A Qualitative Analysis of the Experience of Women Supported by the Integrated Family Health Project to Reach Fistula Repair Services: Their Experience of Repair Services and Re-integration

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Executive Summary

One of the least discussed—yet most devastating—sources of maternal morbidity and mortality is obstetric fistula, a hole that forms between a woman’s bladder and vagina and/or rectum typically following obstructed labor. This injury results in major psychological and physical disability and social stigmatization. Currently, 2 to 3.5 million women and girls in developing countries suffer from this condition, including up to 40,000 cases in Ethiopia. There has been increasing recognition of the importance of linking prevention and curative strategies with rehabilitation and social reintegration programs to more holistically address fistula, yet little research and programming have been oriented towards achieving this goal.

Over the past three years, Pathfinder’s Integrated Family Health Program (IFHP) supported 2,213 Ethiopian women to receive fistula repair treatment. To examine the experiences of a cohort of women after they develop fistula, obtain repair services, and reintegrate back into their communities Pathfinder conducted a mixed-methods study in June 2011. This analysis of some of the qualitative data focuses specifically on their experiences and perceptions after fistula repair surgery. Semi-structured interviews were conducted with a purposive sample of 51 Ethiopian women in Southern Nations, Nationalities, and Peoples’ Region (SNNPR), Oromia, Amhara, and Tigray. Study approval was obtained by each of the four regional health bureaus.

The 51 participants were between 17 and 68 years of age (mean of 35 years), predominantly uneducated (n=38, 75%) and childless (n=27, 53%), and commonly suffered from divorce following their fistula (n=18, 35%). Women received repair services on average 9.8 years after developing the condition, which was completely repaired for 82% of patients (n=42). In contrast, 18% (n=9) of women continued to experience urinary incontinence. Women unanimously reported positive experiences at the fistula repair hospitals, but received highly variable counseling about behaviors to promote their recovery and rehabilitation. Although the majority of women felt a dramatic sensation of relief, happiness, and hope following repair, many continued to feel distress regardless of the success of the procedure. Nearly all were terrified of developing another fistula by having sex, a subsequent pregnancy or doing physical tasks, which drove many to avoid behaviors related to these actions. However, most younger and childless women wanted to have children, especially a son, and were very motivated to deliver at an institution. Many women were also eager to become self-sufficient, but felt hampered by a lack of income-generating opportunities. Nearly all women were willing to participate in fistula prevention and treatment advocacy initiatives.

Pathfinder’s IFHP model of facilitating fistula repair has had a dramatically positive impact on the lives of underserved Ethiopian women. However, women continue to suffer from the physical, social, and mental health and economic consequences of fistula during their rehabilitation. In order to promote Ethiopian women’s more holistic recovery, programs should prioritize integrating a community-based follow-up system to identify women needing further treatment and sexual, reproductive, and mental health support, bolstering linkages to income-generation opportunities, and designing metrics that assess each of these aspects.
Introduction

Sexual and reproductive health problems remain the leading cause of poor health and mortality for women of childbearing age worldwide. The fifth of the United Nations' eight Millennium Development Goals (MDG) calls for a reduction of maternal mortality by three-quarters and providing universal access to reproductive health. One of the least discussed—but most devastating—sources of maternal morbidity and mortality is obstetric fistula, a hole that forms between a woman's bladder and vagina and/or rectum typically after obstructed labor lasting three or more days. Specifically, the persistent pressure on the pelvis from the fetal head interrupts the blood flow to tissue, which causes the tissue connecting the bladder and/or the rectum and the vagina to die (Figure 1). These openings are on average 2.3 cm long (range 0.1-8 cm) and 2.5 cm wide (range 0.1-10 cm) (Figure 2). This injury results in major psychological and physical disability and social stigmatization. Some of the devastating physical ramifications include urinary (vesicovaginal) and fecal incontinence (rectovaginal), foot-drop and other neurological disorders, orthopedic injury to the pubis, bladder infections, amenorrhea, painful sores, skin irritation, kidney failure, and infertility. Only about 20% of post-repair patients will achieve a term pregnancy, and those who do become pregnant are at increased risk of miscarriage or prematurity due to an incompetent cervix. The United Nations General Assembly first recognized the problem of obstetric fistula in 2005. However, it was not until 2010 that the Assembly adopted a resolution sponsored by 172 countries that called for renewed focus and intensified efforts to eliminate obstetric fistula.

Figure 1. Obstetric fistula development

![Figure 1. Obstetric fistula development](source: www.worldwidefistulafund.org/faqs)

Figure 2. Simple vesicovaginal fistula

![Figure 2. Simple vesicovaginal fistula](source: Arrowsmith et al. 1996)

Women with obstetric fistulas are described as the “most dispossessed, outcast, powerless group of women in the world.” This condition was once prevalent in the United States and Europe, but was largely eliminated in the early 20th century as accessibility to quality obstetric care services improved. Now, it is rare in developed countries, but in developing countries, particularly in rural, impoverished areas of Africa, the Middle East, and southeast Asia, it is a very real threat following a complicated childbirth. The underlying risk factors that predispose women to experience a fistula include low educational attainment, poverty, rural inhabitance, early marriage and childbearing, short birth intervals, insufficient prenatal care and family planning services, gender-based violence, and gender inequality. Women who marry and conceive early are particularly vulnerable because their pelvises are not adequately developed to support childbirth. Once women become pregnant, the three delays framework for obstetric care—delay in seeking care; delay in arriving at a health-care facility; and...
delay in receiving adequate care once at the facility—captures the overarching phenomena that lead to obstructed labor, and hence, fistula. At the first level, many women, particularly those living in remote areas, simply do not have access to skilled birth attendance or referral to higher-level emergency obstetric care. Others do not seek what care is available because they are unaware that fistula can be cured, some attributing their condition to an immutable punishment by God, or are afraid of hospitals and the treatments they offer. At the second level, many women lack the financial support, transportation infrastructure, or self-efficacy to get themselves to the services they need. When labor lasts longer than three days, the consequences of the obstruction, including fistula, increases markedly. Lastly, if women do receive obstetric services, they are often poor quality, plagued by inadequate resources and weak medical staff capacity. Life-saving interventions such as using a partograph to track labor events or performing a cesarean section are beyond the technical expertise of most facilities.

According to secondary analysis of national data on the women who reported having obstetric fistula in Ethiopia’s Demographic and Health Survey 2005, the first survey to collect data on obstetric fistula, women who are young, illiterate, live in rural areas, and lack access to prenatal care services were significantly more likely to suffer from obstetric fistula. Specifically, half of the women had no formal education, two-thirds were in rural areas, the mean age at first marriage was 16.5 years, nearly three-quarters had received no or inadequate prenatal care, and 86% had delivered at home. The following concept map (Figure 3) portrays the pathways contributing to the development and consequences of obstetric fistula.

Equally as devastating as the physical consequences, intense social stigma and rejection is another all-too-common consequence from the potent odor from uncontrollable leakage and misperceptions about its cause. As a result, fistula victims often experience isolation from their families and communities, including separate eating and sleeping quarters. These women are often abandoned by their husbands, excluded from social events and religious practice, and are unable to engage in income-generating activities, thereby deepening their poverty. A meta-analysis of data published between 1985-2005 found that 36% (95% CI: 27%-46%) of women suffering from fistula were divorced or separated, whereas a study in Ethiopia reported nearly 70% of fistula victims were divorced. Furthermore, the vast majority (85%) lost their fetus during the delivery that led to their fistula, which can significantly jeopardize their social value and marital relations on top of the pain caused by losing a child. These factors subject them to major psychosocial trauma, depression, low self-esteem, stress, loss of libido and loss of sexual pleasure, and even suicide. Indeed, a prospective observational study using a validated questionnaire (GHQ-28) found that 66 of the 68 women in Ethiopia and Bangladesh had mental health dysfunction, versus 9 of the 28 controls, and 40% had thoughts of ‘killing’ themselves compared with 4% of controls.

Estimates suggest that 2 to 3.5 million women and girls in developing countries have unrepaired fistulas, and that 30,000 to 130,000 new cases occur each year in Africa alone. The highest prevalence is confined to the “fistula belt” spreading across the northern half of sub-Saharan Africa from Mauritania to developing countries of the Middle East. This region is defined by countries with high maternal mortality, and has obstetric fistula incidence rates as high as 2 to 3 per 100 women. Ethiopia has one of the highest maternal mortality ratios in Africa—350 (range 230-676) maternal deaths per 100,000 live births—and has an incidence of obstetric fistula of 2.2 per 1,000 women of reproductive age. Approximately 9,000 Ethiopian women develop fistula each year alone, and between 26,000 and 40,000 are currently living with the condition. However, these estimates are most likely a gross underestimation of the true incidence and prevalence considering fistula usually occur among the most marginalized women who are unable to access health services to diagnose and/or repair the condition.
Obstetric fistula is both preventable and treatable, yet millions of women continue to suffer from this condition. As promulgated by MDG5, the core interventions to prevent fistula and maternal mortality and morbidity at large include universal access to family planning services, access to skilled birth attendants during delivery, timely access to quality emergency obstetric care, and changing harmful, traditional practices. Furthermore, fistula can be repaired through immediate bladder catheterization, which cures 15% to 20% of patients if performed within the first four to six weeks after delivery, or reconstructive surgery, which is reported to be successful in 41 to 93 percent of cases. The discrepancy among these rates is largely due to variance in the definition of success, traditionally measured by the extent of closure and any ongoing incontinence, as well as differences in sample sizes and study location (i.e. hospitals that care for women with more versus less complicated cases) among published clinical studies of fistula repair. Studies have shown that 5 to 50 percent of patients experience stress incontinence after repair due to the high prevalence of urethral injury during obstructed labor. There is also the possibility of recurrence or 'late breakdown' of the fistula typically during physical strain during sexual intercourse, heavy work, or traveling on a very bumpy road. To minimize fistula recurrence, different management policies have been encouraged, including
the Barhirdar Hamlin Fistula Center’s approach to train women with incontinence grades\(^2\) 4 and 5 at discharge to use the urethral plug and those with grades 2 and 3 to perform pelvic floor exercises.\(^{33,34}\)

To optimize successful repair, several classification systems have been developed based on fistula size, location, and etiology (Appendix I, II, III), which guide clinical decision-making around who should operate and what techniques should be employed, though no consensus exists about which method is superior.\(^{35}\) These systems vary tremendously, with some using a dichotomous distinction between ‘simple’ and ‘complex’ fistulas, each with unique definitions, and others involving multi-tiered, categorical descriptions that, again, can lead to subjective interpretation.\(^{36}\) Some describe the anatomy of the fistula, whereas others seek to predict the difficulty of repair.\(^{36}\) For instance, in a nine year prospective study of 1,716 women with obstetric fistula, Waaldijk et al. classified patients’ fistula into six types and four sizes (Appendix II) to facilitate immediate management and repair.\(^{26}\) There was a clear trend in the rate of successful fistula closure and continence using this scale, with closure in 98% of those with the simplest diagnosis (Type I) versus 86% of those with the most complex (Type IIBb), and 0.4% of Type I versus 48.8% of type IIBb experiencing incontinence. In another study of 1,024 fistula patients at the Bahirdar Hamlin Fistula Unit in Ethiopia, those who had a Type 1, size A fistula were more likely to be continent than those with Types 2-4, and sizes B and C, respectively, and special considerations, including scarring or circumferential fistula\(^3\) were significantly predictive of closure failure (p<0.01) and incontinence (p<0.05) (Appendix III).\(^{32}\) In an effort to create a surgical outcomes-based classification system, Arrow et al. retrospectively examined attributes of 229 Nigerian fistula patients and found that the degree of scarring and urethral status also demarcated a successful repair.\(^{36}\) Other facilities have home grown systems, such as a pictorial description of fistulas based on size, level of scarring, and position in relation to the urethra and cervix (Figure 4).\(^{37}\)

The lack of a standardized method of classification makes a comparative assessment of the published fistula literature impossible, thereby undermining establishment of evidence-based practices.

Despite the existence of treatment and management protocols, however inconsistent they may be, there is a dearth of facilities with healthcare staff trained in the skills necessary to perform fistula repair and rehabilitation procedures. In an effort to advance understanding and awareness of where fistula treatment exists and how many women are receiving care, Direct Relief International, the Fistula Foundation, and the United Nations Population Fund (UNFPA) launched the first ever global fistula map which revealed that fistula treatment reached only 14,000 out of the estimated 100,000 new cases each year—a fraction of those in need.\(^{38}\) From July 2011 to September 2012, researchers surveyed over 300 health facilities in 47 countries that had been identified as providing obstetric fistula repair by leading organizations involved in fistula care and prevention efforts. The survey found ten facilities currently operating in Ethiopia, including two government general hospitals and eight specialized fistula hospitals (Figure 5), which provided 1,927 repairs in 2010-2011 (Figure 6).\(^{38}\) The demand for fistula services far outweighs these facilities’ capacity to provide necessary care.

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\(^2\) Incontinence grading system: 1 (cured, no incontinence), 2 (Incontinent with cough, strain, or exertion), 3 (Incontinent on walking), 4 (Incontinent on walking, sitting and/or lying but voiding some urine), 5 (Incontinent on walking, sitting and/or lying but not voiding any urine)

\(^3\) the entire circumference of the bladder and/or urethra is destroyed so that the urethra is completely detached from the bladder
A range of international and local organizations work to combat fistula throughout the globe, most notably the UNFPA, which launched a global Campaign to End Fistula in 2003. The UNFPA currently serves as the secretariat for the International Obstetric Fistula Working Group. This Working Group promotes collaborative partnerships and generates consensus and evidence regarding effective strategies for preventing and treating fistula and reintegrating women living with fistula into society. Under the Continental Policy Framework on Sexual and Reproductive Health and Rights, known as the Maputo Plan of Action, the African Union also committed to addressing fistula. As such, a number of African countries, including Ethiopian, have developed a national strategy to eradicate obstetric fistula, yet financial constraints have limited progress.

These stakeholders have largely focused on interventions to advocate for greater governmental involvement and resource allocation to fistula programs, streamline fistula prevention and management into safe motherhood and reproductive health policies and services, integrate fistula identification and repair training in midwifery courses, promote collaboration between developing countries (South-South) in addressing the underlying factors leading to this injury, and establish more robust epidemiological data collection systems. The World Health Organization (WHO) has developed a range of epidemiological, service delivery, training, and quality of care indicators to standardize monitoring and evaluation of fistula programs (Appendix VI). One of the glaring gaps in these indicators is that of the 19 indicators, only one related to women’s successful reintegration in their society, a hallmark of women’s quality of life, and it is too general to have any meaningful significance.
There has been increasing recognition of the importance of linking prevention and curative strategies with rehabilitation and social reintegration programs to more holistically address fistula. A needs assessment of fistula practitioners and patients in nine African countries (not including Ethiopia) recommended 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 restore their self-esteem after years of isolation and stigma. A limited number of fistula repair facilities had elementary education programs, vocational skills training (such as basket weaving, knitting, tailoring, and soap-making), safe delivery and family planning counseling, or social support programs, and, concerningly, community follow-up was nearly non-existent. The paucity of rigorous research on women’s psychological experience after fistula repair undercuts the design of evidence-based programs that support women regaining a quality life.
Literature Review

Obstructed Labor Injury Complex, defined in 1996 by obstetricians at the Addis Ababa Fistula Hospital, highlights the multidimensional pathology that fistula patients suffer. This concept diverges from the traditional clinical paradigm for understanding the health impact of fistula. Specifically, it is common for women to have serious physical, mental, and social health consequences from their fistula, thus their perceptions of their repair and experiences reintegrating back into their community are crucial to fully define successful treatment. In particular, women derive significant value from their fertility, having normal sexual relations with their husbands, and being a productive member of their community, thus their quality of life—and the perceived success of the repair—may be influenced by these aspects of reproductive and social health. Ultimately, health is defined not only be the absence of illness, but also as a state of physical, mental, and social wellness. A limited number of qualitative research studies have explored women’s psychological, economic, social, and physical health experience after fistula repair, and few have focused on Ethiopia.

Two studies in rural Ethiopia found that women experienced improvement in their quality of life, most notably from improved social relations and sexual function. Nielsen et al. used the King’s Health Questionnaire, a validated assessment tool for the quality of life of women with urinary incontinence, to interview 38 of the 44 women 14-28 months following their repair surgery. This revealed that surgery significantly improved quality of life—visiting friends, travelling by bus or going to the market—among not only those women who remained dry (n=21) but also those who continued to suffer from incontinence (n=13, p=0.001). In comparison to other studies, higher proportions of these women had stable marriages, kept their jobs, and were multiparous (had more than one child), which may have contributed to the consistent improvement in quality of life. A shorter, six-month follow-up study at Barhirdar Hamlin Fistula Center in northern Ethiopia found that 83% of women reported moderate or greater improvement in their lives, most commonly from social reintegration and restoration of their sexual relations and fertility. However, the authors note that the follow-up period was too short to fully evaluate changes in social situation and fertility rates, and the validity of their data may have been limited due to high attrition (38%) and greater participation from women who had residual symptoms.

Research in other African countries that examined women’s post-fistula experience corroborates the results of studies conducted in Ethiopian. For instance, a large cross-sectional study in Nigeria used the 100-point World Health Organization’s Quality of Life-BREF instrument to examine the quality of life of women before and six months after successful repair. Women experienced the most dramatic improvements in their mental health (32.4 ± 8.7 vs. 74.7 ± 3.2, p<0.01), as compared to a less dramatic change in their physical health (67.9 ± 4.4 vs. 69.3 ± 3.4, p<0.01). Notably, there was no difference in their perception of their environmental health (60.3 ± 4.3 vs. 59.7 ± 2.7, p<0.2), as defined by availability of income to meet their needs, ability to perform daily chores, and participate in leisure activities. The fact that women experienced the most significant improvement in their mental health status reinforces the importance of looking at what constitutes a successful repair beyond just physical changes. Furthermore, in Malawi, Yeakey et al. discovered that women described the success of their repair more in terms of social changes not clinical changes. These factors suggest that a more holistic approach must be taken to understand and promote women’s health status after fistula repair.

A number of studies in Ethiopia reveal less positive outcomes, and especially highlight the importance of follow-up care. In a mixed methods study including in-depth interviews and surveys of over 1,900 households, Muleta et al. identified 14 treated women, many of whom complained of persisting health problems, and nearly half said they continued to experience depression. A small study of eight Kenyan women revealed that all women experienced long-term psychological trauma, reduced sense of self-worth, and distress over their ability to conceive children after their treatment. In interviews with Tanzanian women who had received treatment an average of 4.5 years before the study, Pope et
al. found that women felt their ability to return to work, principally in agriculture, and having family support were critical to their reintegration process. However, the women felt hampered by a lack of follow-up care for sexual function and fertility. These studies indicate a deficiency in follow-up care and a clear need for ongoing mental and sexual health support.

In contrast to the aforementioned descriptive studies, one study tested a counseling intervention aimed at strengthening the physical and mental wellbeing of women undergoing repair. Specifically, Johnson et al. evaluated the short-term impact of pre- and post-operative counseling for fistula patients in Eritrea, which significantly improved women’s knowledge about fistula and how to prevent it, self-esteem, and intentions to use family planning and raise awareness about the condition within their family and community. However, this study was limited by a small sample size.

Aim

The aims of this mixed-methods research study were to examine the experiences of Ethiopian women after they develop fistula, and their perceptions of how their lives changed once they received support from Pathfinder International’s Integrated Family Health Program (IFHP) to obtain repair services. This analysis of some of the qualitative data focuses specifically on their experiences and perceptions after fistula repair surgery. The results have been used to develop a conceptual framework of key factors influencing women’s successful rehabilitation, which Pathfinder and other sexual and reproductive health service delivery and policy organizations can use to inform the design and implementation of fistula prevention, treatment, and rehabilitation programs to benefit women living in rural areas in developing countries.

Study Setting

Ethiopia is located on the eastern coast of Africa, nestled between Kenya and Somalia to the southeast, Sudan and south Sudan to the northwest, and Eritrea and Djibouti to the north. It is comprised of nine states, subdivided into 68 zones and smaller administrative divisions, including woredas and kebeles, the smallest level typically including 5,000 people. More than 80% of the country’s 85 million people, the second largest population in sub-Saharan Africa, live in rural areas. Religion is an important part of life, with about half identifying as Orthodox Christian, one third as Muslim, one fifth as Protestant, and a fraction following a traditional practice. Nearly a third live on less than $0.60 USD a day, relying predominantly on agriculture for economic activity. As one of the poorest countries in Africa, Ethiopia’s per capita income is $370 USD, substantially lower than the regional average of $1,257 USD.

Since the end of the Ethiopian Civil War in 1991, the Ethiopian People’s Revolutionary Demographic Front has led an ambitious reform effort, articulated most recently in the five-year development plan (2010/11 – 2014/15), the Growth and Transformation Plan. One the plan’s main priorities is to reduce the maternal mortality rate (MMR) by more than half, from 590 to 267 per 100,000 live births. Ethiopia is also among eleven high maternal mortality countries to be included in the Maternal Health Thematic Fund as part of a larger joint effort between UNFPA, United Nations Children’s Fund (UNICEF), WHO, and the World Bank to strengthen the most effective interventions at improving maternal health, and thus reduce fistula—family planning, skilled attendance at birth, and emergency obstetric and newborn care. High maternal mortality contributes to women’s low life expectancy of 62 years from birth. Some progress has been made, with recent MMR estimates of as little as 210 and as high as 630 per 100,000 live births, which contribute to 5,500 to 16,000 maternal deaths per year. Between 2005 and 2010, the lifetime risk of maternal death improved from 1 in 39 to 1 in 67.

One of the most daunting challenges is the extreme shortage of health workers; there are only 8 physicians, nurses, and midwives per 10,000 population, far less than the 23 per 10,000 standard recommended by the WHO. Without improvement in health worker capacity, it is impossible for Ethiopia’s 192 obstetricians and 1,379 midwives to adequately serve the 24.7 million women of reproductive age, 90% of whom do not receive skilled birth attendance and as high as 12.2% of
whom experience obstructed labor.\textsuperscript{23,48,54} This has direct implications on fistula incidence and prevalence, as women continue to be predisposed to significant risk for developing new cases and cannot access sufficient services for treatment.

**Pathfinder International and the Integrated Family Health Program**

Pathfinder International is a nonprofit organization that works in a broad range of developing countries to improve access to and uptake of quality reproductive health, family planning, and maternal, newborn, and child health services. For over fifty years, Pathfinder has endeavored to ensure that people everywhere have the right and opportunity to live a healthy sexual and reproductive life. Pathfinder began working in Ethiopia in the 1950s when it helped establish the first family planning and reproductive health clinic. Today, Pathfinder provides technical assistance to the government’s community-based health extension program to strengthen the provision of family planning and maternal, newborn, and child health services to 40 million people.\textsuperscript{55}

One of Pathfinder’s flagship programs is the Integrated Family Health Program (IFHP), a 5-year, USAID-funded health program aimed at increasing use of high impact family planning, maternal, newborn and child health practices, products and services. Pathfinder, John Snow Incorporated and local implementing partners are implementing IFHP in 286 woredas in six regions of Ethiopia: Amhara, Oromia, Southern Nations, Nationalities, and Peoples’ Region (SNNPR), Tigray, Benishangul-Gumuz and Somali. Since 2008, one component of IFHP has focused on identifying women with fistula and facilitating referral by providing accommodation and transportation to and from fistula hospitals in SNNPR, Oromia, Amhara, and Tigray. Once women reach a repair hospital, they receive the support and services offered by the hospital. Some of the women present to the facility with major complications including foot drop from nerve damage and severe weight loss, thus they receive food and healthcare for up to three months to regain their weight and health prior to the repair. After repair, women are catheterized for two to three weeks, and typically stay at the hospital for one week longer. In very rare cases, women stay at the facility for three to six months. There, they receive food, clothing, counseling on contraceptive methods, which are available in the health facilities, and are told to consult providers when they want to get pregnant so they can be scheduled for regular prenatal care. Currently, there is no follow-up procedure for women after they leave the fistula hospital. Over the past three years, IFHP has supported 2,213 women to receive fistula repair treatment.

IFHP has also worked closely with community and religious leaders to engage them in training and advocacy activities on the prevention of harmful traditional practices, gender-based violence, and their responsibility to address the community-based risk factors contributing to fistula development and its consequences.

**Methods**

**Study Design**

For the qualitative component of this study, a team of four trained interviewers conducted in-depth interviews using a semi-structured questionnaire (Appendix IV) in June 2011 with women who had experienced a fistula repair surgery with Pathfinder International’s IFHP program support. The interviews were conducted at seven hospitals in all four regions where the fistula program was implemented. The interviewers are native to Ethiopia and conducted all interviews in the local language, including Amharic, Oromo, Tigrinya, Sidamenga, Waleyetegna, and Kembategna. IFHP staff were trained to invite women who received fistula treatment care under the auspices of 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 who had received a fistula repair surgery. The size of the sample was determined based on the objective of achieving thematic saturation.
**Data Collection**

Before implementing the interviews, interviewers participated in a three-day training that addressed maintaining confidentiality and the informed consent process, and qualitative interview techniques, including how to ask questions effectively and how to record, transcribe, and manage data. One interviewer was assigned per region to conduct interviews with all eligible women in the region. The number of interviews completed varied by region: 12 in SNNPR (6 in Yirgalem and 6 in Welayita woredas), Tigray (6 in Ofala and 6 in Adwa woredas), and Amhara, and 15 in Oromia. Interviewers read an information sheet to all participants in the local language to obtain their informed consent and ask for permission to tape record the interview. The informed consent document presented the purpose of the study and explained that their responses would be kept confidential. Interviewers followed an interview guide (Appendix IV) and encouraged participants to speak about the issues and experiences that were most relevant to them. Interviewers ensured they gave extra time to explain and repeat confusing questions and reframe them using words that respondents could understand, if needed. 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. The interviewers drafted reports on the preliminary findings, translated them into English from Amharic or the local language, and shared each 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 (KD) synthesized these four reports, and used axial coding to expand upon and revise the thematic framework. During this stage in the analysis, the local study team was consulted to provide feedback and clarification.

**Results**

Nine domains emerged through the interviews with women post surgery (Table 1), which confirmed some aspects of this topic reported in the literature while illuminating other factors that influence how fistula repair impacts Ethiopian women’s lives.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Sub-theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fistula care services</td>
<td>Unaware of treatment services, Positive experience at the fistula hospital, Variation in post-repair counseling, Language barriers at the hospital, Gratitude for reintegration support</td>
</tr>
<tr>
<td>Physical Health</td>
<td>Suicide, Complaining about inadequate nutrition, Ongoing community stigma</td>
</tr>
<tr>
<td>Mental Health</td>
<td>Sense of relief and hope, Importance of social reintegration, Persisting feeling of inadequacy</td>
</tr>
<tr>
<td>Fear of repeat fistula</td>
<td>Concern about sex and physical work, Avoiding community events</td>
</tr>
<tr>
<td>Domain</td>
<td>Sub-theme</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Marital and relationship status</td>
<td>Upset by husband’s abandonment</td>
</tr>
<tr>
<td></td>
<td>Initiating divorce or separation</td>
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<tr>
<td></td>
<td>Grateful for husband’s supportiveness</td>
</tr>
<tr>
<td></td>
<td>Perceived importance of their fertility</td>
</tr>
<tr>
<td></td>
<td>Boy child preference</td>
</tr>
<tr>
<td></td>
<td>Marriage or remarriage conditions</td>
</tr>
<tr>
<td>Sexual and reproductive health and intentions</td>
<td>Satisfied with sex</td>
</tr>
<tr>
<td></td>
<td>Fear of fistula reoccurrence from sex</td>
</tr>
<tr>
<td></td>
<td>Importance of recovery period before sex</td>
</tr>
<tr>
<td></td>
<td>Husband’s perceived entitlement to having sex</td>
</tr>
<tr>
<td></td>
<td>Frustrated by infertility</td>
</tr>
<tr>
<td></td>
<td>Desire to have a baby</td>
</tr>
<tr>
<td></td>
<td>Interest in family planning</td>
</tr>
<tr>
<td>Returning to work</td>
<td>Avoiding physical work</td>
</tr>
<tr>
<td></td>
<td>Performing household chores</td>
</tr>
<tr>
<td></td>
<td>Frustrated about finances</td>
</tr>
<tr>
<td></td>
<td>Ambition for income-generating activity</td>
</tr>
<tr>
<td></td>
<td>Desire for start-up capital</td>
</tr>
<tr>
<td>Support</td>
<td>Desire to be independent</td>
</tr>
<tr>
<td></td>
<td>Expectations about support</td>
</tr>
<tr>
<td></td>
<td>Family supportiveness</td>
</tr>
<tr>
<td></td>
<td>Community and religious institution supportiveness</td>
</tr>
<tr>
<td></td>
<td>Suggestion for tailored assistance</td>
</tr>
<tr>
<td>Fistula advocacy</td>
<td>Willingness to participate in advocacy</td>
</tr>
<tr>
<td></td>
<td>Informing peers about free treatment, antenatal care, and institutional</td>
</tr>
<tr>
<td></td>
<td>delivery</td>
</tr>
</tbody>
</table>

These findings were used to develop a conceptual framework describing key constructs of Ethiopian women’s experience after fistula repair that influence their conceptualization of the success of the treatment (Appendix V).

**Respondents**

The 51 women who participated in the study were between 17 and 68 years of age, and the average and median ages were 35 and 30 years, respectively (Table 2). Just over half of women (n=27) had no living children, and a quarter (n=12) had either one or two children or (n=11) between three to five children. Most women were uneducated (n=38, 75%) and identified with Orthodox Christianity (n=23, 45%) followed by Islam (n=16, 31%) or Protestant Christianity (n=12, 24%). There were regional distinctions by religion; in SNNPR, all women were Protestant, 11 (92%) and 7 (58%) women from Tigray and Amhara, respectively, were Orthodox Christian, and 10 (66.7%) women from Oromia were Muslim. While most women 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, an equal percentage of women were still married, and the five women who had never been married remained so. According to the DHS, 7.4% of women of reproductive age are divorced.

All women developed fistula following obstructed labor, one reportedly as long as eight days. It was unclear the extent to which the four rape victims’ sexual assault affected their fistula development. Only eight infants (15.7%) survived the delivery 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; it took two weeks at minimum and 42 years at maximum. This successfully helped 82% of patients (n=42) achieve fecal...
and urine continence. Of the common obstetric fistula sequelae, amenorrhea and neurological injury affected one and two women, respectively, and two women said they wanted to have a child but were struggling with infertility. Because many of the women were not currently trying to get pregnant in order to regain their health, the prevalence of infertility is likely underestimated.

Table 2. Characteristics of study participants

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>SNNPR n (%)</th>
<th>Oromia n (%)</th>
<th>Amhara n (%)</th>
<th>Tigray n (%)</th>
<th>Total n (%)</th>
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<tbody>
<tr>
<td>No. study participants</td>
<td>12 (0.0)</td>
<td>15 (0.0)</td>
<td>12 (0.0)</td>
<td>12 (0.0)</td>
<td>51 (0.0)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
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<tr>
<td>20-29</td>
<td>0 (0.0)</td>
<td>2 (13.3)</td>
<td>2 (16.7)</td>
<td>0 (0.0)</td>
<td>4 (7.8)</td>
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<tr>
<td>30-39</td>
<td>6 (50.0)</td>
<td>4 (26.7)</td>
<td>6 (50.0)</td>
<td>3 (25.0)</td>
<td>16 (37.3)</td>
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<tr>
<td>40+</td>
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<td>2 (13.3)</td>
<td>1 (8.3)</td>
<td>3 (25.0)</td>
<td>7 (19.6)</td>
</tr>
<tr>
<td>Religion</td>
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<td></td>
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<td></td>
<td></td>
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<tr>
<td>Orthodox Christian</td>
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<td>5 (33.3)</td>
<td>7 (58.3)</td>
<td>11 (91.7)</td>
<td>23 (45.1)</td>
</tr>
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<td>Protestant</td>
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<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>12 (23.5)</td>
</tr>
<tr>
<td>Muslim</td>
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<td>10 (66.7)</td>
<td>5 (41.7)</td>
<td>1 (8.3)</td>
<td>16 (31.4)</td>
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<tr>
<td>Marital status</td>
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</tr>
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<td>3 (20.0)</td>
<td>6 (50.0)</td>
<td>3 (25.0)</td>
<td>18 (35.3)</td>
</tr>
<tr>
<td>Widowed</td>
<td>3 (25.0)</td>
<td>5 (33.3)</td>
<td>1 (8.3)</td>
<td>1 (8.3)</td>
<td>10 (19.6)</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>2 (16.7)</td>
<td>7 (46.7)</td>
<td>4 (4.0)</td>
<td>5 (41.7)</td>
<td>18 (35.3)</td>
</tr>
<tr>
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<td>1 (8.3)</td>
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</tr>
<tr>
<td>Education</td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>No formal</td>
<td>7 (58.3)</td>
<td>13 (86.7)</td>
<td>11 (91.7)</td>
<td>8 (66.7)</td>
<td>38 (74.5)</td>
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<tr>
<td>Primary or more</td>
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<td>2 (13.3)</td>
<td>1 (8.3)</td>
<td>4 (33.3)</td>
<td>12 (23.5)</td>
</tr>
<tr>
<td>No. living children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>5 (41.7)</td>
<td>7 (46.7)</td>
<td>7 (58.3)</td>
<td>8 (66.7)</td>
<td>27 (52.9)</td>
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<tr>
<td>1-2</td>
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<td>3 (20.0)</td>
<td>4 (33.3)</td>
<td>3 (25.0)</td>
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<td>1 (8.3)</td>
<td>9 (17.6)</td>
</tr>
<tr>
<td>≥5</td>
<td>1 (8.3)</td>
<td>1 (6.7)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>2 (3.9)</td>
</tr>
<tr>
<td>Time since last fistula repair</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(mean in years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>3 (25.0)</td>
<td>2 (13.3)</td>
<td>6 (50.0)</td>
<td>6 (50.0)</td>
<td>17 (33.3)</td>
</tr>
<tr>
<td>1-4</td>
<td>5 (41.7)</td>
<td>2 (13.3)</td>
<td>1 (8.3)</td>
<td>1 (8.3)</td>
<td>9 (17.6)</td>
</tr>
<tr>
<td>5-19</td>
<td>3 (25.0)</td>
<td>5 (33.4)</td>
<td>4 (33.3)</td>
<td>2 (16.7)</td>
<td>14 (27.5)</td>
</tr>
<tr>
<td>≥20</td>
<td>1 (8.3)</td>
<td>6 (40.0)</td>
<td>1 (8.3)</td>
<td>3 (25.0)</td>
<td>11 (21.6)</td>
</tr>
<tr>
<td>Parity at delivery that caused fistula</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<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>
</tr>
<tr>
<td>Second or higher</td>
<td>4 (33.3)</td>
<td>7 (46.7)</td>
<td>5 (41.7)</td>
<td>1 (8.3)</td>
<td>17 (33.3)</td>
</tr>
<tr>
<td>Infants surviving fistula delivery</td>
<td>0 (0.0)</td>
<td>5 (33.3)</td>
<td>2 (16.7)</td>
<td>1 (8.3)</td>
<td>8 (15.7)</td>
</tr>
<tr>
<td>Outcome of final repair</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Successful</td>
<td>8 (66.7)</td>
<td>13 (86.7)</td>
<td>11 (91.7)</td>
<td>10 (83.4)</td>
<td>42 (82.3)</td>
</tr>
<tr>
<td>Stress incontinence</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>1 (8.3)</td>
<td>1 (2.0)</td>
</tr>
<tr>
<td>Unsuccessful</td>
<td>4 (33.3)</td>
<td>2 (13.3)</td>
<td>1 (8.3)</td>
<td>1 (8.3)</td>
<td>8 (15.7)</td>
</tr>
</tbody>
</table>

1 “Successful” repair is defined as the complete absence of urine or fecal incontinence, ‘stress incontinence’ reflects urine leakage only under stress, whereas ‘unsuccessful’ repair is defined as continual urine leakage in the normal condition.

2 Information about the status of the infant after delivery was missing for one woman in SNNPR.

3 One woman is currently pregnant.
**Fistula care services**

Most of the younger women received treatment within three years, while older women experienced fistula for much longer, one even up to 42 years, before learning about and receiving treatment. Nearly all women did not know that fistula was treatable before they had the surgery. It was relatively common for women to think that their condition was a punishment from God, particularly in Tigray, where half the women said something that reflected this view.

Women learned about the availability of fistula services through Health Extension Workers, Ethiopia’s government-supported community health workers, or directly from a woman in the community who had received fistula treatment, word of mouth, and, a few learned from advertisements on a mobile van, the radio or TV. Several women had been referred by local health centers that they had visited to try to have their fistula treated—one woman from Oromia visited a local clinic twice for treatment, but the medical staff did not have the capacity to help, so they gave her a pain reliever and sent her back home. They asked for her address so that they could contact an organization that gave free treatment to pick her up from her home. Finances also dictated the expediency with which women were able to receive care. For instance, a woman in Tigray was worried that she would need a lot of money to get medical treatment for her fistula, which her husband and family would not provide, so she stayed at home for many years. It was only when she heard that there was no charge for the treatment that she went to Mekelle fistula hospital alone.

In contrast, it appeared that women who were either close with their husbands or parents, lived in proximity to a fistula repair hospital, and had contact with Health Extension Workers were able to seek care more quickly. For instance, a young woman in Amhara was able to get an appointment within three months at the nearby fistula repair hospital after her husband and parents supported her to seek care for her prolonged labor. Generally, women sought treatment services alone and were not visited by their families because travel and accommodation were prohibitively expensive.

Women unanimously reported receiving “very satisfying” or “good” services at their respective fistula repair hospital. They overwhelming said they enjoyed the food and the treatment by their physicians.

“I liked everything I received during my three month stay. Clothing, food, and accommodation were good. I spoke with the doctor freely. I asked them ‘what if I fetch water when I go home?’ and they told me not to do heavy work and not to have sex. However, I was afraid to ask ‘for how long do I stay with my mother?’ and ‘what does life mean if I could not give birth?’”

Although most women felt comfortable asking questions without fear or shame, four women in Oromia and one in Tigray were unable express all of their questions and concerns because they faced a language barrier with their physician. This gap in communication may have prevented these women from sharing important information, such as continuing leakage:

“I could not ask what I wanted due to language [Amharic] difficulty. When I left the fistula center to my home, my urine was leaking and there is still no change.”

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

Women remembered receiving instruction not to have sex for three or six months after the repair and to refrain from performing strenuous labor. Women less commonly reported they had been told to avoid traveling for three months, maintain their personal hygiene, deliver at a health institution, take rest during their recovery, and use a family planning method, particularly Depo-Provera, a hormonal injection, to avoid having additional children.

A few respondents provided suggestions for how to improve the services, all of which focused on the length of the recovery time. One woman felt that the stay at the fistula hospital should be decreased
from three months to one week. This concern about the length of stay may stem from financial and
domestic responsibilities, as demonstrated by a woman in Oromia who said that the hospital
suggested she stay for six months but “I could not stay because my children and husband were alone
at home.” Another woman lamented that her daughter had to stay alone for two months while she
recovered at Mekelle fistula hospital.

In addition, many women were grateful for the assistance they received upon their departure from the
hospital, particularly the clothing, soap, and the money to pay for transportation and support their
reintegration into their community. Although not all women reported receiving money, most said they
were given a stipend from the hospital, which averaged 330 to 700 Birr ($20-42 USD). Several women
used the money to buy a cow to replace the one they had sold to cover their medical costs during the
time they suffered from fistula.

**Physical health**

Generally, women had completely recovered from their repair surgery and no longer suffered from
urine or fecal leakage. The majority of women felt a dramatic improvement in their health after fistula
repair. Some women complained of minor ongoing problems due to fistula, 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 attribute these health issues to their
fistula, they may not be related.

Women commonly reported that a major barrier to their recovery was their inability to access a variety
of food, particularly protein.

> “Life in the village for fistula repaired women is not comfortable since they don’t get enough
rest or food.”

This woman explained that her physician said that when her body became nourished she would not
experience leakage anymore, but her poverty prevented her from buying enough food.

A handful of women in 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.”

Several women mentioned financial constraints to seeking follow-up services, which allowed
further physical and psychological damage.

> “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.”

One woman could not afford to return in three months so she waited three years before visiting the
hospital. During that time, her fistula worsened so that now she must use a urinary tube, which is a
significant financial burden as it requires that she return periodically to replace the material. Without
access to follow-up services, a few women’s persistent fistula made them feel such desperation that
they contemplated suicide:

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4 *Injera* is a local bread that is the staple starch in Ethiopia.
“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 wishes to die sooner.”

In addition to financial barriers, a lack of hospital outreach paired with low self-efficacy appeared to stifle women’s ability to receive necessary care. For instance, a young woman from SNNPR 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.

The small number of women whose fistula persisted continued to live in anguish:

“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.”

They stated that people in their village still dislike them because of their fistula, which they attribute to the lack of education and understanding among community members about the circumstances that led them to develop their fistula. Many of these women chose to deprive themselves of food or drinks at social gatherings and community events like tsebel because they fear that they would leak urine.

**Mental health**

Women experienced a powerful sensation of relief, happiness, and hope after their repair, as many did not know that treatment was even 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 every-day affairs, such as being able to visit relatives, 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.

“Before treatment, I thought I was the only woman in Ethiopia with the problem and I couldn’t get together with the community, which now has changed.”

Most women were eager to and felt capable of reintegrating into their community and participating in social gatherings and religious ceremonies such as tsebel. The majority of women in Tigray and SNNPR 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 was isolated. 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.”

One woman explained that her relatives were surprised when she began eating and drinking at social gatherings since she had refused to do so before her repair. She told them “I have got medicine for my gastritis” to explain the change, so most people in her community do not know about her history with fistula.

It was common, however, for women whose fistulas were completely treated to continue to experience residual distress and anxiety from the misery and social exclusion they experienced when they suffered from fistula. 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 in her community were invited for different

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5 *Tsebel* is a religious holiday that celebrates a particular saint chosen by the household.
meetings and trainings, she was not included because everybody thought she was incapable of participating. This ingrained stigma towards fistula has led some women to never speak about the time when they suffered from it so that fewer people in their community were aware of their past. 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.”

_Fear of repeat fistula_

The stories women shared of their experience with fistula (not presented in-depth in this study) were universally tragic, thus nearly all women experienced intense fear that they would experience a relapse. The intense discrimination, feelings of hopelessness and worthlessness, and recollection of being treated inhumanely are captured by the following experience of a woman in Tigray:

_She lost her home after she had fistula because her husband divorced her and her siblings refused to accept her. Her brothers were beating her and her mother insulted her as if she deliberately caused fistula for herself. None of them had seen or heard of a woman with fistula. They couldn’t imagine that it could happen to any woman and that it wasn’t from sin. When they stigmatized her and discriminated against her, she went out of the house. Some members of her community made her a small house where she could stay. Although she asked her brothers to help her seek medical treatment, none of them were willing to help._

The majority of women believed they had an elevated risk of developing another fistula by having sex, a subsequent pregnancy, or doing physical tasks. Thus, many women had been avoiding any sexual activity, marriage or remarrying, or demanding work. Or, if they were not in a position where they could negotiate these decisions, they lived in perpetual fear of developing the condition again. Two women went so far as to avoid cultural activities that involve 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 were especially afraid that their husbands would not send them to the hospital for their next delivery.

_Marital and relationship status_

Many women shared how fistula had put a significant strain on their marriages, often leading to divorce or separation because the husband was unwilling to support his wife.

“My husband took all properties for himself and married another [woman]. My husband said ‘what do I do with you once you got sick at this early age?’ [Now], I have no children and am not remarried.”

It is less common for women to initiate the separation, yet a handful of women had already or were in the process of asking their husbands for a divorce. In one example, a woman from SNNPR won a court case against her husband, which required that he give her a part of their farmland since he had kicked her out of their home and married another wife. Those who felt that their husbands were demanding that they participate in activities that could lead to recurrence of fistula, notably farm activities or having sex, were considering leaving their marriages as well.

However, an equal number of women said that their husbands supported them during the time they had a fistula. At times, men overcame pressure from their relatives to marry another wife since it was a common perception that women with fistula were sinners and could no longer deliver a child or have
sex. After repair, some men also continued to be supportive and assumed more responsibility over the household to enable their wives to recover:

“My husband could not go with friends as his clothes smelt like urine because he spent much of his time with me. Now we are happy. My husband came to the fistula care center and heard 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.”

In general, women felt that their fertility, either during or after their fistula, was a major factor in sustaining their marriage.

“I want to have a second baby as much as possible because my husband may underestimate me since I have only given birth to a baby girl. Husbands in my community expect their wives to give birth to a baby boy as soon as possible. Otherwise, they go to another woman.”

The desperation to have a boy drove one woman to continue to have sex with her husband although she noticed her urine leakage was becoming more severe. Despite the fear of fistula relapse, 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.

Many of the women who had been abandoned by their husbands were not interested in remarrying. A woman from SNNPR was apprehensive that her husband would try to reclaim her as his wife now that her health had improved from the repair surgery and she was doing even better economically than before. Some of the younger women who were no longer married had negative perceptions of men and believed a husband causes fistula:

“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.”

“What does a husband do other than causing fistula? Fearful!”

Those who are 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.

Sexual and reproductive health and intentions

Women had a wide variety of perceptions of and experiences with their sexuality post repair. Older women generally felt ashamed talking about their sexual interest because of their age, whereas younger women were much more open about discussing current and future sexual behaviors. Some of these women had not experienced any difficulty having sex with their husband or partner and were comfortable speaking to them about this aspect of their relationship. Some of these women said there was no change in their sex life from when they had a fistula to after the repair. Others were unhappy with their sex life or strongly disinterested in having any sexual encounter, largely because they attribute their fistula and ensuing problems to sex.

“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 relation; it is the cause of all problems.”

Women were very motivated to follow their doctor’s advice to avoid having sex until they recovered fully, typically between three months to one year after the repair. In some cases, their husbands respected their wishes:

“After the repair, I didn’t have sex with my husband for one year. Now our sex life is back to normal.”
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.

Yet, many husbands felt entitled to having sex when they wanted to, which was terrifying for women who feared that it would lead to another fistula. One woman preferred to sleep on the ground with her children so that she could avoid sex with her husband. Regardless, her husband told her it was her duty to have sex with him because she is his wife and because he is feeding her; this was a major source of conflict for the couple.

Despite the widespread fear of a repeat fistula from sex or childbirth, some women wanted to have children after they recovered. This was especially true of younger women who did not have any children or did not have sons, because there is significant cultural value placed on a woman’s fertility. Women were very conscious 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.

Four of the respondents already had children post repair, and some said the second happiest event in their lives, following fistula repair, was having a healthy baby after the repair because it brought them respect.

“In Sidama culture, a woman who does not have a child does not ask for the property of the husband.”

“I want to have two more children, if God allows, [she has 4 children] because in Sidama culture having children makes women respected.”

Two women were struggling with infertility, and at a loss of understanding why they could not become pregnant.

“I want to give birth but there is nothing for the last eight months, I do not know why.”

This created significant stress because husbands who questioned their wives ability to conceive typically left them to have children with another woman. 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 discussed their experience using or thinking about family planning services, specifically Depo-Provera, Implanon and in one instance, Norplant. Several women in Amhara, Tigray, and SNNPR said they 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 delivering a baby for financial considerations. Furthermore, a few women had stopped using anything because they were interested in having children or suffered from the side effects. Most learned about contraception from doctors at the fistula hospitals or from Health Extension Workers at the nearby health post. However, a small number of women said that although they wanted information about family planning, they had never received this type of guidance from health workers, or they 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.”

---

6 Implanon and Norplant are hormonal methods of birth control that are inserted in women’s upper arms and can last up to three or five years, respectively.
Family planning was not a focus of the study, so it is unclear whether women who did not mention a history of contraceptive use had ever used a method.

**Returning to work**

After fistula repair, all women tried to avoid work that involved heavy lifting, such as fetching water and farming, if possible. Most married women said their husbands tried to compensate for their inability to do farm work, which they had told their husbands was an important part of their recovery process. In only one case did a husband visit his wife after her repair, which left a powerful impression about his role in facilitating her recovery.

“My husband came to the fistula care center and heard when they warn us not to do heavy work, and then after he will not allow me to do such tasks and does it himself.”

However, because Ethiopia’s economy is largely agriculture-based, many women continued to cultivate and sell produce with varying success depending on their respective strength, age, and support systems. Some unmarried women depended on their children to perform farming activities, or had their mothers or brothers to support them financially.

Typically, women felt responsible for household chores, such as cooking breakfast, bread, injera and wot, gardening, and cleaning, or petty trade, such as selling salt, trading coffee, making karibo, areke, suwa, or borde, local alcoholic beverages during holidays, and making traditional household items from grass. 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.” 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 get 20-30 Birr ($1.20-1.80 USD) from daily labor, which she cannot do because she should not carry stones and heavy loads. This loss of income exacerbated their economic hardship and threatened their livelihood, which was already tenuous for the majority of participants. Several women had to sell a cow or rent their farmland to cover their medical expenses from their fistula, and thus were particularly economically vulnerable.

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. One woman in SNNPR said that, after her repair, she has been more involved in trade so she is better able to support her family’s basic needs. Although women were highly motivation to expand their income-generating activities, they were limited by a dearth of start-up capital or credit. To resolve this issue, several 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 SNNPR wanted to buy and sell coffee because it demands less labor, and breed cattle in the long-term, but worried she would not have the capital for either.

**Support**

After repair, the majority of women returned to live with their caretaker(s), usually their husband or a close relative, such as their mother, grandmother, brother, or daughter-in-law. In some cases, their financial and emotional support was a positive experience.

“My husband does not allow me to do anything. He says ‘remember that time you spent with fistula and you must recover well.’ Hence I do nothing.”
There were a few women, however, who strongly disliked their dependency on their caretakers. 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.”

Women generally did not receive support from their community, although a few neighbors brought food and milk, gave money, fetched water, helped with cleaning, baked injera and/or invited women to participate in social gatherings and public meetings. There was considerable variation in women’s expectations for the financial support they did receive from their neighbors or religious community. In SNNPR, several women who received 80 to 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.

There was a noticeable trend in the support, or lack therefore, from Christian versus Muslim sources. Many Orthodox Christian women received money, food, or accommodation from their congregation or from a church shelter, whereas no Muslim women mentioned receiving support from their Mosque or religious community.

Many women suggested that financial support, particularly to fund income-generating activities, would be helpful, but others wanted a milking cow or oxen instead of money. However, one woman felt ashamed to ask for financial assistance from the government Health Extension Workers. Many also suggested that women in recovery would benefit the most from receiving tailored assistance based on their specific needs. In some cases, this would include food support, which seemed to be requested by the most destitute and those who did not have a support person to work farmland. Six women were receiving such support through the Productive Safety Net Program, a government sponsored food security program, and relied on the 15 kg of grain every month for their survival.

**Fistula advocacy**

Women frequently said they were willing to participate in fistula advocacy activities, such as awareness raising about the condition in their communities and supporting women who have a fistula to get treatment so that other women could avoid their horrible experience.

“Having no awareness, I gave birth at home and became a victim of fistula”

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 delivering 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.

One woman in Tigray was trained for five days to provide health education to her community. She volunteered three to four days per week teaching women about fistula and the need to keep personal hygiene and environmental sanitation, seek antenatal care, and deliver at a health institution. Another woman made public speeches about fistula with confidence and believed that her relationship with other people depends on how she approached them. Her confidence may have originated from the significant support network she had from her family, particularly her parents, sisters, husband, aunt, and friends.
Discussion

This study demonstrated the multi-faceted experience of 51 Ethiopian women rehabilitating from fistula repair surgery, and highlighted the existing gaps and opportunities to improve this complex process. The conceptual model (Appendix V) depicts the socio-ecological constructs that emerged as essential to facilitating rehabilitation, and thus can serve as a useful reference for the core elements to a holistic fistula program.

Similarly to other studies of this nature, the majority of women were illiterate, likely because less educated women are more prone to delivering at home without skilled birth attendance, and thus are at an increased risk for developing fistula; only 29% percent of Ethiopian women living in rural areas are literate. Obstructed labor was the primary cause of fistula, although it was unclear the extent to which rape contributed to the fistula develop for the four women who experienced this trauma. Surgery, trauma, or other cause unrelated to obstructed labor affected 6% of the 16,390 patients visiting Addis Ababa Fistula hospital from 1974-2009, which was the largest study of fistula patients in Ethiopia to date.

In contrast to other Ethiopian studies, the average time that passed before women received treatment (9.8 years) was six years longer than patients treated in another study (mean 3 years, 0.2-30), and 67% had incontinence for more than a year as compared to 21% reported elsewhere. Interestingly, younger women waited significantly less time (3.5 years) before receiving treatment than women over 30 years of age (14.2 years), which is likely a reflection of the improved access to fistula repair services from IFHP; increased outreach by the Ethiopian Government, Health Extension Workers and health centers; and awareness campaigns, the mechanism most women credited for teaching them about the possibility of treatment. In addition to older women, those who were poorer and lacked a supportive husband or parents faced greater barriers to accessing repair services.

The divorce/separation rate (35%) was consistent or lower than what has been reported elsewhere (36%, 52%, 69%), which is five times higher than the national average (7%). The discrepancy may be attributed to a higher proportion of older women who have been widowed (20%) in our study as compared to others. Also, 42 women successfully remained dry, generating an 82% rate of consistent closure, which is much higher than the 57% and 50% rates reported in two surgical follow-up studies in Ethiopia. This may result from recruiters favoring women with positive results during participant selection, although, as noted below we do not anticipate that this was a substantial bias. In the largest fistula study in Ethiopia, Muleta et al. reported a 92.5% repair rate, yet 19% of patients experienced residual incontinence after repair. In our study, nine women (17.7%) remained incontinent.

Despite the high “success” rate, and participants’ nearly unanimous perception that their lives had dramatically improved from the IFHP-facilitated fistula repair, many women continued to struggle with aspects of the recovery process that could be alleviated through practical post-repair interventions and community-based follow-up care. A woman’s rehabilitation, which begins immediately after her repair surgery, is typically a ten-day to three-month period in which there is great opportunity to educate and empower women with the knowledge to help them regain a healthy, satisfying life. However, there is no recognized essential package of post-repair services for obstetric fistula patients to date. As such, there was considerable variation in the counseling that women remembered receiving. Notably, discussion of common side effects, such as infertility, amenorrhea, and neurological problems, and instruction on how to do pelvic floor exercises, which has been proven to strengthen the muscles around the urethra to promote maximum control of urination, were omitted altogether. This could have helped the handful of women who experienced infertility (4%), amenorrhea (2%), foot

* This data did not include information from 10 women in Tigray
drop or other neurological injury (4%) feel more capable of managing or attending to their problem, and minimized the extent of urinary incontinence for the nine women (18%) still suffering from it.

It was also striking that women rarely mentioned receiving contraceptive counseling. Providers may believe it is not their prerogative since they assume women will follow their instructions to refrain from sex and will be able to access family planning services from another health worker when they are ready. As this study did not explicitly focus on women’s contraceptive history and perceptions, further inquiry is required to shed light on the contraceptive needs of these women and whether this service is something they prioritize. In the meantime, it is critical to discuss family planning with women during their recovery stay at the hospital since our results suggest they often are unable to negotiate sex with their partners when they return home. Resources to support integration of family planning services within obstetric fistula services are available and should be a mandatory component of both repair and follow-up care.

Currently, IFHP has no systems in place for following-up with patients after they leave the center to inquire about and promote their quality of life. As in most countries where fistula repair services are provided, follow-up of fistula patients is a challenge. According to a recent report of the Secretary-General of the United Nations, “in most countries, only a fraction of fistula patients are offered reintegration services, despite significant needs.” In IFHP, the emphasis has been oriented to getting women to the facility because it is so challenging, which has left women with the often impossible task of returning for additional care. As a result, women in our study had to navigate their ongoing physical and mental health problems, potent fear about and confusion over what could cause their fistula to return, and rebuilding their livelihood alone, since they could not rely on their husbands, families, friends, or follow-up care network to be a resource for such support.

Forty one percent of women (n=21) complained of ongoing physical health problems regardless of their repair status. Some of the perceived side effects have not been documented in the scientific literature as sequelae of fistula, whereas others are directly linked. Community-based follow-up visits to discuss these concerns might help to either treat the problems or, by acknowledging that they might not be related to fistula, attenuate the woman’s psychosomatic reaction. Such outreach could also help fill gaps in services at the fistula repair centers due to issues of language compatibility, which was raised by five women in this study. Follow-up of clients after they return home is also important to ensure that women with unsuccessful repairs are provided with further treatment, as appropriate.

Likewise, all women with unsuccessful and four women with successful repairs continued to suffer from depression, self-induced isolation, or a lack of self-esteem. The seven women with persistent incontinence were in the most desperate state, feeling failure, abandonment, and hopelessness that made suicide an attractive alternative for some. Since the best chance for successful fistula closure is at the first operation, the likelihood of complete continence for these women is minimal. This points to the need for accessible mental health services, and, at the very least, support outlets such as organized groups of survivors and their family members. Furthermore, greater investments must be made in research that builds upon the work of Johnson et al. to determine best practices for promoting women’s knowledge, self-esteem, and mental health after treatment.

The fear of relapse coupled with the lack of clarity about what is safe drove many women to avoid sex, childbirth, remarrying or marrying, physical labor, driving on bumpy roads, and strenuous activities in the short-term or altogether without fully knowing the extent of their implications on fistula recurrence. In a culture where women are valued for their willingness to have sex and ability to have children, especially a son, the small cohort that refused to do so permanently may have more challenges reintegrating in their community. They should be linked to opportunities such as education and job skills training to help them become self-sufficient. They should also receive counseling in divorce entitlements, since only two of the 17 who were divorced or separated due to their fistula had received ownership of their rightful portion of property.
Our study found that the majority of participants wanted to have sex and bear children despite their fear that such behaviors would lead to another fistula. It is critical to establish systems that help these women understand the real risks of repeat fistula and the factors that could lead to it in order to minimize their concerns. Particular emphasis should be placed on targeting those without children or a son who were more likely to share that they planned to have a child in the future. These efforts should include the husband in counseling or education about the importance of delaying sex, using family planning, seeking antenatal care, and delivering at a hospital to help them understand the ways in which they can best support their wives.

Ways to take advantage of the knowledge and motivation of former patients should also be explored as a mechanism to increase awareness of fistula and to organize prevention strategies. The majority of 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 their fistula centers were referred by former patients who are now cured.1 This was mirrored by our study, which found that participants commonly learned about fistula services from a woman who had been treated. Broader community mobilization efforts are also essential to combat the stigma some women reported experiencing firsthand both before and after their repair. As several women received support from their congregation during their rehabilitation, but this was not consistent across religious groups, more research is needed on how best to engage religious leaders as an entry point for hosting community-level discussions about fistula. Lastly, fistula survivors could be invited to serve on a local advisory committee for fistula prevention, treatment, and reintegration program design and implementation since their perspective is clearly essential to the level of impact and success of the program; 2011 marked the first time in history of the Campaign to End Fistula when previous fistula victims participated in the International Obstetric Fistula Working Group’s annual meeting.5

In addition to feeling compelled to be more involved in community mobilization, it was evident that most women were eager to invest in their economic independence, yet felt incapable of doing so. One component of rehabilitation should involving working with women to access credit or resources, such as a milking cow or oxen, to help them achieve their goal of launching a small business enterprise or engaging in income-generating activities. These opportunities are especially important for divorced or separated women who have less economic security than married women. This approach is being pioneered by Healing Hands of Joy, a non-profit that works with the Tigray Health Bureau to train fistula survivors in their choice of income-generating skills, such as weaving or poultry keeping, then provides them with a small business loan.5,59 Women’s self-sufficiency would likely accelerate their rehabilitation in terms of both their physical and mental prosperity—they would be able to buy more nutritious food, more easily avoid arduous labor, and feel a sense of control over their lives.

Although there has been greater acknowledgement that women require more than a medical procedure to fully recover from their fistula, there is little consensus about which interventions and outcomes to prioritize. Without an agenda, the global leaders in the fistula prevention and treatment field have neglected redefining and expanding upon the lone, vague metric related to reintegration.40 Current data collection, mapping, and analysis efforts are—again—largely focused on the epidemiology of fistula repair facilities, number of repairs, training of staff, etc. This exacerbates the problem, since phenomena that are not measured rarely get attention. Programs like IFHP and national governments should consider tracking indicators of program performance that measure both the post-operative experience of women and their experience after they return home.

Limitations

One of the key limitations to follow-up studies of this nature is the challenge of engaging the poorest and most marginalized women, and the inability to reach those who died prematurely due to factors related to their post-repair experience. This leads to the exclusion of women who have experienced the worst post-repair outcomes and can lead to a picture that is more positive than these women’s realities. There is no way to avoid such bias in a study of this kind. Bias toward women with positive
outcomes can also result during participant selection. While this may have occurred in this study, the sample represented diverse backgrounds and experiences with fistula repair and rehabilitation, suggesting that such biases were minimal.

Because the interviews were conducted in one language, transcribed in a second language (Amharic), and summarized in a third language (English), the interviewers (who did the transcription, translation and summarization) may have filtered information. This could have been purposeful (e.g., because they felt that something did not reflect well on a participant) or accidental (e.g., because they felt something was not important to record). Careful training in data collection and transcription was used to minimize this potential bias but it may have occurred.

In a few instances, participants had difficulty answering questions about what interventions they would suggest to support women's rehabilitation after their fistula repair procedure. Thus, it is possible that some of the responses could have been geared towards trying to receive more support from IFHP that benefits them currently but may not relate to their fistula rehabilitation experience, which could have biased the results.

**Conclusion**

The findings of the study show that Pathfinder’s IFHP model of facilitating fistula repair has had a dramatically positive impact on the lives of underserved women and this shows that limited resources can improve the quality of life of many women and their families. However, the results also show that women continue to suffer from the social, mental health and economic consequences of fistula even after the physical problem is cured. As such, the findings shed light on areas for immediate action within fistula repair and rehabilitation services, and for further exploration in the interest of defining a set of essential, holistic reintegration services for obstetric fistula patients. In sum, simple clinical and counseling improvements in the post-operative care regime, implementing a follow-up system to identify women needing further treatment and to address the primary care and sexual and reproductive health needs of these women, offering support structures for mental health and income-generation, and designing metrics that assess each of these aspects would be powerful steps in attending to Ethiopian women’s more complete recovery. These steps are needed to complement ongoing efforts to strengthen the antenatal, delivery and postpartum care systems in developing countries so that fistula can be avoided and to complement the success of projects like IFHP in improving the lives of women by increasing access to repair services when fistula occurs.

Extending the continuum of fistula treatment services beyond the surgical procedure to include these indispensable components of rehabilitative care will require a broad range of stakeholders, including service delivery agents, community leaders, civil society, government officials, and research entities. This could build on the existing work of IFHP at the community level. In addition, fistula survivors should be engaged in such efforts to give voice to their needs and to highlight that the women who suffer fistula are wives, mothers, and daughters from within communities. Finally, IFHP and the fistula prevention and treatment community at large would greatly benefit from more rigorous data on best-practices for improving short-term and long-term post-repair social, physical, and mental health outcomes to bolster support for fistula patients in regaining a healthy, productive and satisfying life. Without a united effort to advance the understanding of “success” in fistula repair recovery, tens of thousands of women in Ethiopia and millions around the world will continue to fall through the cracks and suffer from deplorable, yet avoidable, consequences of this tragic condition.
Appendices

Appendix I. Classification of the degree of anticipated difficulty of the repair

<table>
<thead>
<tr>
<th>Criteria based on the degree of anticipated difficulty of the repair</th>
</tr>
</thead>
<tbody>
<tr>
<td>Defining criteria</td>
</tr>
<tr>
<td>Number of fistula</td>
</tr>
<tr>
<td>Site</td>
</tr>
<tr>
<td>Mixed VVF/RVF</td>
</tr>
<tr>
<td>Size (diameter)</td>
</tr>
<tr>
<td>Involvement of the urethra/continence mechanism</td>
</tr>
<tr>
<td>Scarring of vaginal tissue</td>
</tr>
<tr>
<td>Presence of circumferential defect*</td>
</tr>
<tr>
<td>Degree of tissue loss</td>
</tr>
<tr>
<td>Ureter/bladder involvement</td>
</tr>
<tr>
<td>Number of attempts at repair</td>
</tr>
</tbody>
</table>

* the complete separation of the urethra from the bladder.

Appendix II. Waaldijk fistula surgical classification

<table>
<thead>
<tr>
<th>Classification of fistulas according to type of surgery required based on their anatomic/physiologic locationb</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
</tr>
<tr>
<td>II</td>
</tr>
<tr>
<td>A without (sub)total urethral involvement</td>
</tr>
<tr>
<td>b With circumferential defect</td>
</tr>
<tr>
<td>B with (sub)total urethral involvement</td>
</tr>
<tr>
<td>b With circumferential defect</td>
</tr>
<tr>
<td>III</td>
</tr>
</tbody>
</table>

Subclassification according to size

| Small | <2 cm |
| Medium | 2-3 cm |
| Large | 4-5 cm |
| Extensive | 6 or more cm |

* the complete separation of the urethra from the bladder.
Appendix III. Goh fistula classification

Table 1 Summary of classification according to Goh [2] with the three parameters

<table>
<thead>
<tr>
<th>Classification</th>
<th>Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type: distance from fixed reference point (external urinary meatus)</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Distal edge of fistula &gt;3.5 cm from external urinary meatus</td>
</tr>
<tr>
<td>2</td>
<td>Distal edge 2.5–3.5 cm</td>
</tr>
<tr>
<td>3</td>
<td>Distal edge 1.5–2.5 cm</td>
</tr>
<tr>
<td>4</td>
<td>Distal edge &lt;1.5 cm</td>
</tr>
<tr>
<td>Size: largest diameter in centimetres</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>&lt;1.5 cm</td>
</tr>
<tr>
<td>B</td>
<td>1.5–3 cm</td>
</tr>
<tr>
<td>C</td>
<td>&gt;3 cm</td>
</tr>
</tbody>
</table>

Special considerations

I None or mild fibrosis and/or vaginal length >6 cm, normal capacity

II Moderate or severe fibrosis and/or marked reduction in vaginal length and/or capacity

III Special circumstances, e.g. post-irradiation, ureteric involvement, circumferential fistula, previous repair
Appendix IV. In-depth interview guide for exploring women’s experiences and perceptions after fistula repair surgery in four regions in Ethiopia

<table>
<thead>
<tr>
<th><strong>Home life</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you go back to your former village after you have your fistula repaired?</td>
<td></td>
</tr>
<tr>
<td>If not, what was the major reason not to return back to your former village?</td>
<td></td>
</tr>
<tr>
<td>After you had the fistula repaired whom have you been living with?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Job and hobbies</strong></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>What have you been doing for your livelihood after you had the fistula repaired?</td>
<td></td>
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<tr>
<td>How do you spend your time now?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Challenges and joys</strong></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>When and what were the difficult moments you experienced after you developed fistula?</td>
<td></td>
</tr>
<tr>
<td>What were your happiest moments after your fistula was repaired?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Repair services</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>How did you find out about the availability of an operation to repair fistula?</td>
<td></td>
</tr>
<tr>
<td>How did you feel after you learned that your fistula can be corrected through an operation?</td>
<td></td>
</tr>
<tr>
<td>What did you like about the fistula service you received?</td>
<td></td>
</tr>
<tr>
<td>What did you dislike about the fistula repair services? Can you give me an example?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Physical and mental health</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Did your health condition change since your was fistula repaired?</td>
<td></td>
</tr>
<tr>
<td>If so, can you tell me what is improved?</td>
<td></td>
</tr>
<tr>
<td>Do you have still ongoing health problems? If so, please tell me what they are?</td>
<td></td>
</tr>
<tr>
<td>Who is now responsible for looking after you on a daily basis?</td>
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<table>
<thead>
<tr>
<th><strong>Aspirations</strong></th>
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</thead>
<tbody>
<tr>
<td>What do you want to do in the future? One year from now? Ten years from now?</td>
<td></td>
</tr>
<tr>
<td>Is there anything that you would like to do but fear may be difficult or impossible?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Relationships</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Are your relationships the same or different than they were before the fistula repair?</td>
<td></td>
</tr>
<tr>
<td>If different, how have they changed?</td>
<td></td>
</tr>
<tr>
<td>Whom do you feel close to?</td>
<td></td>
</tr>
<tr>
<td>Did your fistula change your sexual relation with your husband/partner?</td>
<td></td>
</tr>
<tr>
<td>If so, can you explain how it changed?</td>
<td></td>
</tr>
<tr>
<td>Have you ever had sexual contact after the fistula repair? If so, can you tell me with whom?</td>
<td></td>
</tr>
<tr>
<td>What kind of support have you received since your repair?</td>
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<table>
<thead>
<tr>
<th><strong>Advocacy</strong></th>
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<tbody>
<tr>
<td>Would you be willing to participate in community mobilization to prevent fistula or support women with fistula to get repaired?</td>
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</table>
Appendix V. Socio-ecological conceptual model for supporting women after obstetric fistula repair surgery offered by Pathfinder’s Integrated Family Health Program in Ethiopia

IFHP, Campaign to End Fistula, MDG 5, Maputo Plan of Action, National Safe Motherhood and Fistula Action Plan, Safety Net Program, evidence-based research

Income-generating opportunities, community sensitization, gender equality, food access, time of marriage, fertility norms

Sexual and reproductive health services, obstetric care, access to and quality of fistula repair hospitals, mental health services, peer support groups, community-based organizations, Pathfinder International, religious groups, Healing Hands

Support from family & friends, community health workers, peer advocacy

Age, knowledge about fistula, contraceptive use, self-efficacy, educational attainment

Access to Care

**Appendix VI.** Proposed indicators for monitoring and evaluating fistula prevention and the availability and quality of obstetric care and fistula repair

**Epidemiological**
- Estimated number of women living with OF. i.e. Prevalence.
- Estimated number of new cases of OF per year. i.e. Incidence.
- Estimated rate of OF per 1,000 deliveries.
- Number of women treated for OF per year.
- Estimate of unmet need for fistula repair.

**Service delivery**
- Number of midwives, nurses and doctors with midwifery skills per 1,000 births
- Number of doctors or mid-level providers able to perform caesarean-section per 1,000 births
- Proportion of births managed with a partograph
- Number of facilities providing simple fistula repair services
- Number of centres providing specialist fistula services
- Number of fistula treatment services which include social reintegration activities.
- Number of surgeons able to undertake simple repairs
- Number of surgeons able to undertake complex repairs

**Training**
- Number of training facilities (pre service and in service) including OF prevention and treatment as part of the core syllabus
- Number of surgeons undertaking simple fistula repair training per year
- Number of in country surgeons undertaking specialist fistula training (either in country or elsewhere) per year.

**Quality of care**
- Proportion of women with obstetric fistula who have a successful first repair by each facility. Ideally the closure rate should be 85%, of which 90% should be without incontinence. This success rate can also be disaggregated into different types of fistula (see Surgical chapter)
- Proportion of women who have had two or more unsuccessful repairs
- Percentage of women successfully reintegrated in their society after fistula treatment
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