most women remembered receiving instruction not to have sex for three or six months after the repair and to refrain from performing strenuous labor. Some women reported being told to avoid traveling for three months, maintain their personal hygiene, deliver at a health institution, take rest during their recovery, or use a contraceptive method to avoid having additional children.

**Reintegration support**

It was common for women to express gratitude for the assistance they received upon their departure from the hospital, particularly clothing, soap, and the money to pay for transportation
back to their homes. Although not all women received money, most said they were given a stipend from the hospital of 330-700 Birr ($20-42 USD). Several women used the money to replace the cow they had sold to cover their medical costs.

The majority of women returned to live with their husband or a close relative, such as their mother, grandmother, brother, or daughter-in-law. A few women strongly disliked their dependency. Younger, unmarried women were particularly eager to have their own home and become independent. There was an underlying sense of failure associated with relying on parents or siblings for support or livelihood.

After my mother died, my father married another and she is not concerned about me; that is why my brother took responsibility to take care of me. But, healthy women are living with their husbands. How can I say I am the same as them? I depend on my brother. I take the farthest possible corner in his house to sit and am served meals all alone. (Oromia, 25 years old, divorced)

Women generally did not receive support from their community, although a few neighbors brought food, milk, or money, fetched water, helped with cleaning, baked injera and/or invited women to participate in social gatherings and public meetings. Some Orthodox Christian women received money, food, or accommodation from their congregation or from a church shelter. There was considerable variation in women’s expectations for the financial support they did receive from their neighbors or religious community. In SNNP, several women who received 80-135 Birr ($4.75-8.00 USD) from church members or neighbors said this exceeded their expectations while the few dissenters felt the assistance was inadequate.

Fistula advocacy

Women frequently said they were willing to participate in fistula advocacy activities, such as raising awareness about the condition in their communities and supporting women who have a fistula to get treatment. Many women said they were already engaged in such activities either by sharing their experiences at the fistula hospital with women who have fistula or encouraging women not to waste their money visiting health centers that cannot perform the repair. Other common messages include the importance of getting antenatal care and avoiding giving birth at home through traditional healers. A couple of women in Tigray said they talked about fistula in public and told other women not to circumcise their daughters or marry early.

Discussion

This study demonstrated the multi-faceted experience of 51 Ethiopian women following fistula repair surgery, and highlighted the existing gaps and opportunities to improve this complex process. Women in our study had to navigate ongoing health problems, potent fear about and confusion over what causes fistula recurrence, and rebuilding their livelihoods. In many cases they did this alone because they could not rely on follow-up care or their husbands, families, or friends to provide needed support.

Currently, there is no recognized essential package of post-repair services for obstetric fistula patients. As such, there was considerable variation in the counseling that women remembered receiving after their procedure. Notably, discussion of common side effects, such as infertility, amenorrhea, and neurological problems, and instruction on how to do pelvic floor strengthening exercises, which has been proven to strengthen the muscles around the urethra to
promote maximum control of urination, were not reported (Bent and McBride 2008). This could have helped the handful of women who experienced side effects to feel more capable of managing or attending to their problem, and minimized the extent of urinary incontinence for the nine women still suffering from it.

Despite the relatively high rate of complete fistula repair (82%), as in other Ethiopian studies (Nielsen, et al. 2009; Kelly 1995; Muleta, Rasmussen, and Kiserud 2010) many women continued to struggle with ongoing physical and mental health problems. Forty percent of women complained of physical health problems regardless of their repair status. All nine women with persistent incontinence and, notably, four women with complete closure continued to suffer from depression, self-induced isolation, or a lack of self-esteem. Women with an unsuccessful repair were in the most desperate state, feeling failure, abandonment, and hopelessness and even contemplating suicide. This is consistent with a follow-up study in Ethiopia which found that 27% of women with a complete closure and all women with residual incontinence screened positive for mental health disorder (Nielsen, et al. 2009; Browning, Fentahun, Goh 2007). This underscores the importance of community-based follow-up visits, accessible mental health services, and support outlets for survivors and their families. Such outreach could also help fill gaps in services at the fistula repair centers due to issues of language compatibility, a concern raised by five women in this study. IFHP has focused on getting fistula victims to the facility because that alone is so difficult (UNFPA 2008; Wall, et al. 2004), however research has found that rural, community-based follow-up in Ethiopia is feasible (Nielsen, et al. 2009; Browning and Mener 2008).

Our study demonstrated that most women of reproductive age, particularly those without children or a son, planned to have sex and children despite their universal fear that such behaviors would lead to another fistula. The fear of relapse coupled with the lack of clarity about what is safe drove many women to temporarily (and some to permanently) avoid sex, remarrying or marrying, and physically strenuous activity. Similarly, in a six-month follow-up survey at Barhirdar Hamlin Fistula Center, 9% of women avoided sex because they were afraid to damage their repair (Browning and Mener 2008). Thus, it is critical to establish systems that help women and their families understand the real risks of repeat fistula and the factors that may lead to it. Counseling programs such as the one pioneered by Johnson et al. in Eritrea (2010) have shown promise in promoting women’s knowledge about fistula and its prevention. These education efforts could be leveraged by including husbands for greater impact (Nielsen, et al. 2009; Hassan and Ekele 2009).

It was evident that most women were eager to invest in their economic independence, yet felt incapable of doing so. This was particularly true for divorced or separated women since they have relatively less economic security and family support. Women’s expressed desires to access credit or resources, such as a milking cow or oxen, to help them launch a small business or engage in income-generating activities indicate that self-sufficiency is an important steppingstone to regaining a sense of control over their lives. This mirrors results of other studies (Khisa and Nyamongo 2012; Kelly 1995; Ahmed and Holtz 2007). Thus, the utility of economic empowerment initiatives for fistula survivors should be evaluated particularly for divorced and separated women given that divorce rates were five times higher among our sample than among the general population of women of reproductive age (Measure Demographic and Health Survey 2012).

Broader community mobilization efforts are also essential to combat the stigma some women reported experiencing after their repair. Taking advantage of the knowledge and
motivation of former patients should be explored as a mechanism to increase awareness of fistula and to organize prevention strategies. Nearly all participants were motivated to share their experience living with and receiving treatment for fistula to help other women avoid their plight. One study found that up to 30% of patients visiting fistula centers were referred by former patients who are now cured (De Ridder, Badlani, and Browning 2009). In our larger study we also found that participants sometimes learned about fistula services from a woman who had been treated (Donnelly, et al. 2013). Given the gap between the estimated incidence of fistula in Ethiopia and the number of women treated, early identification and treatment remain a priority.

One of the key limitations to community-based follow-up studies of this nature is the challenge of engaging the poorest and most marginalized women. In this study, this may have led to the exclusion of women who experienced the worst post-repair outcomes and thus overestimated the positive impact of the intervention. Bias toward women with positive outcomes was also possible during participant selection. However, the sample represented diverse backgrounds and experiences with fistula repair and rehabilitation, suggesting that such biases were minimal. Because the interviews were conducted in local languages, transcribed in Amharic, and summarized in English the interviewers (who did the transcription, translation and summarization) may have filtered information purposefully or accidentally. Careful training in data collection and transcription was used to minimise this potential bias.

The findings of the study demonstrate that importance of extending the continuum of fistula treatment services beyond the surgical procedure to foster women’s holistic recovery. Specifically, integrating 1) counseling about fistula and its prevention during the post-operative care regime, 2) a follow-up system to identify women needing further treatment and to address ongoing primary care and sexual and reproductive health needs, 3) support structures for mental health and income-generation, and 4) increased engagement of fistula survivors and the family members and communities of women affected by fistula would be powerful steps toward improving the quality of life of women following fistula repair. In addition to such interventions, new metrics are needed to evaluate specific components of rehabilitation (i.e., physical, emotional, social, and economic) to inform efforts to strengthen reintegration support (World Health Organization 2006). Current metrics focus on the epidemiology of fistula repair and fail to recognize the complexity of women’s experiences. Without these indispensable components of rehabilitative care, tens of thousands of women in Ethiopia and millions around the world will continue to suffer from avoidable consequences of this tragic condition even after their fistulas are repaired.

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References


Table 1. Characteristics of study participants

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<th>Characteristic</th>
<th>SNNP n (%)</th>
<th>Oromia n (%)</th>
<th>Amhara n (%)</th>
<th>Tigray n (%)</th>
<th>Total n (%)</th>
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<td>Age (years)</td>
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<td>2 (16.7)</td>
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</tr>
<tr>
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<td>16 (31.4)</td>
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<td>Divorced/separated</td>
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<td>Education</td>
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<td>27 (52.9)</td>
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<tr>
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<td>0 (0.0)</td>
<td>2 (3.9)</td>
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<td>Duration of untreated fistula (mean in years)</td>
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<td>1 (8.3)</td>
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<td>9 (17.6)</td>
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<td>5-19</td>
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<tr>
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<td>11 (21.6)</td>
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<tr>
<td>Parity at birth that caused fistula</td>
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<td>First</td>
<td>8 (66.7)</td>
<td>8 (53.3)</td>
<td>7 (58.3)</td>
<td>11 (91.7)</td>
<td>34 (66.7)</td>
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<tr>
<td>Second or higher</td>
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<td>5 (41.7)</td>
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<td>17 (33.3)</td>
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<tr>
<td>No. live births after obstructed labor that caused fistula‡</td>
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<tr>
<td>Outcome of final repair</td>
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<tr>
<td>Successful†</td>
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<td>42 (82.3)</td>
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<td>Unsuccessful†</td>
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<td>2 (13.3)</td>
<td>1 (8.3)</td>
<td>1 (8.3)</td>
<td>8 (15.7)</td>
</tr>
</tbody>
</table>

† Successful repair is defined as the complete absence of urine or fecal incontinence, ‘stress incontinence’ reflects urine leakage only under stress, and ‘unsuccessful’ repair is defined as continual urine leakage in the normal condition. This was assessed via self-report.
‡ Information about the status of the infant after delivery was missing for one woman in SNNP region.
§ One woman is pregnant.