10 YEARS OF OBSTETRIC FISTULA CARE IN MALI:

A Case Study of Multisectoral, Holistic Treatment for Women and Girls

IntraHealth INTERNATIONAL

Because Health Workers Save Lives.

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Cover photo: Bintou Sangaré (center) lived with fistula for over 20 years before undergoing a repair surgery. She is now fully healed and reintegrated into her community. Here she is with fellow members of a small social club, the name of which roughly translates to, "We don't care what the people behind us think." They pool their money to buy fabric and make matching outfits, which they wear together to mosque, weddings, and other celebrations.

Acknowledgements: We thank the following people for their role in developing this report: Julie Solo, Cheick Touré, Demba Traoré, the Fistula Mali team, Rebecca Kohler, Karen Melton, Margarite Nathe, and David Nelson. We also thank our local partners in Mali—including the Ministry of Health; the Orange Mali Foundation; Women Action Research, Study, and Training Group; the International Association for Maternal and Neonatal Health in Mali; the Medical Alliance against Malaria; UNFPA/Mali, Maison de l'Espoir, and West Africa regional Rotary Club Inner Wheel—as well as our international partners, including Direct Relief, Project C.U.R.E., and Duke Global Health Institute. And finally, we thank the US Agency for International Development for partnering with Mali to achieve the progress outlined in this report.

Introduction

Midwife Kadidia Niare (left) talks with a client at the referral health center, or CSRef, in Koulikoro, Mali. She works with fistula clients throughout their stays there, including making sure they have the food and medicine they need and bathing them during their recovery.

Obstetric fistula is a devastating, disabling condition that affects women and often isolates them from society. It usually strikes the poorest women during childbirth in areas where access to health services is low. The condition is not well known by decision-makers or even by many health workers. It remains the least-supported cause of maternal morbidity, though it is one that can most drastically affect women, families, and societies.

An **obstetric fistula** is an abnormal opening between a woman's genital tract and her urinary tract or rectum, and is typically caused by complications of prolonged, obstructed labor. Women who suffer from fistula often leak urine and/or feces. They face physical, moral, psychological, and social suffering, despite the fact that most cases can be fully repaired through surgery.

The World Health Organization estimates that **more than 2 million women** are living with obstetric fistula in Asia and sub-Saharan Africa. In West Africa, obstetric fistula occurs 3 to 4 times per 1,000 births. To deal with this silent problem, the United Nations, under the auspices of UNFPA, began a world campaign in 2003 to eliminate obstetric fistula.

The Situation in Mali

In Mali, obstetric fistula is a true public health problem. According to the National Strategy for Fistula in the Ministry of Public Health and Hygiene (MSHP), 1,804 to 2,405 women are at risk of developing fistula per year. The principle factors contributing to this risk are:

- high fertility rate (6.1)
- low use of modern contraceptive methods (10.1%)
- early childbearing age (under 18)
- low rate of births in health centers with qualified health workers (59%)

> "Before, there were rumors and myths about fistula being a curse. A lot of people didn't know it was related to childbirth, but thought it was witchcraft. Now they know it's a health issue."
>
> *—Demba Traore, Fistula Mali*

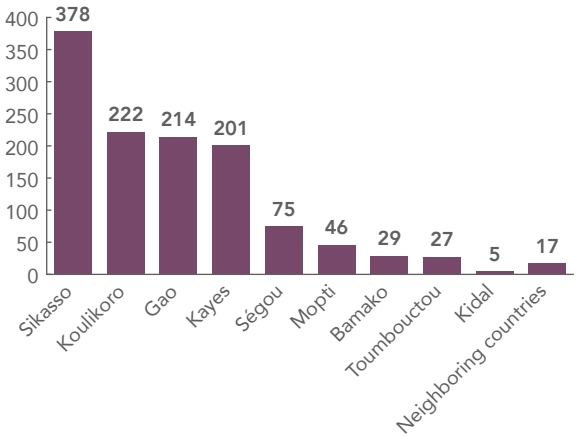
The Government of Mali is committed to ending this social plague and has demonstrated that by taking part in the global campaign to eliminate fistula decreed in 2003 by the United Nations and by developing a National Strategy for Prevention and Treatment of Obstetric Fistula. Since then, with the support of partners such as the US Agency for International Development (USAID), the country has made significant progress in the comprehensive management of obstetric fistula.

In 2006, only 16% of women in Mali had heard of fistula, and treatment was available only in Bamako or Mopti. By 2012, over half (52%) of women knew about fistula. Mali only had two fistula surgical treatment sites in 2009, but has since increased to nine sites in 2018, which has led to the decentralization of fistula surgery throughout the country.

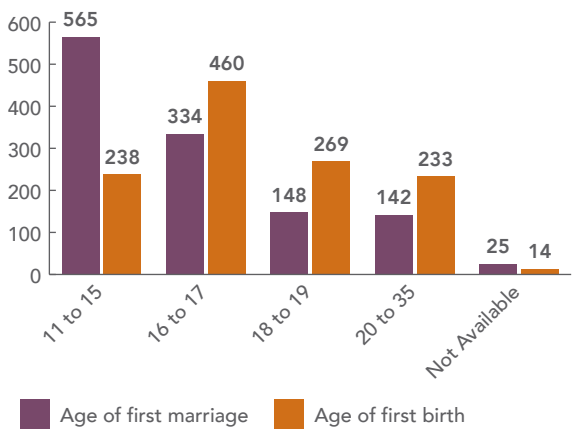
USAID has contributed significantly to achieving these results by funding two projects: Fistula Care (2009-2013) and Fistula Mali (2014-2019). Both projects were executed by IntraHealth International in Mali.

This report explores Mali as a case study for the region and globally.

Home regions in Mali and neighboring countries of women who received fistula surgeries through Fistula Mali



Age of first marriage and birth for women treated for obstetric fistula through Fistula Mali



Health workers at the CSRef in Koulikoro. Mali is working to make comprehensive fistula care available at smaller facilities like this, which will bring services closer to women's homes and cut down on travel time and expense.

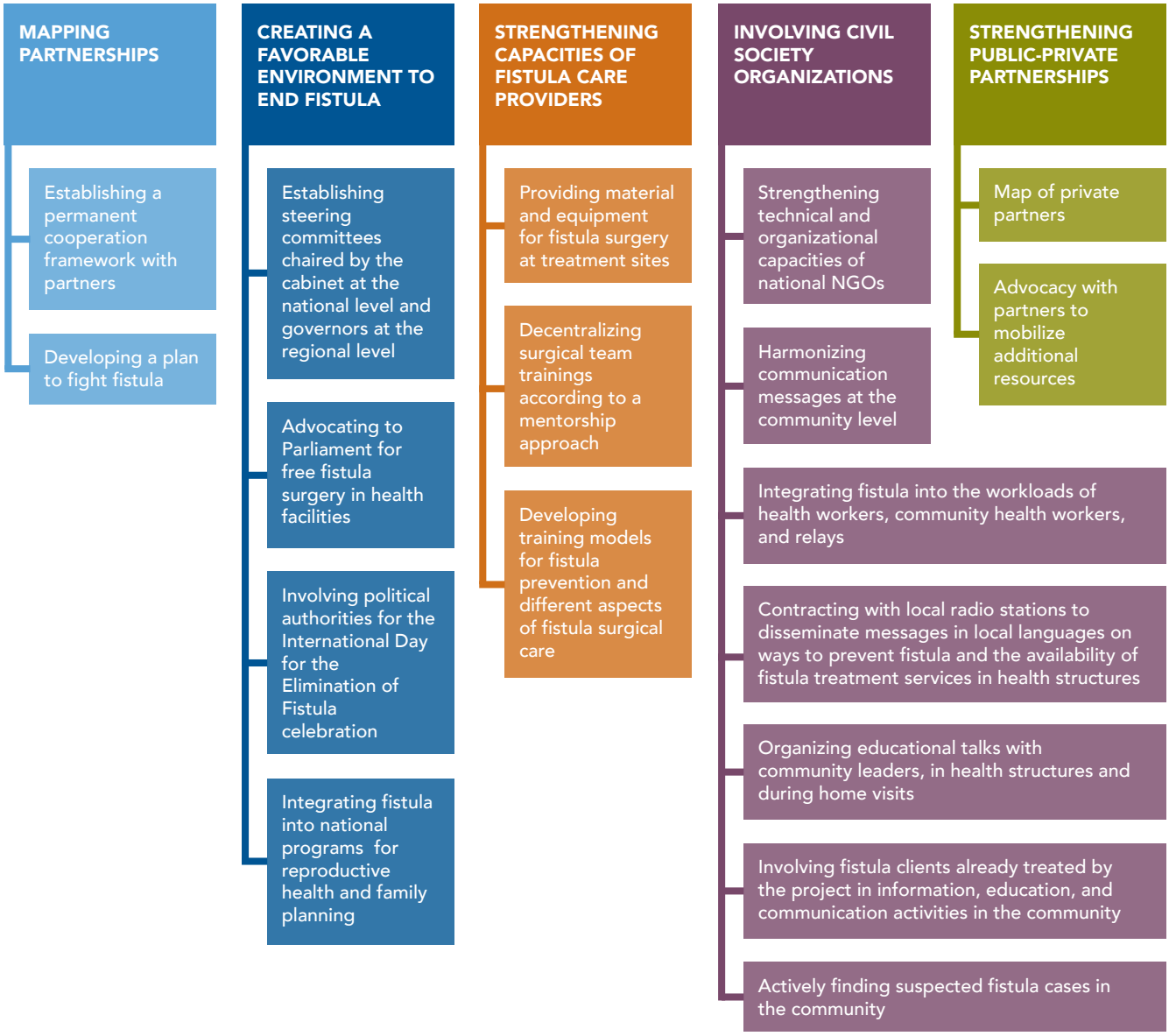
A TIMELINE OF THE GOVERNMENT'S FISTULA EFFORTS IN MALI

1982:	University Hospital Center Point G in Bamako becomes the first site in Mali to offer fistula treatment.
1993:	Hospital Sominé Dolo in Mopti becomes the second center capable of surgical fistula repair.
2000:	The Oasis Center at University Hospital Center Point G is constructed to serve as reception and housing for women with fistula and their families.
2005:	The government of Mali joins the United Nations Global Campaign to End Fistula.
2009:	The National Strategy for the Prevention and Treatment of Obstetric Fistula is validated.
2013:	The National Celebration of the International Day for the Elimination of Obstetric Fistula is established by the United Nations General Assembly to occur every May 23. Fistula is integrated into the *Plan Décennal de Développement Sanitaire et Social*, reproductive health strategic plans, and reproductive health and family planning standards, procedures, and policies.
2016:	The final evaluation of the National Strategic Plan for the Prevention and Treatment of Obstetric Fistula 2009-2015 takes place.
2017:	The second Strategic Plan for the Elimination of Obstetric Fistula 2018-2022 is validated.

Since 2009, all efforts to end obstetric fistula in Mali have been supported by the US government through USAID.

CONCEPTUAL FRAMEWORK FOR MALI'S APPROACH

USAID and IntraHealth aim to strengthen Mali's health system to ensure sustainable results. The Fistula Mali project is based on five strategic, complementary approaches: mapping the actors involved in fistula care by intervention level, advocating for an environment favorable to ending fistula, strengthening the capacities of fistula care providers, and the involvement of civil society organizations and public-private partnerships.



Fistula surgeons at work in Kayes, Mali.

Key Interventions from Mali

These five key interventions have led to Mali's great progress in fistula care:

DECENTRALIZING FISTULA SURGERY

Geographically accessible care for women with fistula is one of the most important strategic aspects of Mali's national fistula plan. But analysis showed that the country did not have the human resources expertise in fistula surgery to achieve this. In the context of limited resources, developing local human resources is vital, so IntraHealth developed a new mentorship approach to train surgical teams in the intervention zones.

The technique is based on observing the competencies of learners in real time and in their own work environments. The team found that all surgeons in the project intervention areas did not have the skills to independently carry out clinical diagnosis and/or operate on obstetric fistulas.

The mentorship approach took place in four stages:

- the development of training modules for diagnosis and surgical techniques of obstetric fistula
- the design of knowledge and skills assessment tools for surgeons
- the organization of campaigns for the surgical treatment of fistula cases
- the assessment of surgeons' skills at each fistula repair campaign site, according to national standards

Between June 2014 and April 2018, this approach built the capacity of 25 fistula surgeons. The skills assessment showed that 100% were able to both diagnose fistula and prevent fistula during deliveries according to national standards. Further, 56% (14/25) could perform simple obstetric fistula surgeries under the supervision of a trainer, and 44% (11/25) were at level III, meaning they were able to perform surgeries on all levels of obstetric fistula without supervision.

As a result, all sites with level III fistula surgeons introduced routine surgery into their hospitals, which contributed to better care for clients in the intervention areas. Paramedic staff involved in the treatment of fistula (before, during, and after surgical care and during psychosocial support and family planning services) were also trained.

MSHP surgical fistula sites have increased from three in 2013 to seven sites in 2018.

OPTIMIZING PERFORMANCE AND QUALITY AT FISTULA TREATMENT SITES

An analysis using IntraHealth's signature approach for problem-solving and capacity-building, called Optimizing Performance and Quality (OPQ), revealed that the challenges to providing high-quality fistula care and services at treatment sites could not be sustainably solved without the action of health workers. OPQ is a systematic process and set of methods for analyzing the performance of professionals, organizations, systems, and interventions to improve individual or institutional performance. Its purpose is to strengthen the quality of services and care provided to women with fistula and their families by establishing a work environment that helps clients access and use maternal, neonatal, and infant health services.

According to most providers involved in fistula treatment at the intervention sites, the approach has improved their working environment.

Master trainers work side-by-side with surgeons in Kayes, Mali, as they perform fistula repair surgeries.

How local fistula training helped prevent an Ebola outbreak in Mali

When a little girl showed up at the hospital in Kayes in 2014 with what seemed to be symptoms of Ebola, no one wanted to touch her for fear of becoming infected. But a pharmacist named Jonas Kamaté (above) knew he could help. He had gone through the infection-prevention training offered as part of IntraHealth's comprehensive fistula training for the local health team.

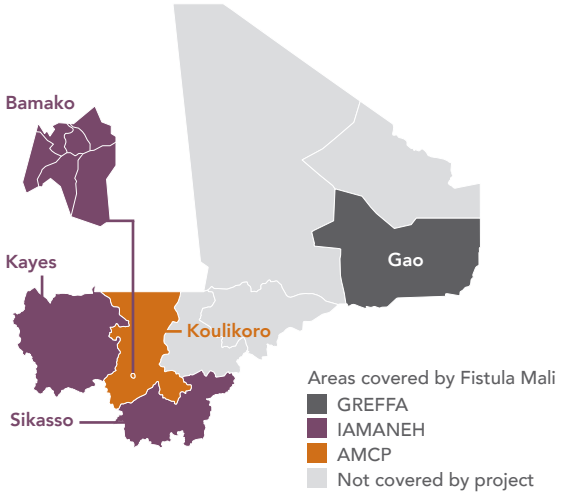
"The project training gave me the courage to confront Ebola when it came to Kayes," Kamaté says. "I did the blood draw and sent it to Bamako, and it came back positive. The little girl died, but she was the only one at our hospital to be infected. It did not spread, thanks to the training. Infections and complications have decreased at the hospital since the project began, but we could do more."

This was one of only two Ebola cases in Mali during the West Africa outbreak. The other was in Bamako.

STRENGTHENING NATIONAL NGOS' FISTULA CARE CAPACITIES

IntraHealth's technical approach in Mali focuses on strengthening the health system at all levels by working with local partners, including civil society organizations.

It is within this framework that three national nongovernmental organizations (NGOs) were selected to implement the third objective of the initial project: to educate communities on the of causes of fistula and how to prevent it. These NGOs were:



- Research, Study, Women-Action Training Group (GREFFA)
- International Association for Maternal and Neonatal Health in Mali (IAMANEH Mali)
- Medical Malaria Alliance (AMCP)

Three key criteria guided the choice of these NGOs: their experience in implementing reproductive health/family planning programs at the local level, their expertise in behavior change communication at the community level, and their willingness to collaborate with international NGOs for a dynamic and mutually beneficial partnership.

These subrecipients of the Fistula Mali project gain communities' support by:

- Talking with community leaders and urging them to promote the prevention of obstetric fistula and encourage their communities to access necessary health services.
- Sensitizing the population to reduce discrimination and stigmatization of women suffering from fistula.
- Strengthening the capacity of community health workers and community relays to treat of obstetric fistula at the community level.
- Recruiting and transporting women who may be suffering from fistula to treatment sites.
- Offering psychosocial support to women with fistula and to their families.
- Promoting modern contraceptive methods for women suffering from obstetric fistula.

During the five years of the project, the subrecipients recorded the following results:

- **1,067** community health workers and community relays trained on fistula prevention and screening for women who may be suffering from fistula.
- **6,017** educational talks with community stakeholders (such as the Association de Santé Communautaire religious and community leaders, women's groups,

and youth groups) on the factors that contribute to fistula and ways to prevent it, ending social discrimination, and the availability of treatment services in health facilities.

- **36,747** radio broadcasts in local languages.
- **1,938** women with suspected cases of fistula recruited for care. Their referral to treatment sites resulted in 31 treatment and surgical team training campaigns.
- **81.3%** (1,160/1,426) accuracy rate in screenings carried out by community NGOs supported by the project. These NGOs previously correctly identified cases of fistula in women less than 50% of the time.

WHAT IT TAKES TO FIND HARD-TO-REACH CLIENTS IN NEED

One of the most difficult parts of providing fistula care in Mali is identifying the women who need it. Many women with fistula are ostracized from their communities and go into hiding. Many live in hard-to-reach areas—including deserts and communities without roads, electricity, or running water—that are sometimes referred to as "deep Mali." This is why outreach and community health workers from local NGOs are essential. They travel into the remotest villages, develop relationships with their communities, and bring health-related messages and education that often lead them to the women most in need of fistula repair services.

To involve more community leaders, the project partnered with women's groups such as Nièta, which means "moving forward" or "being progressive." Nièta is a group of friends, neighbors, and activists working in Kayes and the surrounding area, educating communities and encouraging pregnant women to get prenatal care and to give birth in health facilities. The group works to end child marriage, eliminate female genital mutilation, and promote education and family planning. Often, they discover women with obstetric fistula and put them in touch with surgical repair campaigns, which makes them a vital link in fistula care outreach.

STRENGTHENING PUBLIC-PRIVATE PARTNERSHIP

IntraHealth attracted additional partners for Fistula Mali and the country's efforts to end fistula through its two-year Clinton Global Initiative Commitment to Action[1] platform during 2015–2017. The goal was to mobilize additional resources to restore dignity to women who suffered from fistula. These partners included international organizations (including Direct Relief, Project C.U.R.E., and Duke Global Health Institute) and organizations at the national level (telecommunications company Orange Mali Foundation, UNFPA/Mali, Maison de l'Espoir, and West Africa regional Rotary Club Inner Wheel).

One major challenge of fistula care in Mali has been the length of the hospital stay required for fistula repair candidates before and after surgery, which ranges from three to four weeks. Facilities have struggled to find space for the influx of patients during fistula repair campaigns, as they may only have the capacity to hospitalize up to 30 patients at a time. This issue affects the quality of services all patients

[1] Established in 2005 by President Bill Clinton, the Clinton Global Initiative convenes global leaders to create and implement solutions to the world's most pressing challenges. IntraHealth and its partners worked with the government and communities of Mali to offer holistic fistula services to 800 women across seven regions. The commitment brought new financial resources and partners to Mali's efforts to address fistula.

"When I started at the foundation, it was already supporting women with fistula. They gave 50 surgical kits every year and were supporting the Oasis Center at the Point G Hospital in Bamako. I saw these women with fistula suffering terribly, but I didn't know what more we could do to help them. Then we received a request from IntraHealth to talk.

"Cheick Touré [who leads IntraHealth's efforts in Mali] brought all the Fistula Mali project staff and partners together for a meeting to talk about what everyone could contribute to help these women. It came up during that conversation that there was no dedicated space for them at the hospitals when they come for their surgeries.

"So we built a welcome center for fistula clients at Sikasso Hospital in southern Mali. And we are now building another one at the Koulikoro referral health center, as well."

—Hawa Diallo, general administrator, Orange Mali Foundation

receive. To resolve this, IntraHealth worked with the Orange Foundation to build and equip two welcome centers (at Sikasso Hospital and at the Reference Health Center of Koulikoro). In addition to this support, IAMANEH Mali, with financing from a Spanish cooperative, constructed a third welcome center at Kayes Hospital in 2017.

Contributions from other partners in the CGI initiative led by IntraHealth are:

- **Direct Relief and Project C.U.R.E.**, which provided three sites (Kayes, Koulikoro, and Bamako) with medical and surgical materials and equipment.
- **Duke Global Health Institute**, which introduced the mental health assessment approach for women with fistula and the possibility of integrating holistic management of fistula treatment into health facilities. Institute researchers worked with Fistula Mali to test an approach for understanding and addressing the mental health needs of women with fistula. The results of their study showed that, initially, 84.4% of patients tested met the criteria for some level of depression. During a follow-up, this percentage had fallen to 69.2%. The survey showed that almost two-thirds of participants (65%) had experienced self-harm or suicidal thoughts during the previous two weeks, which shows the intensity of mental distress caused by fistula. All participants who had signs of moderate or severe depression received counseling or were referred to mental health services. These results have led the MSHP to integrate this approach into its new strategic fistula elimination plan for 2018–2022.
- **Inner Wheel District Bamako 901**, which provided dignity kits for women, including food and hygiene products.

IntraHealth also mobilized its own resources to finance a pilot project for the socioeconomic reintegration of women with fistula in the Sikasso region through income-generating activities. This project, carried out with two national NGOs (Maison de l'Espoir and IAMANEH Mali), enabled 46 women who had been treated for fistula to pursue income-generating activities that ensured their financial autonomy.

Mali's multifaceted approach has created health care benefits beyond fistula care, including improving overall health-seeking behavior. By training health workers on fistula and integrating it into broader maternal health activities, Fistula Mali has linked fistula services to family planning, prenatal care, and childbirth.

Throughout the country, these efforts have enabled thousands of women who suffered from fistula to restore their dignity. In fact, of the 1,140 treated fistula cases that were paid for by the USAID Fistula Mali project, three-quarters are closed and dried (that is, completely healed). In addition, 78% of women treated for fistula adopted a modern contraceptive method before leaving the hospital. This is noteworthy given the low usage of modern contraceptive methods in Mali.

"The most important thing for treating obstetric fistula is human resources—the surgeons, the people who clean the rooms, nurses, urologists—all of them are important."

—Dr. Kalilou Outtara (above), surgeon and master trainer in Kayes, Mali

Comments from direct beneficiaries of the income-generating activities and their families:

"Thanks to the support of the income-generating activity project, I was able to save 10,000 CFA and use it for home improvements, including fixing our bathroom, and for my prescriptions during the malaria crisis. I am very proud."

—Kounandy Diallo

"Thanks to the support of the project, I paid for the consultation fees and prescriptions for my daughter-in-law. This was unimaginable before. Her husband is unemployed, and he was not able to pay for such expenses. This has strengthened our family bond. I am very proud."

—Sincina

"Pointless arguments have given way to intimate conversations and listening to each other. I do not pay for clothes, shoes, and jewelry anymore. My wife gives me pocket money for my personal needs. I am very pleased, and I help her with her business when she is traveling."

—Mamadou Berthé, husband of fistula client Ramatou Mallé

"All the little costs, especially those for our children, are now covered by my wife. It's really been a relief. Today, I take care of the flour supply from the wholesalers."

—Bocari Coulibaly, husband of fistula client Kadiatou Sangaré

Fistula clients and their family members get to know one another during a repair surgery campaign at the hospital in Kayes, Mali.

OPERATIONAL RESEARCH

To encourage the use of evidence-based data for decision-making, IntraHealth conducted six operational research projects. These projects can be grouped into five categories:

- How quality of care affects the risk of fistula occurrence, including studies on cesarean data and completed birthing charts in health centers.
- Barriers to care for women suffering from fistula, including studies on the feasibility of fistula surgery at lower-level health facilities (including a pilot study at Koulikoro Reference Health Center) and decentralization of surgeon trainings using the mentoring approach.
- How health structures can be organized to provide high-quality services, including by introducing the OPQ approach at intervention sites and strengthening the capacity of human resources for health.
- How building the capacity of national NGOs can improve the global management of fistula in Mali.
- Mapping women treated for fistula by region and their sociodemographic and clinical profiles to better inform maternal health interventions.

The results of this research have been shared with policy-makers and technical and financial partners in the country to help them make data-based decisions that improve fistula treatment and prevention in Mali.

During 2014–2018, Fistula Mali:

- **provided obstetric fistula repair surgeries for 1,214 women**
  - **75%** of those women had fully closed fistulas after surgery
  - **68%** had completely closed and dry fistulas after surgery
- **trained 520 health workers to provide fistula care services**
  - **25** were surgeons, and **11** of those can now perform all obstetric fistula surgeries without supervision
- **trained 1,628 health workers in family planning and reproductive health**

Oumou Sall (fifth from left, top row) is now fully recovered from her obstetric fistula and part of her community once more.

Saiba Coulibaly (left), 75, and Malado Traore, 73, in their village outside of Dioila, Mali.

Two friends transformed

For three days, Malado was in labor, but unable to give birth. She was only 17, and it was her first baby. Finally, someone helped her into a donkey-drawn cart and carried her to a clinic in the nearby town of Dioila.

"They had to force the baby out," Malado says. Her newborn did not survive.

Aside from the emotional pain, the trauma to Malado's body was extensive. When the health workers helped her stand up after the birth, she realized urine was leaking out of her—and it didn't stop from then on. Nerve and muscle damage gave her such trouble walking that soon she had to use a cane to get around. Twice, she attempted suicide.

Soon she learned that less than a kilometer down the road, a young woman named Saiba was going through the same thing.

Saiba had been married at 15 and was now having her third child. A few days into her labor she still couldn't deliver. So she too made her way to Dioila, where her baby was finally born, but did not survive. A few days later, Saiba was leaking urine.

"I didn't know what was happening to me," Saiba says. "I would spend all day crying."

Eventually, no one else in their communities wanted to get close to them because of the smell, and so they became friends. And for the next 50 years, both women lived with the condition, changing and washing their clothes constantly and feeling as if they had lost all dignity.

Then in 2016, during the first fistula repair campaign organized by IntraHealth's Fistula Mali project, a local health worker, matron Djénéba Boiré, heard a radio announcement calling on women with Malado's symptoms to come to the Koulikoro CSRef health center, where they would receive all the care they needed at no cost to them.

Djénéba told Malado, now 73, who quickly passed the news to Saiba, 75. And together they set off for Koulikoro.

Today, both Malado and Saiba are completely healed.

"We consider it our role in the community now to tell every pregnant woman we see that she must go for prenatal care," Malado says. "And that she must deliver in a health facility."

There is still great need in Mali for fistula repair surgeries, including among many women in their sixties and seventies who have lived with the condition for decades.

A version of this story originally appeared in ONE.

Toward Sustainable Achievements to End Fistula in Mali

What does sustainability for fistula care look like? The team for the midterm evaluation of the global Fistula Care Plus project defined sustainability for treatment as "the existence of an enabling environment (i.e., a national strategy), geographically and financially accessible treatment for women suffering from fistula, and the availability of skilled human resources in health care to offer quality obstetric care at all levels of the health system."

Mali has made significant progress on the three elements of sustainability, despite the ongoing insecurity caused by religious extremists, which has been a major challenge for Mali's government in mobilizing resources to address fistula. The highest authorities in the country have continued their political commitment by validating Mali's Second Strategic Plan for the Elimination of Obstetric Fistula, 2018-2022. This MSHP plan has incorporated all the interventions and strategies mentioned above, the most important of which are:

- **Expanding fistula surgery to referral health centers** to make fistula treatment available in more geographic areas.
- **Involving national NGOs** to improve communities' knowledge of risk factors and prevention, and to help find women who may be suffering from fistula in their communities and refer them to treatment sites.
- **Mobilizing additional resources** by revitalizing public-private partnerships to build capacity in treatment sites and aid in the socioeconomic reintegration of women suffering from fistula back into their communities.
- **Decentralizing surgical team training** in limited-resource settings.
- **Providing holistic fistula treatment in health facilities** and integrating these services into maternal health care.
- **Sharing operational research data** with all stakeholders for decision-making that improves reproductive health programs and resource allocation.

"I have regained my dignity," says Oumou Sall (right) after a fistula repair surgery from which she has now fully healed. "I never thought that it could end. But I am thankful."

Four Lessons for the West Africa Region

Mali's experience in improving the treatment and prevention of fistula provides lessons for other countries that are now addressing this issue:

1. **Secure government commitment** from all levels of decision-making based on scientific evidence to create a favorable institutional environment and enable more partners to coordinate for the elimination of this social scourge.
2. **Involve civil society organizations.** Work with partners who know and are known by the communities. Build local capacity among health care teams and partners. This leads to stronger commitments, expands contributors' skills and reach, and is a crucial step on the journey to self-reliance.
3. **Pursue public-private partnerships**, which allow for crucial innovations and additional resource mobilization. The private sector can become a powerful ally in educating communities to change their behaviors and use more health services and in improving the overall quality of health care.
4. **Document and share the innovations and results of operational research** that have contributed to greater use of fistula services and to services that are tailored to the needs of clients according to sociocultural context.

Gender inequality exacerbates the experience of fistula

Awa Diakité (above), the youngest daughter in her family, was a very social and happy girl. But when she was 14, she was married, and at 15 she became pregnant. For 8 days, she was in labor. The traditional birth attendants could not help her deliver her baby, and eventually she went to Kita for a cesarean section. By that time, her baby had already died.

This is when Awa developed fistula. For the next 8 years, her husband humiliated her, refusing to sleep in the same room with her or to buy her the things she needed. He would have left her if his uncle had not forbidden it.

Awa underwent fistula repair surgery through a Fistula Mali campaign in Kayes in February 2016 and is now fully healed. Today she grows and sells peanuts and cooks beans for an income. Her relationship with her husband has improved, she says, but he still refuses to buy things for her and he wants to take on a second wife. She gave birth to three more children while she had fistula and while she does not want to have more children, she says she probably will, because her husband wants to.

If Awa could speak to all the women of Mali, she says she would tell them this:

"This is a sickness that is accompanied by a lot of suffering, but I was able to be healed. You shouldn't let it keep you from living your life and doing your usual activities. Be patient. One day you can be healed."

Appendix 1: List of documents

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Back cover photo: Members of Nièta, a multigenerational group of women and girls in Kayes, Mali, are a crucial link in the health care chain in Mali. They dispel myths about family planning and female genital mutilation and urge families not to let their daughters marry until they're at least 18. And they often find women with obstetric fistula and help connect them to surgical repair campaigns.

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