Building a Country-Wide Fistula Treatment Network in Kenya: Results From the First Six Years (2014-2020)

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Abstract

It is estimated that one million women worldwide live with untreated fistula, a devastating injury primarily caused by prolonged obstructed labor when women do not have access to timely emergency obstetric care. Women with fistula are incontinent of urine and/or feces and often suffer severe social and psychological consequences such as profound stigma and depression. Obstetric fistula affects economically vulnerable women and garners little attention on the global health stage. Exact figures on fistula incidence and prevalence are not known. In Kenya, results from a population-based survey suggest that approximately 120,000 reproductive-aged women have experienced fistula-like symptoms.

In 2013, Fistula Foundation designed a program to significantly increase country-wide fistula treatment capacity in Kenya by addressing key barriers that limit women's ability to receive treatment. Launched as Action on Fistula, and later becoming the Fistula Treatment Network, this model created a network of hospitals, a training center for surgeons and healthcare providers, and robust community outreach and reintegration activities. The Fistula Treatment Network was implemented by Fistula Foundation in collaboration with the Ministry of Health and Kenyan non-governmental and community-based organizations. Fistula Foundation and its donors provided the program's funding, with seed funding, representing about 30% of the program budget, provided by Astellas Pharma EMEA.

Over a six-year period, 2014-2020, the network supported 6,223 surgeries at seven hospitals, established a fistula training center and trained eleven surgeons, trained 424 Community Health Volunteers, conducted extensive outreach to all 47 counties in Kenya, and contributed to the National Strategic Framework to End Female Genital Fistula. At 12 months post fistula repair, 96% of women in a community setting reported that they were dry and not experiencing any incontinence and the proportion of women reporting normal functioning increased from 18% at baseline to 85% at twelve-months.

The Fistula Foundation's Fistula Treatment Network model increased access to fistula care services, strengthened the healthcare workforce, improved understanding of fistula and reduced stigma in a community setting. This integrated approach is an effective and replicable model for building capacity to deliver comprehensive fistula care services in other countries where the burden of fistula is high.

Background

Obstetric fistula is a devastating childbirth injury primarily caused by prolonged obstructed labor combined with lack of access to emergency obstetric care, specifically a timely cesarean section. Despite being both preventable and largely treatable, women of all ages can develop obstetric fistula in the absence of appropriate care. Fistula formation can occur when women experience delays in accessing critical obstetric care due to factors such as lack of money for transportation, long distances to health facilities, or delays getting to a facility or receiving prompt care once they arrive.¹

Obstetric fistula is associated with chronic disability that has severe physical, psychological, social, and economic consequences. Women with obstetric fistula experience constant leaking of urine and/or feces

through the vagina and in addition can experience stillbirth, excoriation of the skin, amenorrhea, vaginal stenosis, infertility, orthopedic injury, and neurologic disorders.² Due to the strong smell associated with incontinence and misperceptions about the cause of the fistula, many women experience severe stigma and isolation and can suffer from depression and suicide ideation. Many women with fistula are outcast from their husbands and families and living with the condition makes it even harder for them to earn income, further driving them into poverty.

Obtaining accurate prevalence or incidence data for fistula is notoriously difficult. Women with fistula tend to be poor, live in hard-to-reach rural areas, and are very often socially isolated. Furthermore, fistula is a relatively rare morbidity for which data are frequently available only from clinical settings; accurate estimation of the number of women living with fistula in the community via population-representative surveys is challenged by the low prevalence combined with the need for clinical diagnosis.³⁴ Currently available estimates on the number of women globally living with fistula range from one million to as many as two million.⁵ Incidence is estimated at 50,000-100,000 new cases per year.⁶

Reconstructive surgery is the primary form of treatment for women with obstetric fistula, and it has been shown to significantly improve a woman's physical and psychological health.⁷⁻⁹ According to Landry et al., women from five countries in Africa and Asia reported significant improvements to their quality of life just three months post-surgery, including their ability to eat with others, work, and attend social gatherings.¹⁰ However, many women often wait a long time for fistula surgery due to lack of awareness or knowledge about the condition, limited or inaccessible transportation to a surgical facility where treatment is available, and lack of adequately trained surgeons, full time nursing care, or equipped facilities.¹

The international response to address the challenge of obstetric fistula was spearheaded by the United Nations Population Fund (UNFPA) and partners in 2003 with the launch of the global Campaign to End Obstetric Fistula. The campaign has focused on fistula prevention, treatment, rehabilitation, and reintegration for women with fistula and is currently active in over 55 countries.¹¹

Efforts to Address Fistula in Kenya

Kenya was an early participant in the global Campaign to End Fistula in 2004 and since this time the Kenyan Ministry of Health (MOH) and Division of Family Health and Reproductive and Maternal Health Services Unit have instituted many strategies and policies aimed at reducing maternal mortality and morbidity, including the removal of all delivery fees at public hospitals in 2013. Such policies should have decreased the incidence of fistula and other maternal morbidities but did not expressly focus on increasing access to fistula treatment. The Kenya Health Sector Strategic and Investment Plan (2013–2017) includes management of obstetric fistula as an essential service yet no existing government policy outlines how this service will be delivered or resourced.¹² Since the launch of the Campaign to End Fistula, multiple non-governmental organizations (NGOs) have joined the Ministry of Health and UNFPA to support fistula treatment activities, including AMREF Health Africa, Direct Relief, Freedom from Fistula

Foundation, Flying Doctors Society of Africa, MUMCOP, One By One, Women and Development against Distress in Africa (WADADIA).^{13–16}

Needs assessments jointly conducted by the Kenyan Ministry of Health and UNFPA in 2004 found the actual fistula burden in the country difficult to quantify; however, they estimated that 3,000 new fistula cases occurred each year, with approximately one to two fistulae for every 1,000 deliveries.¹⁷ The latest Kenyan Demographic and Health Survey (2014) reported a 1% lifetime prevalence of women self-reporting with fistula-like symptoms, equating to approximately 120,000 Kenyan women aged 15–49 having experienced the condition.^{18,19} Other indicators of maternal health suggest ongoing challenges: Kenya's maternal mortality ratio remains high at 362 maternal deaths per 100,000 live births, and significant disparities exist between urban and rural populations in the proportion of women delivering in a health facility or with a skilled provider (50% vs. 82%, for urban and rural inhabitants, respectively).¹⁸

It is difficult to obtain reliable data on the number of fistula surgeries conducted annually in Kenya. Stakeholders track surgeries supported through their organizations but reporting to the Ministry of Health is inconsistent. The Global Obstetric Fistula Hub (formerly Global Fistula Map) a collaborative effort of UNFPA, Fistula Foundation and Direct Relief that aimed to improve visibility of provision of fistula surgery, shows an average of 822 fistula surgeries completed annually between 2010–2013. However, this data is self-reported and may be incomplete.²⁰

Prior to 2014, routine surgery was rare and was primarily done in three hospitals countrywide—two of which were based in Nairobi.²¹ Long distances to Nairobi, cost of transport, and fear and anxiety in traveling to an unknown urban center resulted in many women unable to access these routine services.^{22,23} Most fistula surgery was done through fistula repair “camps” – short-term mobilization of women with suspected fistula, screening, and repair for those affected at provincial or district hospitals under guidance from visiting expert surgeons. Camps were held roughly once a year – or when funding from a donor partner was available – and focused on particular regions. The temporal nature of these camp services meant that not every woman living with fistula was reached or able to receive fistula treatment in a timely manner.²¹

Limited availability of trained fistula surgeons has been a chronic issue in addressing the need for fistula care in Kenya. Prior to 2014, training of fistula surgeons was done primarily through the fistula repair camps. Health providers reported that these venues were useful for mentorship of surgeons, however the intention of having the surgeon continue to provide routine surgery after the end of the camp was seldom achieved. In addition to the limited ongoing mentorship available after the camp ended, lack of available operating theater space at busy public hospitals, limited bed space for post-operative care, and limitations in availability of essential supplies and equipment made providing routine services very difficult.²¹

Low awareness of fistula, high rates of stigma, and misperceptions about the condition further hindered women's ability to access treatment.^{21–23} Civil society organizations involved in fistula programming

worked to reach communities with information about fistula causes, prevention, and treatment availability. Mass media like radio was commonly used as a key mobilization tool prior to fistula repair camps. One regional program in western Kenya, *Let's End Fistula*, a collaboration between three organizations, focused on training fistula survivors to be community ambassadors to help build trust in the community, improve referrals to the treatment center, and provide support for women when they returned back to their communities post discharge.²⁴ Reintegration and rehabilitation of women after fistula surgery is broadly recognized as an important aspect of fistula care, albeit one that has not received much attention in Kenya, or in the broader global community.^{25,26} Even after successful closure of the fistula, many women may still suffer social stigma, economic hardship, and possible fistula reoccurrence.²⁷

Given these demonstrated needs, Fistula Foundation developed and implemented a country-wide, multi-strategy approach to support routine treatment and reintegration services for women with obstetric fistula. In the current paper, we report on the Fistula Treatment Network (FTN) objectives and achievements during the six years of the project, from May 2014- April 2020.

Methods

Creation of the Fistula Treatment Network (FTN)

In 2013 Fistula Foundation developed the Fistula Treatment Network model, conceived of by Fistula Foundation CEO, Kate Grant. Fistula Foundation's vision is to ensure that all women with obstetric fistula in Kenya have access to timely, quality fistula treatment and comprehensive post-operative care. The program launched in 2014, led by Fistula Foundation's Vice President of Programs, Lindsey Pollaczek, creating a network of hospitals and organizations whose focus was to provide routine fistula care and improve identification, referral, and post-repair reintegration services. The goal was to carefully select hospitals and community organizations to provide broad geographic coverage while ensuring continuous availability of high-quality services. Fistula Foundation provided grant funding to cover the full cost of fistula care and treatment, surgeon and health provider training, and community outreach and reintegration activities.

Expand availability of routine fistula treatment services

FTN conducted stakeholder meetings with the MOH, NGOs, and community-based organizations (CBOs) working in fistula programming to assess the current landscape, gaps, and opportunities for growth. The criteria for selecting regional hubs for routine fistula services to form the network was based on perceived fistula burden, using proxy measures of percentage of facility-based deliveries and percentage of births attended by a skilled provider, as well as personal communication with fistula surgeons with experience working in specific regions and experiencing high numbers. Priority was given to locations where i) women were not presenting for care due to low awareness or lack of transport funds; ii) we could leverage existing assets, such as a pre-trained fistula surgeon; iii) routine services were not available or

limited due to high user fees for fistula surgery or limited surgical equipment, supplies, theater time, and ward space. We sought out locations where hospital administrators and county officials demonstrated strong support to invest in a routine service over a camp-based approach. Understanding the importance of robust community mobilization, we considered regions where we could build partnerships with existing, reliable CBOs or NGOs working in reproductive health services that would be able to create strong linkages between the communities and the treatment centers.

Health Provider Training

FTN worked in partnership with the International Federation of Gynecology and Obstetrics (FIGO) to provide targeted training for fistula surgery in the country. In 2014, FIGO representatives accredited the FIGO training center at Gynocare Women's and Fistula Hospital in Eldoret. That same year, four Kenyan surgeons attended a Training of Trainers event in Tanzania, to be qualified as surgeon trainers using the FIGO and Partners *Global Competency Based Fistula Training Manual*,²⁸ the training curriculum used by FTN.

After certification of the trainers, a Review Committee was established to review prospective applicants for acceptance into the training program using the FIGO criteria. These included whether the applicant had practiced surgery for a minimum of three years, whether the applicant was supported by their institution and county government to attend a six-week residential training, and whether the applicant was likely to immediately and on a long-term basis put their newly-gained skills to use upon returning to their home facility.

Community Mobilization and Outreach

A cornerstone of FTN was the development of a robust community outreach program. In 2014 FTN partnered with the Kenyan NGO Women and Development Against Distress in Africa (WADADIA), an organization with experience in fistula programming at the community level. FTN provided a grant to WADADIA to enable the organization to expand into more counties of western Kenya. Four additional community organizations, Daraja Mbili Vision Volunteers, Maisha Empowerment Initiative, Bomu Hospital, and Women Health and Education for Development (WOHED) were recruited over the course of the six years to join FTN and received grants to implement outreach in their respective coverage areas. These organizations were selected based on their track record of strong community engagement, focus on sexual and reproductive health and gender equality issues, and their geographic catchment areas – ensuring they were always linked to a referral center where treatment was available.

Reintegration Post-Repair

After hospital discharge, some women have ongoing psychological, social, and economic needs, and benefit from support to reintegrate with their communities and families. The goals of the FTN reintegration program were to enhance fistula survivor's quality of life through holistic recovery and to prevent fistula recurrence. The three key pillars of the FTN reintegration model were psychosocial support,

economic empowerment, and reproductive health services. This component of FTN was adopted following lessons learned from the first phase of the program (2014-2017). Working with our community outreach partners, who had already developed a high level of trust within their communities, FTN began to support key reintegration activities in May 2017. FTN's reintegration programs include follow-up visits, community support groups, income generating activities, vocational training, educational support, and the creation of male advocacy groups.

Consent to participate

At the community level women who were identified through the FTN partners were counseled and prepared for what to expect during their referral, treatment, and reintegration process. Family members were involved whenever possible so that both the woman and the family understood what was involved in fistula treatment as well as in the post-operative reintegration period. All women provided written consent (thumb print for non-literate patients) for referral to the treatment center and further evaluation. Following diagnosis at the hospital, pre-operative counseling and another signed consent was collected by the hospital staff prior to the surgical intervention.

Monitoring and Evaluation

Program data was primarily collected from two sources: the hospitals providing the fistula surgery and the community outreach organizations focused on patient identification, referral, and reintegration post-repair.

Surgical data was directly entered onto a standardized form appended to the hospital medical record. At the end of each month, the resident fistula surgeon and program manager from each hospital entered the data onto a standardized data collection instrument in Microsoft Excel and submitted it to the Fistula Foundation Kenya Office. Data quality was assessed by the Fistula Foundation M&E Officer, and any discrepancies or incomplete data were clarified immediately, with payment to the hospital contingent on accurate and complete reporting. Fistula Foundation staff made quarterly on-site visits to review physical patient files to ensure completeness of patient records, including signed consent forms, and consistency with data submitted on the data collection instrument. Foundation staff called a random sample of 15-25% of patients treated at each facility each month (a minimum of 2-5 patients) to validate their treatment and outcome records. In addition, the Fistula Foundation Medical Advisor, an experienced fistula surgeon, reviewed the data and the progress at the facility and followed up on any clinical questions or opportunities for mentorship.

The community-based outreach data was also entered into a standardized data collection instrument that was used across all field-based teams. Community data included records on patient identification, community screening, referral, and post-repair outcomes related to continence status and psychosocial wellbeing. This data was collected quarterly from the five Kenyan NGOs/CBOs that comprised FTN's outreach network and reviewed for completeness and accuracy. The community teams also completed a referral form for each woman who was sent to the treatment center, and the treatment center in turn

completed the form and sent the woman home with it to help the team better address follow-up needs of the woman (for example in case she required a follow-up surgery or visit at the facility).

Review meetings for outreach teams and treatment centers were conducted routinely to discuss data and other programmatic issues, including an Annual Stakeholder Meeting to improve coordination and communication between the teams and enhance holistic patient care and treatment. Finally, annual audits for hospital and outreach teams were conducted by an independent auditor to assess the veracity of the financial and programmatic reports.

Measures

Hospital data captured basic patient characteristics including county of residence, age, duration of time living with fistula; data related to patient physical screening and clinical diagnosis (incontinence type and surgical diagnoses); fistula cause (obstetric, iatrogenic, or traumatic); procedure type and surgeon-rated level of difficulty (simple, intermediate, difficult); and outcome at hospital discharge (fistula closed and dry fistula closed but incontinent, and fistula not closed and incontinent). Data from follow-up visits, for example due to a change in continence status or a need for additional treatment plan, were also tracked.

Outreach data captured patient characteristics to assist with tracking and following up with clients. Outreach teams also recorded the patient's referral method (community outreach worker, health facility, radio, rally, sports, other), outcome of verbal screening at community level using the Obstetric Fistula Community Based Assessment Tool (OF-COMBAT) tentative diagnosis of VVF, urinary incontinence, RVF, 3rd and 4th degree perineal tears, or perineal tears and stool incontinence combined with level of confidence in tentative diagnosis: highly likely, likely, and least likely and date of referral to hospital.²⁹ In Phase 2 of the program (May 2017 - April 2020) reintegration data capture was added to the standard follow-up procedure. Baseline data were collected at 2-4 weeks post-discharge with follow-up data collected either in-person or over the phone at 3, 6, and 12-months following discharge. The post-repair questionnaire included questions related to continence status (always, sometimes or never), socializing ability, ability to work, functional status, self-esteem, quality of partner communication, quality of life, interest in having additional children (now, later, not at all), participation in support groups, participation in psychosocial support and number of sessions, and economic outcomes (primary income generating activity, participation in vocational training, household income, savings, and ability to meet household expenses).

Analysis

Analysis of patient data was descriptive in nature. We characterized the sociodemographic and clinical characteristics of FTN-supported surgeries and patients supported for surgery using proportions, means and standard deviations, and medians and interquartile ranges, per variable type. We then described the surgical outcomes achieved overall as well as the surgical outcomes achieved by surgical procedure type, provider-reported surgical difficulty, incontinence duration, and number of fistula surgeries. Duration of fistula in years was compared across program years using one-way analysis of variance. Participant

endorsement of post-repair physical and psychosocial status was described across follow-up data collection periods, with trends over time modeled using generalized least squares regression with random effects to accommodate for our longitudinal data structure.

Result

Expand Availability of Routine Fistula Repair Services

In the first year, FTN established partnerships with four hospitals: Jamaa Mission Hospital, Gynocare Women's and Fistula Hospital (formerly Gynocare Fistula Centre), Cherangany Nursing Home, and Kisumu County Hospital (Figure 1). Subsequently, Bomu Hospital, Kisii Gynocare Center, and Narok County Hospital were added as fistula surgeons completed their training and re-located. Partnerships with hospital and county administrations were established, and community mobilization networks were created. Six of seven partner hospitals had a permanent fistula surgeon on site. The exception was Bomu Hospital that hosted the same FTN-trained visiting surgeon each quarter. Hospitals were clustered in Nairobi, western, rift valley, and the coastal region, which closely matches the population density of the country.

The Foundation provided payment to the FTN treatment sites to cover the full cost of fistula surgery – including screening, pre-and post-operative care, physical therapy, psychosocial counseling, and follow-up care for women who experienced complications or required additional management. The Foundation also provided operating theater equipment, surgical instruments, headlamps, equipment and consumable supplies for the ward as well as equipment necessary for data collection and documentation (like laptops and cameras). FTN sites also distributed Fistula Care Packs, individual kits of personal hygiene products, to each woman at the time of discharge.

Patient Characteristics

During the program period, a total of 6,223 surgeries were conducted at the seven hospital locations (Table 1). The median patient age at first surgery was 34 (IQR 25-54). Women came from all counties of Kenya, including neighboring Uganda, with most patients coming from the western counties of Bungoma (13%), West Pokot (12%), and Kisii (10%; Figure 1).

The mean time living with fistula-related incontinence was 8.3 years (SD 9.2; not shown); however, the mean number of years living with fistula decreased significantly across program years, with mean 9.3 years (SD 9.9) in 2014-15 compared to 8.1 (SD 9.2) in 2018-2019 ($p < 0.001$).

Surgery Outcomes

The majority of women had one surgery recorded in FTN records (93%). The most common type of surgical procedure conducted was vesico-vaginal fistula (VVF) repair (39.4%) with repair of 3rd and 4th degree perineal tears the second most common (30.0%; Table 1). The symptoms of unrepaired third and

fourth degree perineal tears are nearly identical to fistula—incontinence of flatus and stool—and have been injuries that have been fairly commonly observed in other fistula treatment programs in Kenya.³⁰ Recto-vaginal fistula (RVF) repair comprised 21.6% of cases. The majority of procedures (90.5%) resulted in an outcome of fistula closed and the woman continent at discharge. Some variation in surgical outcome was observed by procedure type, level of difficulty, and number of procedures done.

Health provider training and capacity building

The first cohort of two fistula surgeons was trained for a six-week period in September 2014 at the FIGO-accredited Gynocare training center in Eldoret. This initial training was followed by ongoing mentorship of surgeons through surgical workshops, on site visitation by members of FTN, participation in other surgical training opportunities through partner organizations, and opportunities for exposure to other trainers in different environments. Furthermore, interested doctors with little fistula surgery experience could shadow the trained surgeons prior to full enrollment in the training program, which helped both the doctor and FTN assess if fistula surgery training would be a good fit.

Over the six-year period, FTN supported training for 11 fistula surgeons, seven from Kenya and four from east and southern Africa. The seven Kenyan surgeons trained through FTN conducted 2,003 surgeries during the period. The remaining surgeries (4,220) were conducted by the senior surgeons in FTN who were trained prior to 2014. Four of these surgeons became trainers for FTN and assisted the trainees with ongoing mentorship and guidance. The success rate for the surgeons trained (fistula closed and dry) was 96%. Approximately 58% of the procedures performed by surgeon trainees were 3rd and 4th degree tears and RVF repairs which typically result in higher rate of success.

The FTN expanded in 2017 to include more health providers involved in the care and treatment of women with fistula. This expansion was made following feedback from the surgeons at the 2016 Stakeholder Meeting. From 2017-2020, 19 nurses were trained through FTN hailing from 5 centers. Nurse training began with a 2-week training at the Gynocare FIGO Training center for two nurses at a time and continued with on-site mentorship visits to the individual centers for ongoing coaching and support. Health providers in FTN also expanded to include surgeons from different disciplines, including urology, plastic surgery, and orthopedics. These providers were valuable in helping to address the needs of the most complex cases. These providers worked together with the network of fistula surgeons, who were primarily gynecologists, to share expertise and find the best solutions for the individual patients.

Beyond the clinical training, FTN helped foster a strong community of practice for providers involved in fistula care. Across the network, standardized care protocols were adopted, including clinical management tools, procedures and protocols to improve the quality of patient care and guide decision making, and standardized patient data collection forms. A WhatsApp group was created as a virtual forum to support real time collaboration and communication between the surgeons. Through this channel surgeons discussed and solicited feedback on treatment plans for complicated cases, and

shared outcomes on what worked and what failed, helping other surgeons in the network benefit from the experience of their colleagues.

Annual FTN stakeholder meetings brought together the surgical team and community outreach teams to promote dialog, improve coordination and mutual understanding, and find the best solutions to meet the holistic needs of patients at the hospital and community levels. The surgeons were supported to attend conferences hosted by the International Society of Obstetric Fistula Surgeons (ISOFS) between 2014 and 2019 in Uganda, Nigeria, and Nepal, to learn from colleague surgeons, share their research, and further build a global community of fistula care providers.

Community Mobilization and Outreach

Through the network of five community organizations, FTN implemented a broad range of outreach and mobilization activities in collaboration with 19 County Governments in Kenya. However, people across the country were reached with fistula information through mass media mobilization, and women from each of the 47 counties of Kenya received fistula treatment.

Key community outreach activities included:

Training for Community Health Volunteers (CHVs), Health Providers, and Local Leaders: CHVs were trained using a curriculum developed by FTN that included modules on fistula prevention, fistula signs and symptoms, screening, identification, referral of clients, post-operative reintegration support, and strategies for effective community engagement. After training, CHVs were given a small monthly stipend and mobile phone airtime allowance to improve communication with communities and patients. After screening, CHVs also used mobile phones to send mobile money (M-pesa) to women with likely fistula to facilitate their transportation to the nearest treatment center. CHVs submitted monthly reporting on the number of women screened and referred for fistula, the number of outreach activities conducted, and the number of community members reached through their efforts. In addition to training CHVs, FTN also trained nurses, midwives, clinical officers, and other cadres of health providers based in health centers in order to improve early diagnosis and referral of women suspected with fistula. Finally, FTN sensitized influential community leaders and chiefs, the gatekeepers in many communities to support women with fistula and dispel entrenched myths and misperceptions that spread stigma.

Community Engagement and Mobilization Activities: FTN partners conducted community meetings and hosted events including rallies and roadshows—which often involved music, community theater, and puppetry – using “info-tainment” to generate excitement and interest while passing important information about fistula. WADADIA used an innovative approach to spread awareness by sponsoring the *Let's Kick Fistula out of Africa* women's soccer team that played in the Kenyan Premier League. The team traveled around the country to participate in matches and used the half time as an opportunity to disseminate information to large crowds.

Fistula Hotline and IEC Materials: FTN established a Fistula Hotline where people could call for more information or seek a referral for themselves or a family or community member. The hotline number was distributed through mass media including radio announcements and live radio talk shows that were broadcast in local languages throughout the country. FTN also printed and disseminated information, education and communication (IEC) materials including posters, banners, flyers, tote bags, keyrings, and calendars with the hotline number. Calendars were particularly effective as people kept them on their walls for many years, displaying the photographs and illustrations as part of their home or office décor and providing a good conversation starter for visitors.

FTN worked to improve the verbal screening process to strengthen case identification and referral. The Obstetric Fistula Community Based Assessment Tool (OF-COMBAT) was developed to provide enhanced verbal screening to more accurately identify potential fistula cases eligible for referral from cases that were less likely fistula (and more likely another type of incontinence.)²⁹ The outreach organizations conducted 6,714 verbal fistula screenings and 4,690 fistula surgeries were performed for women referred through community outreach activities, representing 75% of total surgeries conducted through the network. Community outreach methods resulting in the most referrals were Community Health Volunteers, radio messages, and health facility staff sensitization, which were responsible for 63%, 13%, and 10% of referrals, respectively.

To strengthen adoption of community engagement strategies for obstetric fistula, FTN worked with the MOH to develop a training curriculum for CHVs on identification, referral, and support for women living with obstetric fistula. At the time of this writing, FTN was in the process of planning a Training of Trainers for 10 county-level facilitators to roll out the curriculum to high need areas. Additionally, FTN supported other national efforts on obstetric fistula by contributing to the MOH National Strategic Framework to End Female Genital Fistula in Kenya together with AMREF and UNFPA, and by supporting the Beyond Zero Campaign of the Kenyan First Lady Hon. Margaret Kenyatta to roll out effective community outreach and reintegration programs in high need areas.

Reintegration Post-Repair

FTN's reintegration program was initiated in May 2017. The reintegration activities included follow-up and monitoring of women after surgery in their home environment, enrollment in survivor-led support groups, income generating opportunities, vocational training, educational support, and establishment of male advocacy groups.

From 2017 to 2020, 2,691 women underwent fistula surgery and were thus eligible for reintegration support. The outreach teams and CHVs conducted follow-up visits, in person or over the phone, to monitor and assess the survivors' specific needs and determine the appropriate reintegration interventions. During the follow-up visits a questionnaire was administered to assess physical and psychosocial wellbeing. Most participants were followed-up with at least once (83.4%), and over half were followed-up with at least twice (61.7%) (Figure 3).

The physical and psychological outcomes across the 12 months post repair were encouraging. At 12 months post repair, 96% of women (n=1,092) reported that they were dry and not experiencing any incontinence (Table S2). Increases in socializing and working ability, and normal functioning were substantial from baseline through twelve-months. Over the twelve-month follow-up period, the proportion of women reporting being able to socialize “fully” with family and friends increased from 43% to 86%, the proportion of women reporting being able to fully work increased from 20% to 86%, and the proportion of women reporting normal functioning increased from 18% to 85%. Mean self-esteem increased from 4.3 at baseline (SD 1.5) to 6.3 (SD 1.4) at 12 months (Table S2).

Twenty support groups in 6 counties of Kenya were established and 423 women became participating members. The support groups established their own structures and elected their own officers to govern meetings. The support groups were comprised of between 20-25 members each, and typically met monthly. Nearly half (9) went on to register as Self-Help Community Based Organizations (CBOs) with the Kenyan government, which allows them access to greater opportunities and resources.

Beyond emotional and psychological support, these groups were a platform for income generation. The different groups selected the activities they felt best suited their members or the market in which they lived, including farming/horticulture, poultry farming, goat and cattle rearing, fish farming, and catering, and FTN provided seed funding to support these activities. The members also participated in table banking and merry-go-round savings practices, whereby members would all contribute a small amount of money to the kitty each month and would rotate access to those funds to each member in turn. FTN also supported women to enroll in training programs in tailoring, hairdressing, bead making, and computer literacy. Roughly 60% of women who graduated from skills programs have been able to turn the knowledge and skills acquired into practice by starting their own business, and others have been employed by small business owners in their counties. Most of the women utilizing their skills have reported improved income and nutrition at their household level. Women have acquired some degree of financial independence, which gives them the ability to make informed choices about their lives.

A powerful part of the reintegration support was seeing that women with lived experience of fistula can be powerful ambassadors to help identify and support other women with fistula from their communities. These fistula survivors are also effective advocates in mobilizing their communities around treatment and prevention messages and health-seeking behaviors. *Voices of Hope and Action: A Fistula Survivors Movement* has started with WADADIA, whose aim is to train and empower women with lived experience of fistula to be able to advocate for improved access to sexual and reproductive health services and to create more visibility and awareness of the particular needs of this population.

Finally, Male Advocacy Groups were created so men could be better informed to talk with other men in their communities about fistula, about the importance of supporting their partners with this condition, and about preventing fistula by encouraging women to go to the health center or hospital to give birth with a skilled birth attendant instead of at home in the village as has long been the tradition. Involving the husband and other male family members in the fistula survivor’s treatment also helped improve

adherence to the post repair instructions such as abstaining from sexual intercourse during the recovery period.

Discussion

FTN sought to increase access to treatment for women living with fistula in Kenya and develop the capacity of health providers, hospitals, and community-based organizations to strengthen fistula care and reintegration support. Results from process and outcome assessment highlight program achievements and the positive impact of fistula repair surgery and follow-up on women's continence status and quality of life. The data show clear improvement in measures of social and emotional health and livelihood across the 12 months women were followed up with after fistula surgery.

FTN highlighted that community outreach is fundamental to case identification and referral of patients. Women with fistula are highly stigmatized, isolated, and often live in hard-to-reach rural areas. More than 80% of women who were treated through FTN came as a direct result of community organization engagement, the majority of which through CHVs who developed trust and confidence with their community members and could provide ongoing support over a prolonged period. The creation of the OF-COMBAT screening tool also helped improve the identification and referral of patients and helped community members explain to women how this decision was reached. This helped build confidence in the program and reduced program transportation costs by ensuring only women who had likely fistula were referred to the treatment center.

One of the major factors FTN weighed in expanding access to care was balancing the need to bring services closer to where women lived while also ensuring high quality surgical treatment. FTN strategically decided to provide training and ongoing mentorship for a smaller number of surgeons as opposed to spreading training over a large number of surgeons in every county. Adequately training a fistula surgeon requires sufficient clinical exposure during their training, a large enough case load in their respective home institutions to maintain and improve their surgical skills, and a referral mechanism for cases outside of their competency level. In the second phase of FTN after the treatment network was largely established, we further focused training activities almost entirely on building capacity of those already trained to be able to take on more complex cases. The 2021 UNFPA Obstetric Fistula Manual suggests that this approach, of “quality over quantity” when it comes to training of specialist fistula surgeons, is the best way to ensure that women have access to truly expert care and optimizes their likelihood of a successful surgical outcome.⁴ This strategic approach required strong case identification and referral systems linking communities to specialists at limited target facilities for ensuring access, both of which were critical components of the FTN approach.

Still, finding and retaining fistula surgeons to be based in geographically strategic locations was a challenge. During this project period FTN was unable to find a resident surgeon from coastal Kenya motivated to train in fistula surgery. Instead, we opted to fly out a Nairobi-based fistula surgeon every quarter to provide surgery which allowed for consistency, on-site mentorship of the resident team, and

improved follow-up care for women who required multiple interventions. Additionally, two of the seven surgeons trained through FTN opted out of the program following completion of their training, despite sustained efforts by FTN to motivate and incentivize this work.

Post-repair reintegration activities were added to FTN following stakeholder feedback that the program was missing an opportunity to support more holistic healing and empowerment for women with fistula. Research has shown that this component of fistula care has benefit in improving physical, psychosocial, and economic outcomes for women, and is supported by many fistula stakeholders,²⁶ but is often overlooked and under-resourced.

FTN reintegration activities also provided an opportunity for community teams to collect data on women's long-term physical and psychosocial outcomes that were not possible through the treatment center, providing greater insight into the trajectory of post-repair recovery and contributing to the relatively limited literature on long-term continence status and quality of life outcomes for women after fistula repair. While appropriate controls are not available to robustly compare the impact of our reintegration programming, and the literature suggests that successful surgery alone is associated with substantial improvements in quality of life;^{7,9,10,31} the few published controlled interventions incorporating psychosocial support report significantly improved self-esteem and reduced suicidal ideation, with non-significant intervention differences in depression, anxiety and post-traumatic stress disorder. However, these studies provided only short-term psychosocial support which did not extend past hospital discharge. Other uncontrolled psychosocial support interventions programs have reported increased confidence, self-esteem, and emotional health.³²⁻³⁴ Our findings on improvements in socializing ability, ability to work, and normal functioning across time largely follow a similar pattern to those reported by El Ayadi et al in Uganda,⁸ by 12-months following surgery, particularly in light of the higher surgical success rates seen within the population served by our program; however our interventional context may be responsible for the continuing substantial increases in these outcomes following 6 months, after which El Ayadi et al observed less steep gains. While tested modalities align theoretically with improved outcomes; robust research design would allow testing of gains possible by program types and intensity and inform cost effectiveness of various approaches. FTN has since adapted our data collection instruments to allow for better understanding of outcomes across levels of support group participation and types of economic empowerment interventions.

Building the holistic Fistula Treatment Network in Kenya was not without its challenges. Data collection, review and analysis was an ongoing challenge at the hospital as well as community level. Monthly monitoring of patient data records by Fistula Foundation staff helped improve completion and submission of reports but this process required continuous support. Data management tools were limited to Microsoft Excel; use of a relational database with mobile device data collection tools could have helped mitigate some of these challenges. Ultimately, we would also want fistula data to be included in the Kenya HMIS II System so that the data on fistula prevalence is incorporated into national data sets, as visibility on the issue remains low in part due to limited data availability.

The strength of the FTN network model is more than its ability to markedly improve access to treatment but also to provide a holistic support system for women with fistula, from community identification, referral to the hospital for fistula surgery, and then follow-up and reintegration. The integration of local community-based organizations and public and private hospitals was a unique structure that allowed women to get the best care while also allowing each partner to focus on their strengths - hospitals and surgeons to concentrate on clinical care and community organizations on improving awareness, case identification, referral, and reintegration. FTN sought to address each aspect of the treatment journey for women, removing financial, psychosocial, and logistical barriers to expedite her ability to receive the care she required. Not only this, but for many women enrolled in the reintegration programs, FTN sought to move them beyond the status quo following surgery to elevate their overall psychosocial health and economic wellbeing.

Conclusion

The Fistula Treatment Network was effective in increasing access to fistula care services, strengthening the fistula care workforce, improving understanding of fistula and reducing stigma in a community setting. The program continues with financial support from Fistula Foundation and private donors. This integrated approach can be a useful model for delivery of comprehensive services in other countries where the burden of obstetric fistula is high.

Abbreviations

FTN	Fistula Treatment Network (FTN)
CBO	Community Based Organization
CHV	Community Health Volunteer
FIGO	International Federation of Gynecology and Obstetrics
IEC	Information, Education and Communication
ISOFS	International Society of Obstetric Fistula Surgeons
MOH	Ministry of Health
NGO	Non-governmental Organization
OF-COMBAT	Obstetric Fistula Community Based Assessment Tool
UNFPA	United Nations Populations Fund
WADADIA	Women and Development against Distress in Africa

Declarations

Ethics approval and consent to participate

All women were counseled and gave informed consent to participate in the comprehensive range of services provided by the FTN consistent with local medical and social care protocols, from the time of verbal screening at the community level, referral to the treatment center, physical examination and provision of fistula treatment, and post-operative care and follow-up in the community setting. Program data were collected for evaluation purposes. Data analysis activities were self-certified as not human subjects research following University of California San Francisco Institutional Review Board definitions.

Consent for publication

Not applicable

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

LP made substantial contribution to the program design and implementation and the writing of the manuscript; AME made substantial contribution to the analysis and interpretation of the data and the revising of the manuscript; HCM made substantial contribution to the design and implementation of the work and the review of the manuscript. All authors approve the final version of the manuscript.

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Tables

Table 1. Characteristics of FTN-supported fistula-related surgeries, Kenya, May 2014-April 2020

	Surgeries		Women	
	n=6,223		n=5,720	
	n	%	n	%
Number of surgeries recorded				
1			5,327	93.1
2			319	5.6
3 or more ^a			74	1.7
Procedure type				
VVF Repair	2,469	39.7	2,251	39.4
3rd/4th Degree Perineal Repair	1,792	28.8	1,718	30.0
RVF Repair	1,350	21.7	1,233	21.6
Urethral Fistula Repair	217	3.5	194	3.4
VVF/RVF Repair	131	2.1	123	2.2
Other ^b	264	4.2	201	3.5
Age, median (IQR)	34 (25-54)		34 (26-45)	
County	(n=6,223)		(n=5,720)	
Bungoma	799	12.8	755	13.2
West Pokot	716	11.5	667	11.7
Kisii	596	9.6	541	9.5
Homa Bay	464	7.5	420	7.3
Uasin Gishu	391	6.3	354	6.2
Narok	353	5.7	328	5.7
Others ^c	2904	46.7	2655	46.4
Incontinence type	(n=6220)		(n=5,717)	
Urinary only	3,045	49.0	2,750	48.1
Fecal only	2,947	47.4	2,756	48.2
Both urinary and fecal	228	3.7	211	3.7
Incontinence duration, in years	(n=6,157)		(n=5,648)	
1 year or less	1,708	27.7	1,556	27.5

1-3 years	974	15.8	889	15.7
3-5 years	661	10.7	605	10.7
5-10 years	995	16.2	921	16.3
10 years or more	1,819	29.5	1,683	29.8
Presumed cause of fistula	(n=6,150)		(n=5,648)	
Obstetric	5,853	95.2	5,400	95.6
Iatrogenic	153	2.5	134	2.4
Traumatic	144	2.3	114	2.0

Notes: ^aNumber of surgeries: 3 (n=51), 4 (n=14), 5 (n=6), 6 (n=2), and 7 (n=1). ^bSurgery type: ureteric fistula repair (78 surgeries, 70 women), sling or urethroplasty (51 surgeries, 39 women), urinary diversion (51 surgeries, 42 women), vaginoplasty (38 surgeries, 24 women), other (51 surgeries, 40 women). ^cOther counties (Figure 1; full specification of counties in Table S1).

Table 2. FTN-supported fistula-related surgeries by outcome, Kenya, May 2014-April 2020

Surgical Characteristics	N	Surgical Outcome					
		Fistula not closed		Fistula closed, incontinent		Fistula closed and continent	
		n	%	n	%	n	%
All procedures ^a	6198	388	6.3	203	3.2	5607	90.5
Procedure type							
VVF repair	2459	233	9.5	129	5.3	2097	85.3
RVF repair	1341	46	3.4	37	2.8	1258	93.8
VVF/RVF repair	130	11	8.5	7	5.4	112	86.2
3rd/4th degree perineal tear repair	1790	45	2.5	15	0.8	1730	96.7
Urinary diversion	46	4	8.7	1	2.2	41	89.1
Vaginoplasty	38	6	15.8	0	0.0	32	84.2
Urethral fistula repair	217	21	9.7	7	3.2	189	87.1
Ureteric fistula repair	78	11	14.1	1	1.3	66	84.6
Sling or urethroplasty	51	5	9.8	5	9.8	41	80.4
Other	48	6	12.5	1	2.1	41	85.4
Procedure difficulty							
Simple	2594	45	1.7	32	1.2	2517	97.0
Intermediate	2338	115	4.9	69	3.0	2154	92.1
Difficult	1257	227	18.1	102	8.1	928	73.8
Incontinence duration, in years							
1 year or less	1701	111	6.5	57	3.4	1533	90.1
1-3 years	971	70	7.2	29	3.0	872	89.8
3-5 years	660	35	5.3	17	2.6	608	92.1
5-10 years	991	54	5.5	31	3.1	906	91.4
10 years or more	1810	115	6.4	65	3.6	1630	90.1
Procedure number							
1	5700	313	5.5	176	3.1	5211	91.4
2	389	49	12.6	21	5.4	319	82.0

3 or more ^b	73	16	21.9	4	5.5	53	72.6
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Notes: ^aOutcome data were missing for 25 surgeries. ^bSurgical outcome of fistula closed and continent was achieved by 72.3% of 3rd procedures, 78.3% of 4th procedures, and 46.2% of 5th or higher procedures.

Figures

Figure 1

See image above for figure legend.

Figure 2

FTN-supported fistula surgery sites and number of women who underwent surgery by county, Kenya, May 2014-April 2020

Figure 3. Community Outreach Outputs

- 5 Kenyan organizations supported
- 424 Community Health Volunteers trained and mobilized
- 20,050 Outreach activities conducted
- 4,299 Health facility providers sensitized
- 3,453 Radio and media spots aired
- 1,964,452 Community members reached with fistula messages

Figure 3

See image above for figure legend.

Figure 4

Trajectories of psychosocial status during post-surgical follow-up

Figure 5. Reintegration Program Outputs

- 5,515 follow-up visits conducted
- 20 support groups established in 6 counties
- 423 women enrolled in support groups
- 170 women participating in skills and vocational training
- 2 Male Advocacy Groups established with 30 members

Figure 5

See image above for figure legend.

Supplementary Files

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