

obstetric fistula:

MOVING BEYOND THE SILENCE IN AFRICA

CAMPAIGN TO END FISTULA

When people first learn about obstetric fistula, their reaction is often to reject hearing more. The subject is just too unpleasant. Yet rejection is exactly what happens to women living with fistula.

Obstetric fistula is the most devastating of all pregnancy-related disabilities and affects an estimated 50,000-100,000 women each year. It usually occurs when a young, poor woman has an obstructed labour and cannot get a Caesarean section when needed. The obstruction can occur because the woman's pelvis is too small, the baby's head is too big, or the baby is badly positioned. The woman can be in labour for five days or more without medical help. The baby usually dies. If the mother survives, she is left with extensive tissue damage to her birth canal that renders her incontinent.

The results are life shattering. The woman is unable to stay dry and the smell of urine or faeces is constant and humiliating. Nerve damage to her legs can also make it difficult to walk. Rather than being comforted for the loss of her child, she is often rejected by her husband, shunned by her community and blamed for her condition. Women who remain untreated not only face a life of shame and isolation, but may also face a slow, premature death from infection and kidney failure. While some women receive support from their families, others are forced to beg or turn to sex work for a living.

HOW FISTULA OCCURS

During obstructed labour, the prolonged pressure of the baby's head against the mother's pelvis cuts off the blood supply to the soft tissues surrounding her bladder, rectum and vagina. The injured tissue soon rots away, leaving a hole, or fistula. If the hole is between the woman's vagina and bladder, she loses control over her urination, and if it is between her vagina and rectum, she loses control of her bowels. Reconstructive surgery can mend this injury, but most women are either unaware that treatment is available or cannot access or afford it.

Preventing the Tragedy

Obstetric fistula is a preventable and treatable condition, one that no young woman should have to endure. Causes include childbearing at too early an age, poverty, malnutrition, lack of education and limited access to emergency obstetric care. Prevalence is highest in impoverished communities in Africa—particularly sub-Saharan—and Asia.

The World Health Organization estimates that over two million women are living with obstetric fistulas today. Estimates are based on the number of people who seek treatment in hospitals and clinics and are therefore likely to be grossly underestimated. Most young women suffer in silence.

Fortunately, most fistulas can be corrected surgically, even after several years. The cost ranges from \$100-\$400 USD, but this amount is far beyond what most patients can afford. If done properly, surgical repair can have a success rate as high as 90 per cent and women can usually have more children. Attentive post-operative care, for a minimum of 10-14 days, is critical to prevent infection while the surgery heals. Education and counselling are also needed to help restore the young woman's self-esteem and allow her to reintegrate into her community once she is healed.

Fistula was once common throughout the world, but has been eradicated in areas such as Europe and North America through improved obstetric care. Obstetric fistulas are virtually unknown in places where early marriage is discouraged, young women are educated about their bodies and skilled medical care is provided at childbirth.

“You know, my dad first heard that this [fistula] could be fixed on the radio and he told me about it. If he hadn’t been listening to the radio that day, I would still be leaking.”

— A fistula patient in Uganda

Recognizing the Problem: A New Study

Reliable data on obstetric fistula are scarce. The full extent of the problem has never been mapped. To address this need for information, UNFPA, the United Nations Population Fund, partnered with EngenderHealth to conduct a ground-breaking study on the occurrence of fistula in sub-Saharan Africa and the capacity of hospitals to treat patients. A team of experts travelled to nine countries over a period of six months to visit hospitals that provide fistula surgery and to interview doctors, nurses, midwives and patients. They also met with government officials and U.N. representatives. Countries included Benin, Chad, Malawi, Mali, Mozambique, Niger, Nigeria, Uganda and Zambia. Results from this nine-country study will lay the groundwork for future action to prevent and treat fistula in the region.

Understanding the Context

Sub-Saharan Africa is a region devastated by AIDS, malaria, famine, endemic poverty and years of political instability. This backdrop presents numerous challenges to the quality of health care. Many public hospitals are located in crumbling facilities and face chronic shortages of funding, staff, equipment and surgical supplies. Consequently, some women who reach hospitals in need of emergency obstetric care, such as Caesarean sections, do not receive adequate or timely treatment.

The profiles of young women living with fistulas in sub-Saharan Africa are achingly similar. They are usually under 20 (some as young as 13), illiterate and poor. Many have been abandoned by their husbands, forced out of their homes, ostracized by family and friends and even disdained by health workers. Without skills to earn a living, some have no choice but to turn to commercial sex work to survive. Despite these hardships, the women interviewed in each of the nine countries showed another common trait: tremendous courage and resilience.

MEASURES TO ADDRESS FISTULA

The best strategies to address fistula include:

- Postpone marriage and pregnancy for young girls;
- Increase access to education and family planning services for women and men;
- Provide access to adequate medical care for all pregnant women and emergency obstetric care for all who develop complications;
- Repair physical damage through medical intervention and emotional damage through counselling.

Critical Needs

Because of poverty and the stigma associated with their condition, most women living with fistulas remain invisible to policy makers both in their own countries and abroad. The new study by UNFPA and EngenderHealth outlines the following critical areas that need to be addressed in order to lower the incidence of fistula in the region:

● INFORMATION AND AWARENESS

In many rural areas, girls are married off when they experience their first menstrual flow—between 10 and 15 years of age. Postponing the age of marriage and delaying childbirth can significantly reduce their risk of obstructed labour. Better education for women and their families about the dangers of pregnancy and childbirth and the value of emergency obstetric care is crucial. Information about family planning, sexually transmitted infections and HIV/AIDS should also be provided. Culturally sensitive advocacy campaigns on maternal health and obstetric fistula could educate communities about the danger signs of complicated pregnancies and the need to get prompt medical attention. Women who have been successfully treated for fistula could also be trained to help

“For us, it is a real morale boost to care for fistula clients...when these ones realize that they are dry and can go on with their lives, they are so happy.”

— Nursing sister in Zambia

with community outreach. Support from local and national policy makers is needed for all educational efforts and to improve data collection on fistula.

● EMPOWERMENT OF WOMEN

Women have the right to education and health care. Yet girls are frequently denied secondary schooling, which tends to delay marriage and give them skills to earn an income. Social and cultural barriers also limit a woman’s ability to seek medical care when needed. In many countries, pregnant women require permission from their husbands or male relatives to see a doctor. Cultural beliefs around the causes of obstructed labour—such as infidelity or being cursed—further limit a woman’s ability to get treatment. Legal and social change is needed to improve the status of women and provide girls with access to proper nutrition, health care and education. Men’s involvement is crucial to achieve this change and to give young women other options in life besides childbearing.

THE NEED FOR CAESAREAN SECTIONS

About 15 per cent of all pregnancies result in complications and require emergency medical intervention.

Caesarean sections can relieve obstructed labour and should account for between 5 and 15 per cent of all births.

● TRAINING

Reconstructive surgery for fistula requires a trained surgeon and skilled nurses. Carefully monitored post-operative care is also crucial to a patient’s recovery. In each of the nine countries visited, there was an urgent need for more doctors and support staff to handle the demand for treatment. Many hospitals relied heavily on the assistance of expatriate doctors. Local surgeons and nurses should be trained in fistula repair and their skills should be updated

regularly. Midwives should immediately refer patients to emergency obstetric care when they detect obstructed labour. Referral systems and transportation to hospitals should be established and supported. Since emergency obstetric care is especially scarce in rural areas, financial incentives should be offered to attract skilled medical personnel to areas with the greatest needs.

● EQUIPMENT

Basic medical equipment and supplies must be in place in order to perform successful fistula surgery. In most of the hospitals visited, lack of supplies—from suture material to a safe supply of blood—was a major problem. Financial support is urgently required to properly equip hospitals and help women in need.

● TRANSPORTATION

Many women suffering from fistulas live in rural areas, far from medical help. Safe and reliable transportation to a hospital is often scarce or too expensive for poor women and their families. Many women interviewed had travelled for months on foot, by donkey or any other means available in search of a hospital that could treat them. Better transportation and communication systems between remote villages and hospitals should be a priority. Midwives can play a key role in the referral process, but measures to get women to hospitals quickly must first be established.

THE THREE DELAYS

Fistulas tend to occur as a result of three classic delays:

- a delay in the decision to seek medical attention;
- a delay in reaching a health care facility;
- a delay in receiving emergency obstetric care at the facility.

SUBSIDIZED CARE

Fistula surgery needs to be accessible and affordable to poor women. Some patients arrive at hospitals accompanied by family members after travelling long distances and having exhausted the last of their resources. Then they may need to find money for surgery, food at the hospital and lodging for their relatives. Poverty makes even moderate fees difficult to afford. In each country, one or two fistula centres that can provide free or subsidized services are needed. They should be located in areas that will serve the largest number of clients and should be easy to access.

SUPPORT SERVICES

Fistula survivors who have been shunned and isolated typically experience intense feelings of shame, self-loathing and depression. They may blame themselves for their situation. Education and counselling can help restore their self-esteem after surgery. Information on family planning, the need for a Caesarean section for future pregnancies and HIV prevention is also essential. Social rehabilitation programmes can help women reintegrate into their communities and reconnect with their families. Life skills training can give women the means to earn an income once they are healed and prevent them from resorting to measures such as commercial sex work to survive. Social support services, offered in conjunction with hospital care, will significantly enhance a woman's physical and mental well-being.

TO READ THE FULL REPORT, VISIT WWW.UNFPA.ORG/FISTULA

UNFPA, the United Nations Population Fund, is the world's largest multilateral source of population assistance. Since it became operational in 1969, the Fund has provided close to \$6 billion to developing countries to meet reproductive health needs and support sustainable development issues. UNFPA helps women, men and young people plan their families and avoid accidental pregnancies; undergo pregnancy and childbirth safely; avoid sexually transmitted diseases, including HIV/AIDS; and combat discrimination and violence against women.

FOR MORE INFORMATION, VISIT WWW.UNFPA.ORG



ONE WOMAN'S STORY

Miriam grew up in a small village in Uganda, a two-day walk from the nearest road. She was the youngest of six children and her parents could not afford to send her to school. She got married at 13, right after she reached puberty, and was pregnant at 14. All her female friends and relatives told her that it was a woman's fate to suffer during childbirth, so she tried to be brave during her five days of painful labour. When her baby boy was born dead, Miriam felt ashamed to have disappointed her husband and family, but was relieved that her suffering was finally over. Sadly, Miriam had developed a fistula and had lost control of her bladder. She thought she was cursed and lay in bed with her legs curled up tightly to stop the flow of urine. After six weeks, she was still wet and her husband took her back to her family. He did not want a wife who was "damaged".

Fortunately, Miriam's family was very supportive, but she found it difficult to help with the subsistence farming in her condition. If she tried to collect water from the well, she was ostracized by other women, who considered her "unclean". No one knew a cure was available. Miriam lived with fistula for two years before her father heard of a doctor who could "cure women who were leaking". After much sacrifice, her family saved enough money to take her to the clinic, where Miriam was successfully operated on. Her family then convinced her husband to take her back and she became pregnant a year later. The doctor had told Miriam she needed a Caesarean section for her next birth, so she returned to the hospital and delivered a healthy baby girl. This time, childbirth was an occasion for celebration.

ENGENDERHEALTH, the 2002 United Nations Population Award laureate, is one of the world's leading agencies providing technical assistance and training for family planning and reproductive health services in developing countries. Founded in 1943, EngenderHealth currently works in partnership with governments, multi-lateral and bi-lateral organizations, NGOs and other institutions in over 30 countries to make reproductive health services safe, available and sustainable.

FOR MORE INFORMATION, VISIT WWW.ENGENDERHEALTH.ORG

