

Executive Summary

“The sun should not rise or set twice on a labouring woman” —*African proverb*

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

Obstetric fistula is a devastating pregnancy-related disability and affects an estimated 50,000–100,000 women each year.¹ While fistula is a global problem, it appears to be particularly common in Africa. Fistula is a condition that often develops during obstructed labour, when a woman cannot get a Caesarean section (C-Section). Obstruction can occur due to malnutrition and pregnancy at a young age (which both lead to small pelvis width, and thus pronounced cephalo-pelvic disproportion). The woman can be in labour for five days or more without medical help, although obstructed labour for even a single day can yield damaging outcomes. If the obstruction is not interrupted in a timely manner, 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, leading to tissue necrosis. The baby usually dies, and fistula is the result.

If the fistula is between the woman’s vagina and bladder (vesico-vaginal), she has continuous leakage of urine; and if it is between her vagina and rectum (recto-vaginal), she loses control of her bowel movement. In most cases, permanent incontinence ensues until the fistula can be surgically repaired. In addition, most women are either unaware that treatment is available, or cannot access or afford it.

Unable to stay dry, many women live with the constant and humiliating smell of urine and/or feces. Nerve damage to the legs can also make it difficult to walk. Affected women are often reject-

ed by their husband or partner, shunned by their community and blamed for their condition. Women who remain untreated may not only face a life of shame and isolation, but may also face a slow, premature death from infection and kidney failure. Because of their poverty and their lack of political status, not to mention the stigma that their condition causes, these women have remained largely invisible to policy makers both in and out of their countries.

Preventing the Tragedy

Obstetric fistula is a preventable and treatable condition, one that no woman should have to endure. Direct causes of fistula include child-bearing at too early an age, malnutrition and limited access to emergency obstetric care. Some of the indirect causes, such as poverty and lack of education, prevent women from accessing services that could preclude the onset of such conditions. Prevalence is highest in impoverished communities in Africa and Asia.

The World Health Organization estimates that over two million women are currently living with obstetric fistulas. Estimates are based on the number of people who seek treatment in hospitals and clinics and are, therefore, likely to be much too low as many women never seek care.²

Fortunately, most fistulas can be repaired surgically, even if they are several years old. The cost ranges from \$100–\$400 USD, but this amount is far beyond what most patients can afford. If done properly, the success rate for surgical repair is as high as 90 per cent and women can usually continue to bear children. Attentive post-operative care, for a minimum of 10–14 days, is critical to prevent infection, catheter blockage and breakdown of the repair site while the surgery heals. Education and counselling are also needed to help restore the 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, women are educated about their bodies have access to family planning and skilled medical care is provided at childbirth.

Strategies to address fistula include preventative methods (postponing marriage and pregnancy for young girls and increasing access to education and family planning services for women and men, and providing access to quality medical care for all pregnant women to avoid complications); curative methods (repairing physical damage through surgical intervention); and rehabilitative methods (repairing emotional damage through counselling, social rehabilitation and vocational training).

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 incidence of fistula in sub-Saharan Africa

and the capacity of hospitals to treat patients. A team of researchers travelled to nine countries over a period of six months to visit public and private sector hospitals that provide fistula surgery and to interview doctors, nurses, midwives and patients. Over 35 facilities in Benin, Chad, Malawi, Mali, Mozambique, Niger, Nigeria, Uganda and Zambia were visited during this rapid assessment process. The team also met with government officials and U.N. representatives. Results from this nine-country study will lay the groundwork for future action to prevent and treat fistula in the region.

In the countries in which facility-based assessments were conducted, it was learned that many of those who suffer from fistula are under 20 (some as young as 13); they are also often illiterate and poor. Many have been abandoned by their husbands or partners, forced out of their homes, ostracized by family and friends and even disdained by health workers. Rarely do they have the skills to earn a living and some may turn to commercial sex work to procure an income for themselves, further heightening their social and physical vulnerability. Despite these hardships, the women interviewed showed another common trait: tremendous courage and resilience.

Understanding the Context

INDICATORS	Total Fertility Rate (2000-2005)	Maternal Mortality Ratio (Deaths per 100,00 Live Births)	Infant Mortality (Per 1000 Live Births)	% of Births with Skilled Attendants	Contraceptive Prevalence (%) (Any Method)	HIV Prevalence Rate for Women (%) (age 15-24)
COUNTRY						
Benin	5.68	880	81	60	16	3.72
Chad	6.65	1,500	116	16	8	4.28
Malawi	6.34	580	130	56	31	14.89
Mali	7.0	630	120	24	8	2.08
Mozambique	5.86	980	128	44	6	14.67
Niger	8.0	920	126	16	14	NA
Nigeria	5.42	1,100	79	42	15	5.83
Uganda	7.10	1,100	94	38	23	4.63
Zambia	5.66	870	80	47	25	20.98

Source: UNFPA State of World Population 2002

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. Because health care infrastructures are fragile and becoming more so in most of the countries visited, it is increasingly difficult for providers to maintain their level of skill and successfully repair fistulas once they have occurred. Many public hospitals face chronic shortages of funding, staff, equipment and surgical supplies. This lack of essential and emergency obstetric options means that services at facilities capable of performing emergency C-sections are still out of reach for women who want and are able to access treatment.

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 assessment 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 just after they experience their first menstrual flow—between 10 and 15 years of age. In some cases, early marriage for girls occurs before the onset of their menstrual cycle, as a way to ensure virginity. 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 warning signs of pregnancy complications and the need to get prompt medical attention. Women who have been successfully treated for fistula could also be trained to help with community outreach. Support

from local and national policy makers is needed for all educational efforts.

- **EMPOWERMENT OF WOMEN**

Women have the right to education and health care. Yet girls are frequently denied 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 seek 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.

- **TRAINING**

Reconstructive surgery is a delicate procedure that requires a specially 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 is an urgent need for more doctors and support staff to handle the demand for treatment. Many hospitals rely 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, 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—is a major problem. Financial support is urgently required to properly equip hospitals and help women in need.

- TRANSPORTATION

Many women with 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. Three classic delays (a delay in the decision to seek medical attention, a delay in reaching a health care facility and a delay in receiving emergency obstetric care at the facility) must be addressed in order to change the odds so that women get the high quality care they need.

- 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 sums 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 C-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 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.

The critical needs outlined above must also encompass the fundamental preventative, curative and rehabilitative interventions that contribute to reducing the incidence of obstetric fistula. Essential training of providers includes the broad range of emergency obstetric care to which fistula repair training can be added, in order to provide the highest quality of care possible. This includes setting up linkages to the community to help women access services on time, diagnosis of actual or potential complications *before* they occur, and monitoring the progress of labour to initiate early referrals when problems arise. Facilities must also have the necessary range of supplies and equipment to carry out emergency surgical procedures (such as C-sections) for women, so that morbidities such as fistula are limited. Transportation issues can be addressed with working ambulance systems and radio networks that enable facilities to communicate effectively with each other during maternal emergencies. And finally, subsidized care should be available for women who cannot afford set fees, so that treatment for maternal care and complications is widely accessible.