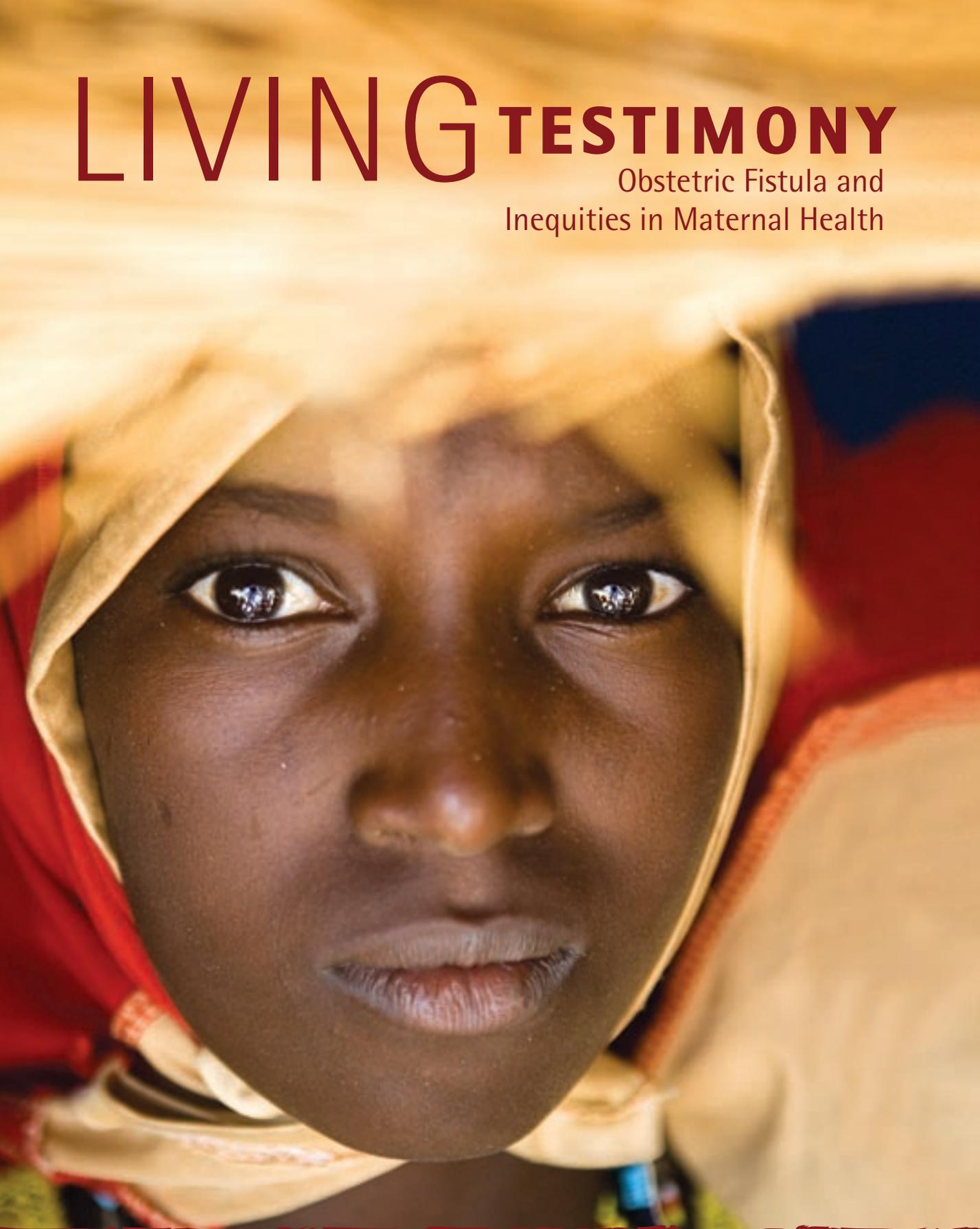


LIVING TESTIMONY

Obstetric Fistula and
Inequities in Maternal Health



GLOBAL ADVOCACY FOR SAFE MOTHERHOOD

“In most countries, the neglect of women’s reproductive rights severely limits their opportunities in public and private life, including opportunities for education and economic and political empowerment. The ability of women to control their own fertility forms an important basis for the enjoyment of other rights.”

Beijing Platform for Action, ¶197 (1995)

The prevention and treatment of obstetric fistula is a key aspect of reducing maternal mortality and morbidity. In 1987, the Safe Motherhood Initiative was born at an international conference in Nairobi, Kenya, making safe motherhood a global public health priority. The landmark 1994 International Conference on Population and Development (ICPD) in Cairo launched a human rights-based approach to population and development.

“[Reproductive] rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health.”

ICPD Programme of Action, ¶7.3 (1994)

Both ICPD and the Millennium Development Goals (2000) call for skilled attendance at 90% of all births and a 75% reduction of maternal mortality by 2015. Globally, more than half of pregnant women give birth with a skilled attendant. Yet each year over 60 million women deliver without skilled care, predominantly at home.¹

During the 2005 UN General Assembly, a resolution on the *Girl Child* linked early marriage and limited access to reproductive health care to obstetric fistula. That same year, the Johannesburg Call to Action to Make Motherhood Safer by Addressing Obstetric Fistula urged governments across Africa to do just that. Currently, the interagency Partnership for Maternal, Newborn and Child Health seeks to expand efforts and mobilise resources to address the critical link between maternal and child survival.

“By addressing gender equality, girls’ education and strengthening health systems—in particular, access to family planning and maternal health services—together, we can make obstetric fistula history in every community in Africa.”

Johannesburg Call to Action, (2005)

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FOREWORD

Women who have endured an obstetric fistula are living testimony to the challenges of maternal health. Hearing their stories helps us to understand how to address these challenges more effectively.

The persistence of fistula is an unacceptable reminder of the enormous inequities between rich and poor nations, and between rich and poor women within nations, in access to and quality of reproductive health care. Fistula reveals how poverty and gender inequality limit women's exercise of their reproductive rights.

Complications related to pregnancy and childbirth are among the leading causes of death and disability for women of reproductive age in many parts of the developing world. More than half a million women die from pregnancy-related complications each year. Furthermore, an estimated 210 million women are left with disabilities, including obstetric fistula—perhaps the most severe childbirth-related injury due to its devastating mix of medical, social, and psychological consequences.

This publication explores knowledge, attitudes, and perspectives on pregnancy, delivery, and fistula from 31 country-level needs assessments conducted in 29 countries in the Campaign to End Fistula (see inside back cover for the complete list). Experiences of women living with obstetric fistula, their families, community members, and health care providers are brought to light. This information represents important research on the social, cultural, political, and economic dimensions of obstetric fistula, drawing attention to the factors underlying maternal death and disability.

We hope this publication will serve as an advocacy tool to strengthen existing programmes and encourage further research on how to increase access to vital maternal health services, including fistula prevention and treatment. We implore policy makers, programmers, and researchers to listen to these women's voices and consider the promising practices and strategic recommendations described herein.

What we have learned so far can help point the way, but much more still needs to be done. We cannot afford to wait—the costs to women, communities, and health systems are simply too great to delay action. Too many of the world's most disadvantaged and vulnerable women have suffered this preventable and treatable condition in silence. Too many women are dying unnecessarily in childbirth. It is time to put an end to the injustice of fistula and maternal death.

Thoraya Ahmed Obaid
Executive Director

United Nations Population Fund UNFPA, the United Nations Population Fund, is an international development agency that promotes the right of every woman, man, and child to enjoy a life of health and equal opportunity. UNFPA supports countries in using population data for policies and programmes to reduce poverty and to ensure that every pregnancy is wanted, every birth is safe, every young person is free of HIV/AIDS, and every girl and woman is treated with dignity and respect. UNFPA and its partners launched the global Campaign to End Fistula in 2003.

Jill W. Sheffield
President

Family Care International The mission of Family Care International (FCI) is to ensure that women and adolescents have access to the high-quality information and services they need to improve their sexual and reproductive health, experience safe pregnancy and childbirth, and avoid unwanted pregnancy and HIV infection. For more than 16 years, FCI served as the secretariat of the Safe Motherhood Inter-Agency Group and currently serves as co-chair of the Partnership for Maternal, Newborn and Child Health.

EXECUTIVE SUMMARY



Here I am sitting waiting for God to do whatever he wants to do with me... I stay quiet and do not say anything. People offered to lend my husband money so that I could get treated. He refused, saying that he has other wives.

*40-year-old Bissa woman,
Burkina Faso*



The death or disability of a girl or woman due to complications during childbirth is avoidable and unjust. More than 2 million women living with obstetric fistula provide living testimony to this injustice. The existence of this condition reveals societal and institutional neglect of women.² Women living with fistula are the survivors, yet their lives are devastated and in most cases their voices have been silenced.

Caused by obstructed or prolonged labour without skilled medical care, obstetric fistula results in serious physical as well as psychological effects. The newborn usually does not survive the trauma. Despite its devastating medical and social impact, obstetric fistula is not a public health priority. Women continue to suffer in silence and isolation even though obstetric fistula is preventable and treatable, even in resource-poor settings. States have an obligation to provide adequate preventive care during pregnancy and childbirth, fistula treatment, and rehabilitative support.

In 2002, UNFPA and EngenderHealth gathered groundbreaking data on obstetric fistula in nine countries in sub-Saharan Africa. These initial findings highlighted critical areas of need to lower the incidence of fistula and treat existing cases.³ In response, UNFPA and partners launched the Campaign to End Fistula in 2003.

Inspired by the many dedicated individuals and institutions working in this area, the Campaign seeks to eliminate obstetric fistula while raising awareness about gaps in maternal health services and gender inequities that inhibit the exercise of women's rights. By late 2006, more than 40 countries in Africa, the Arab states, and Asia were part of the Campaign to prevent fistula, treat affected women, and reintegrate women post-surgery.



Photo credit: GMB Akash/Panos Pictures/On behalf of UNFPA



Photo credit: Micol Zarb/On behalf of UNFPA

To date, 31 country-level needs assessments have been conducted in 29 countries⁴ and many provide new insight into the social, cultural, and economic aspects of obstetric fistula. This publication aims to raise awareness about the underlying dimensions of maternal mortality and morbidity by reviewing the findings of the 31 country-level assessments on obstetric fistula. Specifically, this publication:

- Highlights how perceptions, knowledge, and attitudes related to pregnancy and delivery affect maternal mortality and morbidity, including obstetric fistula;
- Emphasises how social norms and cultural practices impede or facilitate access to sexual and reproductive health care services; and
- Provides policy, programming, and research guidance to promote safe motherhood while addressing obstetric fistula.

Across country assessments, the typical fistula patient was young, developed the fistula during her first pregnancy, and lived in a rural area. Additionally, obstetric fistula was observed among women who had delivered four or more children. Many adolescent girls and women living with fistula did not utilise health services because of their limited decision-making power and attitudes and misperceptions about pregnancy and childbirth. Furthermore, political insecurity and economic instability impeded transportation and access to maternal health care services. Finally, in most regions where women lived with fistula, treatment services were minimal to nonexistent.

This publication includes strategic recommendations for policy makers, programmers, and researchers on the social, cultural, political, and economic dimensions of maternal health, as seen through the lens of obstetric fistula. Recommendations to improve maternal health care include:

- Promote legislation and policies to reduce maternal mortality and morbidity, and to address underlying sociocultural factors;
- Strengthen health system capacity to provide skilled maternity care that is accessible, affordable, and culturally acceptable;
- Strengthen health system capacity to manage obstetric fistula sensitively, ensuring that care and treatment are subsidised and accessible;
- Raise awareness on sexual and reproductive health and reproductive rights to address obstetric fistula;
- Promote the empowerment and reintegration of women into communities post-surgery;
- Involve women who have lived with fistula as equal participants in maternal health programme planning, implementation, and evaluation;
- Promote partnerships to share key lessons and to catalyse collective action; and
- Support research on obstetric fistula to improve understanding of the impact of maternal morbidity and barriers to accessing vital reproductive health services.

INTRODUCTION



[Obstetric fistula] is a terrible problem. The behaviour of a community varies from one area to another, from one ethnic group to another. In some cases, the victims are obliged to isolate themselves, deserted by their husbands. In other cases, they are accepted.

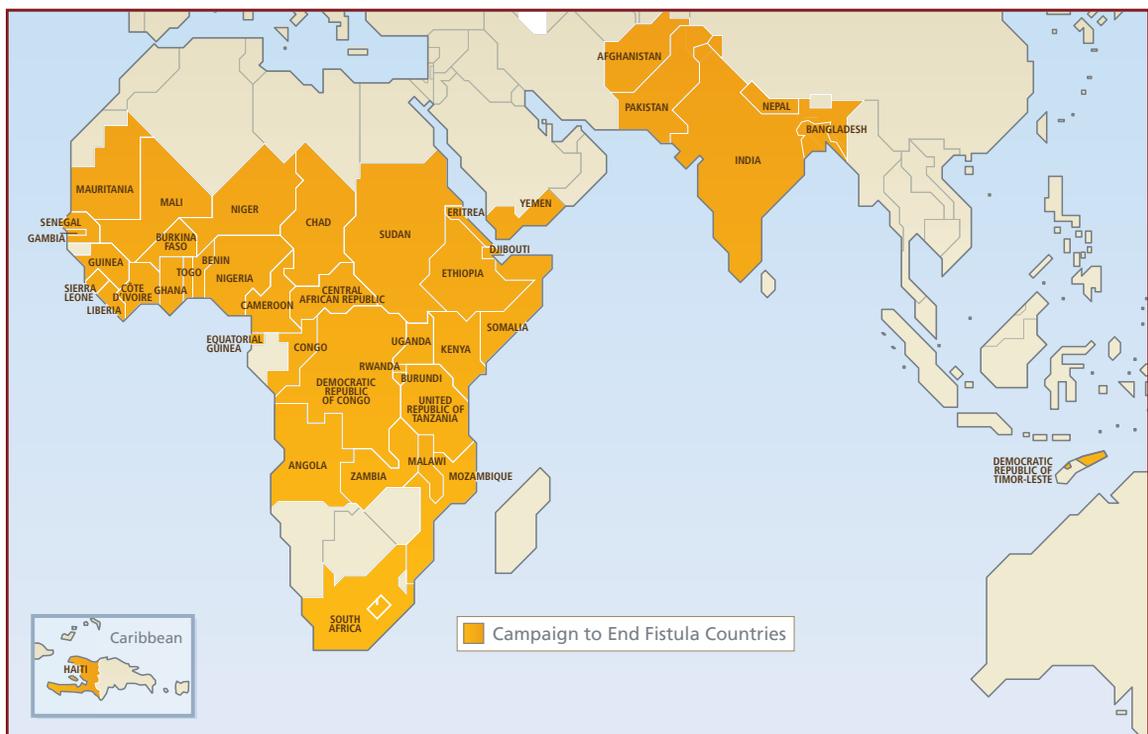
*Dr. El-Hadji Ousseynou Faye,
Head of Maternal Health,
Senegal*



Globally, the burden of death and illness due to pregnancy- and childbirth-related complications is massive. Every minute one woman dies and another 20 suffer from a devastating disability, including obstetric fistula. Fistula is prevalent where maternal mortality is highest, especially where emergency obstetric care, referral systems, and infrastructure are

poor. Exact prevalence rates are unknown,⁵ yet it is generally accepted that a minimum of 2 million girls and women live with untreated obstetric fistula,⁶ and at least 75,000 new cases occur each year.⁷ Moreover, estimates indicate that up to 90% or more of the babies do not survive the traumatic labour.

The last decade has seen some progress in reducing maternal mortality in Asia, Latin America, and northern Africa. However, there was little or no improvement in sub-Saharan Africa, where risks were greatest for maternal death and illness and neonatal mortality.⁸ A recent review of more than 2,250 published studies on maternal mortality revealed a lack of research on obstructed labour, unsafe abortion, and haemorrhage in view of their burden on maternal health. Furthermore, research on the cultural and political determinants of maternal mortality was limited,⁹ highlighting the need to better understand critical underlying risk factors for maternal mortality and morbidity—including obstetric fistula—such as a girl's or woman's low social status, limited access to health care, knowledge and perceptions about maternal health, sociopolitical context, cultural norms, and poverty.¹⁰



Since 2003, the global Campaign to End Fistula has worked to reduce the incidence of obstetric fistula through advocacy, research, and programme interventions, and to improve and increase access to treatment services for women with obstetric fistula. The Campaign's exploratory needs assessments shed light on social, cultural, political, and economic contexts in which fistula occurs and contribute to our understanding of maternal mortality and morbidity. Data was gathered from key informants, service providers, girls and women living with fistula, and community members through interviews, surveys, focus groups, and document reviews.

The assessments highlighted unique country experiences, common challenges, and successful approaches. However, more data needs to be gathered regarding women whose fistulas have been treated, models of reintegration, health care provider attitudes, and costs of fistula to families and the health care system. This data can help show the role of provider attitudes in adolescent girls' and women's access to vital maternal health services, determinants in the affordability of fistula treatment, opportunities and challenges in life after fistula treatment, and determinants of maternal health and economic well-being.



Photo credit: GMB Akash/Panos Pictures/On behalf of UNFPA

This advocacy publication includes:

- An overview of the findings from 31 country-level needs assessments conducted in Africa, Asia, and the Arab states from 2001 to 2006 on the cultural, social, economic, and political determinants of fistula;
- Detailed findings from six select countries: Bangladesh, Burkina Faso, Cameroon, Democratic Republic of Congo, Eritrea, and Sudan;
- Promising practices; and
- Strategic recommendations for policy makers, programmers, and researchers as they relate to the social, economic, and political contexts in which obstetric fistula occurs.



Photo Credit: GMB Akash/Panos Pictures/On behalf of UNFPA

OBSTETRIC FISTULA



I endured 5 days with delivery pains. I was finally transferred to the hospital and the foetus was dead. After 3 weeks, I started to feel constant flows in my vagina, and the odour was very bad. The situation has persisted for 10 years.

*26-year-old woman,
Equatorial Guinea*

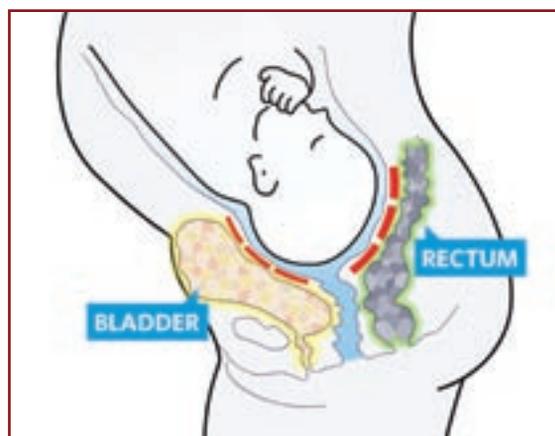


Prolonged labour and obstructed labour are major causes of maternal mortality and morbidity such as obstetric fistula. They occur in approximately 5% of births, causing 8% of maternal deaths. Often, labour is prolonged when the mother's pelvis is too small or the baby is too large for a vaginal delivery. Adolescent girls may be especially at risk for obstructed labour, as their pelvises may not be fully developed.¹¹

When adolescent girls and women experience prolonged labour for as short as 24 hours and are unable to travel to a health facility for a Caesarean section, the compression of tissues between the baby's head and the woman's pelvis cuts off blood flow to the bladder and rectum. The tissue dies within 3–10 days, resulting in an opening, or fistula, between the vagina and the bladder and/or rectum and chronic incontinence for the woman. Severe nerve damage often affects a woman's ability to walk.^{12,13} In up to 90% of cases, the baby is stillborn or dies within weeks.

Other types of gynaecological fistula do exist and are usually the result of cervical cancer, radiation therapy, or injuries resulting from surgery. Fistula may also result from sexual violence, more often in conflict and post-conflict settings.¹⁴ However, the vast majority of fistula globally are due to obstetric causes.

Leaking urine and faeces can lead to other medical complications, including genital sores/ulcerations, dehydration, frequent infection, and kidney disease. Social isolation and stigma often lead to psychological trauma, including depression, anxiety, and in some cases suicide. Since the effects of the fistula may result in loss of financial support or inability to work, many women are pushed further into poverty. Ensuring fistula treatment services and psychosocial support for reintegration post-surgery is therefore imperative.



The fact that obstetric fistula has been virtually eliminated in the developed world is a clear reminder that the problem can be prevented through improved access to high-quality maternal health services, including family planning, skilled delivery care, emergency obstetric care, and postnatal care. Moreover, the fact that the majority of cases occur among young women and adolescent girls means that we need to help them to delay pregnancy and have greater access to maternal health care.

Fistula prevention, treatment, and reintegration require consideration of the broader sociocultural factors, such as low status of women, lack of decision-making autonomy, marriage and pregnancy at a young age, lack of knowledge about labour complications, and a culture of home birthing. Health system factors include insufficient emergency obstetric care and skilled attendants, and delayed or unavailable Caesarean sections.

PERSPECTIVES ON OBSTETRIC FISTULA AND MATERNAL HEALTH



There is no joy anymore in being with others, loneliness takes over. You lose your habits for cooking, visiting others - and all this makes me sad.

*Woman,
Burkina Faso*



This section presents the voices of adolescent girls and women living with fistula, and their family members, communities, and health care providers. Information was gathered through interviews, focus groups, hospital chart reviews, and surveys. Respondents shared their perspectives on maternal health, life with obstetric fistula, the causes of fistula, the context in which it occurred, treatment, and reintegration.

Life with Obstetric Fistula



Nobody wants to stay with me due to the smell of urine. Even my husband sometimes blames me for my condition.

*22-year-old woman,
Bangladesh*



Across the country assessments, the majority of women interviewed had married young, lived in remote and low-resource areas, and had limited access to obstetric care services. Most developed obstetric fistula during their first pregnancy, but a significant number, experienced fistula later in life after previous vaginal deliveries. Some women, especially those living in remote areas, had no health care during pregnancy and had laboured at home. Distance, poor roads, and cost were noted as barriers to maternal health care in many of the assessments.

Home deliveries with elder female relatives or traditional birth attendants were a common tradition across countries. Family pressure was highlighted, especially in Kenya, Bangladesh, and Burkina Faso, as limiting utilisation of health services. In many countries, use of antenatal care was associated with bad luck and difficult deliveries were linked with infidelity and witchcraft.

Reactions and levels of support from family members and husbands varied across the assessments. Women and adolescents living with obstetric fistula frequently described rejection by husbands and family members. Women reported being physically isolated from their families in West Darfur and mistreated by in-laws in Burkina Faso. In contrast, husbands continued to support their wives in some cases. For example, more than half of the 71 women living with fistula interviewed in the Central African Republic indicated that their husbands provided moral and financial support.



I am distasteful in the eyes of others. It is God's will.

*48-year-old woman,
Mali*



Across country assessments, many women living with fistula viewed their condition as the will of God or even a punishment from God. Women told of living on the margins of society due to their own self-imposed isolation because of the smell, embarrassment, and fear of ostracism from the community. Women also spoke of their inability to practice any type of economic activity and hence their financial dependence on others. Some women in Mali were excluded from religious activities as they were perceived as unclean. Fistula patients in Bangladesh described being given less priority for admission due to limited beds and reproach related to the smell of urine.

*“Everyone has rejected me.
Cure me or kill me!”*
Woman,
Bangladesh

Access to treatment was closely tied to affordability of surgery, financial means, geographic access, and knowledge on treatment. Obstacles to treatment included the cost of surgery (ranging from US\$20 to US\$400) plus transport and lodging. Treatment was not affordable for numerous women in all countries. Many accepted their condition as a curse. Conversely, some women received financial assistance from their biological family and friends. In Tanzania, women reported travelling 500 kilometres or more to reach a major fistula centre. Distances were probably too great financially and socially for many others.

THREE DELAYS DURING A PROLONGED LABOUR THAT IMPEDE WOMEN'S ACCESS TO QUALITY CARE:

- *Decision to seek care from a skilled attendant:* Cultural preference for home delivery, limited knowledge of maternal health, and limited transport delayed decisions to seek care. Frequently, family members determined when and where to seek care, often in conflict with the needs and wishes of the woman.
- *Reaching a health care facility:* Even when a decision to seek care had been made, poor roads, the high cost of transportation, and long distances delayed women's access to health facilities and emergency care.
- *Receiving emergency obstetric care at the facility:* Once some women reached a health facility, skilled personnel and/or supplies were lacking and emergency obstetric care was delayed.

The assessments highlighted the need for more advocacy and education regarding treatment and reintegration programmes. A 26-year-old Sudanese woman was studying midwifery “in order to assist women in rural areas not to go through [her] personal experience”. She gives testimony to how a woman who has lived with fistula can be empowered to be a catalyst for social change. Thanks to a scholarship from the Geneina Midwifery School in the Sudan, she is embarking on a career to promote maternal health and to fight against obstetric fistula.

Life after Fistula Treatment

“When I returned to the village, those who did not believe that I was healed were embarrassed when I saw them. I have become a person again.”

48-year-old woman,
Mali

Limited information is available on women's lives after fistula treatment. Women in Mozambique spoke of great pressure to become pregnant again after surgical treatment. More than half of the 568 women seeking treatment at two national hospitals in Mali from 2000 to 2002 were no longer sexually active. In Eritrea, women who had undergone surgical treatment described sex as improved but still painful. Those who had refrained from sexual intercourse lacked the desire or interest in sex. Six women in Eritrea still experienced leakage after surgery and felt isolated.

“I did not know that one day I would be like other women, because the problem was big.”

48-year-old woman,
Tanzania

Reintegration care was not commonly available at health facilities providing fistula treatment. Assessments recommended skills training and the creation of job opportunities for fistula patients after a successful treatment to facilitate reintegration into society and a productive and independent life.



Photo credit: Sven Torfinn/Panos Pictures/
On behalf of UNFPA

In some settings, women had experienced such severe stigma that they were reluctant to return home and were living in or near the hospital where they received treatment. But successful treatment drastically changed the lives of many women as well. In a study conducted by the Women's Dignity Project in Tanzania, nearly all women who had undergone successful fistula treatment indicated that they no longer felt isolated from the community. Many described feeling like a "normal human being", and were able to return to their ordinary lives. The majority indicated that they were able to engage in economic activities and perform daily chores with little difficulty. Self-esteem improved markedly for many women after treatment because they could now attend community and family gatherings.

*“I want to start a new life.
I want to have friends.
I want to share my story.”*
32-year-old woman,
Eritrea

In many studies, treated fistula patients and their families were highlighted as potential community-level educators for the prevention and treatment of obstetric fistula and promoters of maternal health and safe delivery. For example, after receiving treatment, four Eritrean women reported advising community members on safe motherhood practices and prevention of obstetric complications. A 19-year-old Eritrean woman was happy with the outcome of her fistula operation and noted that she would recommend the surgery to other women in her village, advising them not to delay treatment.

Family Members of Women Living with Obstetric Fistula

“If people are aware, they can prevent fistula and solve this problem. Being informed, they have better self-esteem.”
Father of an 18-year-old woman
living with fistula,
Eritrea

Across most countries reviewed, family members played a critical role in determining access to essential obstetric care—in some cases elder women, and in other cases husbands. In many situations, family members described delivery as a private affair for only close female relatives. Cultural norms and a lack of confidence in the health sector kept many women from receiving care before, during, and after birth. Strong preference for home delivery for first births was cited across many of the countries. Decisions about when and where to seek care were made by male elders in Malawi, by female elders in Eritrea, and by mothers-in-law, husbands, and other family members in Burkina Faso, Bangladesh, and Ghana. Such family decisions were often in conflict with the pregnant woman's wishes and health needs.

“A woman's primary doctor is first and foremost her husband. It is necessary that the husband support his wife before or after awareness of the condition.”
Man,
Côte d'Ivoire

Family consultations often created long delays in seeking assistance from a health facility when birthing complications arose. In many countries, a woman's unfaithfulness to her husband was considered the cause of a difficult labour, thus influencing decisions to transport her to emergency obstetric care. Nigerian men interviewed did not want women to have antenatal care for fear of HIV testing. In Burkina Faso, men stated that they were not involved in pregnancy and childbirth and admitted to having no knowledge of maternal health, but were responsible for making decisions when there was a complication.

Most husbands interviewed in Bangladesh indicated that their wives no longer had interest in sexual intercourse after the fistula occurred. In Bangladesh, Mozambique, and the Central African Republic, some

husbands had remarried after the fistula occurred and the wives affected by fistula remained in the household as servants. Some women said that they had failed in their duties as sexual partners.

“I am embarrassed when my friends come by. If she passes next to them, I can tell that they are upset by the odour. I am really tired by all of this.”

54-year-old man, Mali

A 52-year-old husband described his hopes for his wife's fistula treatment by saying, "I will be born for a second time. She will be born for a second time. She will socialise. She will go to town. She will visit her brother."



Photo credit: Lucian Read/WpN/On behalf of UNFPA

Voices from the Community

“Usually the woman provokes this. When she leaves her husband and has sexual relations with another man, it happens that her husband will cast a spell on her and she will have a fistula.”

*Elderly woman,
Burkina Faso*

The causes and treatment of obstetric fistula were not well known within most communities, especially given its hidden nature, and the condition was shrouded in a complex web of misperceptions. Across country assessments, many community members linked difficult labour and

fistula to a spell cast by someone offended by the woman or as a punishment for the woman's infidelity. In Côte d'Ivoire, community members believed that obstetric fistula was due to supernatural causes or promiscuity. Interviewees in Burkina Faso linked obstetric fistula to adultery and to the "evil eye".

“Fistula occurs when the woman eats food that is not good for her when she is pregnant. During delivery, the child is so big that it tears the mother.”

*Woman,
Cameroon*

Focus group participants in Côte d'Ivoire displayed attitudes of rejection and discrimination towards women living with fistula. Community assessments in Kenya and Tanzania indicated that women who gave birth by Caesarean section or had obstetric fistula were not womanly. Sometimes the very idioms used to describe this condition reveal prejudices and misunderstanding. For example, in Mali obstetric fistula was described as "a woman who becomes silent when the urine starts to flow" and "a wish come true from a co-wife in a polygamous marriage". In Burkina Faso, women living with fistula were described as "the woman ruined by birth" and punished by the fistula.

In contrast, in select communities in Kenya and Cameroon, assessments showed higher levels of community support and sympathy for this condition. In other countries, a number of community-based organisations were developing reintegration and counselling programmes with limited resources. In West Darfur, these included social and psychological support as part of the treatment process.



Traditional Birth Attendants

*“This is not a good illness.
It is a shameful illness... it is
more than AIDS. It is death.”*

*Traditional birth attendant,
Côte d'Ivoire*

Like other community members, some traditional birth attendants indicated that difficult labour is caused by conjugal infidelity or doing something that is prohibited. They believed that if a woman admits the “truth”, her labour will be eased. Healers in Benin described helping women living with fistula to overcome their “curse”. In Mali, traditional

FEMALE GENITAL MUTILATION/ CUTTING (FGM/FGC)

Various forms of FGM/FGC are practiced in many of the countries highlighted in this report, including Eritrea, Mali, Djibouti, Somalia, Sudan, and others. FGM/FGC consists of cutting away part or all of the female clitoris, labia majora, and labia minora. With infibulation, the clitoris and part of the labia majora and minora are excised. The remaining parts of the vulva are sewn or pinned together, leaving only a small opening for the passage of urine, menstrual flow, and sexual intercourse.

Some types of FGM/FGC, particularly infibulation, may be correlated with prolonged, obstructed labour, which in cases where timely obstetric care is not provided could result in obstetric fistula. A 2006 WHO study found increased risk of obstetric complications with certain types of FGM/FGC.¹⁵

birth attendants believed that fistula occurs when a pregnant woman consumes sweet foods or certain grains such as rice or small millet. In other countries, traditional healers cited cervical cancer or a tear caused by the baby's hair as possible causes of obstetric fistula.

Community members in Burkina Faso indicated that traditional birth attendants often prolonged labour and delayed access to a health facility by trying to extract the baby or shift its position. Community members in Niger described how traditional birth attendants dangerously pressed their elbows or knees on a woman's belly, trying to speed up delivery. Additionally, community members described how traditional birth attendants held a pregnant woman upside down precariously and shook her in the hope of repositioning a breech presentation.

*“The results of [pregnancy] management by
TBAs are disastrous due to the delays.
They [wait] too long, do not know where to
start, and do not even know where to stop.”*

*Health care provider,
Kenya*

Traditional birth attendants in Bangladesh and Burkina Faso revealed limited knowledge of fistula and admitted that they were not capable of treating fistula. In several country studies, women and their families were stripped of their assets by traditional healers who had promised to cure the fistula but were not able to do so.

When asked what steps are needed to solve the fistula problem, one traditional birth attendant in Côte d'Ivoire stated, “You have to create awareness, you have to tell everybody.”

Health Care Providers

“The existence of fistula is the barometer of maternal health in the country. If year by year fistula decreases, we know that maternal health is improving.”

*Dr. Kalilou Ouattara,
fistula surgeon, Mali*

Health care providers in general noted a lack of awareness among community members on the causes and consequences of obstetric fistula. In particular, providers noted contributing factors such as the low status of women, limited knowledge of the consequences of prolonged labour, early childbearing, and few female health care providers. According to health professionals interviewed in Côte D'Ivoire and Sudan, fistula occurs almost exclusively in women delivering at home with a traditional birth attendant.

The reluctance to seek out a health care provider during pregnancy and labour was frequently due to the lack of obstetric services in the regions where women lived. Appropriate medical attention was often lacking at facilities, and women did not get the quality care they needed, especially in cases of emergency. For example, health care providers across countries and regions noted an insufficient number of qualified personnel attending deliveries.

“OB/GYNs have shown little interest in learning how to perform fistula repairs. Even providers who have the skills to do simple repairs refuse. One probable reason is stigma.”

*Health care provider,
Mozambique*

Few specialist surgeons or obstetric gynaecologists were identified to be trained in fistula surgery in most countries. Many delivery personnel interviewed had no knowledge of obstetric fistula. Limited opportunities and incentives existed for training in fistula detection and treatment. Few local physicians or visiting expatriate doctors performed fistula surgeries, and most treatment facilities lacked basic equipment.



Photo credit: Lucian/WpN/On behalf of UNFPA

Information about fistula and timely referrals were found to be lacking in health facilities in many countries. Women in Eritrea noticed the fistula problem while still in the hospital, but received no information about treatment. In Zambia, women living with fistula were referred to hospitals that did not offer treatment. Health providers in Bangladesh said that patients lacked information on the availability of fistula treatment services. Even free services were not sufficient for the poorest patients in Bangladesh, as they could not afford medicine, transportation, food, and accommodations.

Some women travelled great distances and even across national borders to receive treatment. District administrators in Benin noted that women seek treatment in Niger, Nigeria, or Togo to maintain their anonymity. In Benin, fistula care was described as a luxury surgery for a social crisis. Hospital providers in Burkina Faso indicated that women delayed seeking treatment with a health professional or even going to a health facility due to a lack of financial resources. Few telephones and limited ambulance service made referrals for treatment difficult in many countries.

THE CONTEXT IN WHICH OBSTETRIC FISTULA OCCURS

“

Because of the cultural requirement to deliver the first baby at home, Chepchumba... aged 14 laboured at home with the traditional birth attendant [for] 2 days... They walked ... another 2 days to the hospital ... and delivered a stillbirth and ... developed sepsis and [fistula].

Health care provider,
Kenya”

This overview examines the context in which fistula occurs, including social and cultural norms, the political setting, and the economic situation that often define women's lives. A girl's or woman's background and her role in her environment influence her sexual and reproductive health outcomes, including her risk for obstetric fistula.



Photo credit: Lucian Read/WpN/On behalf of UNFPA

Social and Cultural Context

Cultural beliefs and social values prevented adolescent girls and women from making decisions about their own bodies as well as their health in all countries. Generally, women living with fistula had low literacy skills, low status in the family, and few years of schooling. Knowledge regarding family planning and safe motherhood was often limited and access to contraceptives restricted.

“

I married when I was 14 years old.

My family did not discuss with me the age when I marry and who I marry because a woman has no opinion in such matters.”

26-year-old woman,
Sudan

Across assessments, large proportions of women delivered at home with extremely low rates of Caesarean births in rural areas. Among the women who gave birth at home, many were assisted by female family members or traditional birth attendants with no formal training. When complications arose during pregnancy, access to necessary obstetric care was often avoided or delayed due to family pressures for home deliveries and misperceptions of the causes of complications.

In many assessments, child marriage and early childbearing were the norm and increased vulnerability by contributing to gender inequities in education, work, and decision-making. Girls were married at their first menstrual flow (10 to 15 years old) in numerous countries, and as young as age 9 in Nigeria. These adolescent girls often had less access to reproductive health information and services, as well as contraceptives. Conversely, where cases of fistula were noted among older women with children, pregnancies were not well spaced and high fertility rates were prevalent.

Political and Economic Situation

“The doctors [told] my husband to take me to Ouagadougou. There was no money. That is why this thing dragged on for 21 years.”

*50-year-old woman,
Burkina Faso*

Poverty and gender inequality were evident throughout the assessments. The data illuminated grave disparities in the quality of life between poorer and wealthier women. Poverty and women's status had a negative impact on access to family planning and skilled care, as well as maternal health outcomes. Research findings showed that most women who developed fistula tended to live in rural, low-resource areas with limited access to health facilities that might offer high-quality antenatal and delivery care. Long distances to health facilities and a lack of resources added to delays in getting quality care in the case of complications during labour.

“The security situation affected the movements of vehicles to and from localities and thus affected the traditional referral help for clients of obstructed labour.”

*Dr. Salih, fistula surgeon,
West Darfur, Sudan*

Several countries were in conflict or post-conflict situations or had been affected by civil war in neighbouring countries, including Central African Republic, Chad, Côte d'Ivoire, Sierra Leone, Somalia, Sudan, Democratic Republic of Congo, and Uganda. A country's political instability contributed to the precarious health of its population. Political unrest reduced financial resources for health services, destroyed the health infrastructure, and contributed



Photo Credit: GMB Akash/Panos/On behalf of UNFPA

to high maternal and infant mortality and morbidity. Insecurity in conflict zones made transportation to health facilities difficult. Destruction of roads impeded the distribution of food, medicine, and supplies. In some cases heavy fighting had destroyed clinics and electrical and water systems.



SELECT COUNTRY ASSESSMENTS: KEY FINDINGS



If my three girls were boys ... they would carry me to Ouagadougou so that I could get treated.

*40-year-old woman,
Burkina Faso*



Country-level needs assessments provide important lessons learned and strategic recommendations for future policy, programming, and research. This section highlights the methodologies utilised and the major findings from six select countries: Bangladesh, Burkina Faso, Cameroon, Democratic Republic of Congo, Eritrea, and Sudan.

Bangladesh



It is difficult to continue work and do other things. White discharge, blisters, and itching are all disturbing.

*22-year-old woman,
Bangladesh*

In Bangladesh, more than 40% of people live in poverty and the status of women is low. The average age of marriage is 15 years old, and motherhood and early childbirth are considered extremely important cultural obligations. Most pregnant women do not receive antenatal care (63%) and most births occur at home (92%), primarily with the assistance of untrained traditional birth attendants, relatives, or friends. In this context, the underlying factors make the likelihood of fistula high. According to a national study, it is estimated that more than 416,000 women live with fistula.¹⁶

From July to September 2003, EngenderHealth and UNFPA conducted an analysis of obstetric fistula in Bangladesh, including a literature review and qualitative research. In-depth interviews were

conducted with fistula patients (132), relatives/caregivers (72), service providers (30), and policy makers to assess the overall situation of fistula in Bangladesh. The study examined individual, familial, and socioeconomic risk factors of obstetric fistula, and challenges in providing care and rehabilitation. Researchers highlighted the grave need for raising awareness at the community level on potential labour complications and emergencies. Furthermore, the study revealed that significant numbers of women are unaware of fistula treatment possibilities.

More than half of the fistula patients interviewed in Bangladesh had developed obstetric fistula as an outcome of their first pregnancy (54%). The majority experienced prolonged labour (72%) during a home delivery (68%). All had knowledge of antenatal care, but more than half were not comfortable using the health facility due to family objections, lack of privacy, and discomfort with male practitioners. Most of the fistula patients interviewed were illiterate (68%), likely contributing to misconceptions and superstitions about pregnancy and birth.

Prevention and management of fistula cases

Service providers remarked that it is critical that “the [health] care system be more responsive to the prevention and management of fistula cases.” The utilisation of antenatal care was very low across Bangladesh. Most fistula patients had limited understanding of potential labour complications and obstetric emergencies. Researchers indicated that safe delivery would require that doctors at local and district levels have appropriate knowledge and training in the management of delivery complications, the early management of obstetric fistula, and the capacity to refer fistula cases to district or university hospitals that provide treatment. Findings emphasised the need to address stigma and discrimination because health facilities gave low priority for admission to fistula patients.

Barriers to and facilitators of treatment

Twelve out of 27 women had lived with fistula for more than 10 years, largely due to challenges in overcoming barriers to access and treatment. Interviewees described embarrassment in discussing the topic, lack of funds, no caregiver, distance from the health facility, and lack of knowledge on fistula and treatment. Interestingly, having lived with fistula for years, several women finally had sought treatment because the constant urination had worsened and they were uncomfortable attending religious gatherings.

Underlying factors

The role of gender affects decision-making power and health choices for women. Men who are educated regarding reproductive health issues are more likely to be supportive during pregnancy and make better health decisions. Researchers recommended sensitising men on reproductive health and the importance of supportive, responsible behaviour among men—even from adolescence when adult behaviour patterns are formed. Researchers noted that women were not recognised as equal partners in relationships and marriage in Bangladeshi society. Husbands and female elders were primary decision makers regarding access to health facilities and emergency obstetric care, often restricting women's access.

Health providers described how the prevailing culture attributed difficult labour to a woman's unfaithfulness. Women living with fistula experienced disregard and mistreatment from husbands and in-laws during and after a problematic delivery. One doctor noted that in a 30-year practice only one husband had accompanied his wife for the treatment of fistula. In contrast to the health providers, the women themselves did not mention social isolation or mistreatment by their husbands, despite more than half being separated, divorced, or widowed. Women interviewees indicated that they were no longer of use to their husbands as a sexual partner. In fact, many accepted a shift within the household from wife to maid as their husbands took on another spouse.

Burkina Faso

“Everybody says it is because I committed adultery that I have fistula. Some make fun of me. In this type of situation, can I continue to go anywhere?”

*46-year-old woman,
Burkina Faso*

Maternal and child mortality rates in Burkina Faso are among the highest globally. Estimates of maternal deaths range from 484 to 1,400 deaths per 100,000 live births according to the Demographic and Health Surveys from 1998/1999. The same data shows that 39% of pregnant women receive no antenatal care, and births are attended primarily by traditional birth attendants (42%), health personnel (31%), and family members (19.8%).

Two qualitative research assessments were conducted in three health regions in Burkina Faso in 2004. Twenty health agents, 24 key stakeholders/ community leaders, and 4 fistula survivors in each of three districts (12 women total) were interviewed. Twelve focus group discussions were held in each district with men, young women, and older women. In addition, a retrospective review of hospital registers was carried out in 2004 in all hospital facilities in Burkina Faso (n = 347). The average age of fistula patients was 28 and almost half (49%) of patients sought treatment within a year. Among those with children, the median number of live births before the fistula occurred was two. Patients were in monogamous (47%) and polygamous (37%) marriages.

Perceptions of the causes of fistula

Generally, the respondents attributed fistula occurrence to punishment for bad behaviour. In addition, antenatal care is believed to bring on complications during delivery. However, those who linked fistula with pregnancy often mentioned cultural factors, such as early marriage, early sexual activity and early pregnancy, female genital mutilation/ cutting, and traditional birth attendants' practices.

Intergenerational differences in knowledge regarding causes of prolonged labour and risks of fistula were evident. Young women had greater awareness of fistula than older women. Younger women made a link between childbirth and the onset of the fistula. Some said that fistula was due to a tear during childbirth, the duration of labour, and the size of the baby. Older women interviewed said that a woman with fistula provoked her situation. Only one-third of the ninety men interviewed at the community level knew about fistula.

Traditional versus modern treatment

Most women living with fistula, following community customs, first sought treatment with a traditional healer. This was due in part to limited financial resources and women's dependence on their husbands and mothers-in-law. These treatments, albeit quite costly, never produced the desired results. Many women declared that they received traditional treatments in vain for many years. After these unsuccessful attempts, some sought modern treatment.

Researchers noted that younger women and some men had greater confidence in professional health care providers. Seeking professional treatment was linked to financial autonomy, accessibility of treatment, and information about treatment possibilities. Only a tiny proportion of women living with fistula had access to information concerning treatment. Overall, women who had undergone surgery for fistula constituted a very small minority in Burkina Faso. The community had little knowledge and lacked the means to take care of fistula cases. Sadly, many women were abandoned and left to their own means.

Over half of the 24 traditional healers interviewed mistook fistula for urinary incontinence. The healers admitted that they were not capable of treating fistula with their potions, nor with their physical treatments. They considered the illness to be linked to a trauma, a tear, which could only be healed by suture. Almost all healers affirmed that surgery performed in a health facility by health

professionals was the only way to resolve the problem. Even with this confession, none of the traditional healers would admit to the women that they were incapable of dealing with their condition.



Photo credit: Lucian Read/WpN/On behalf of UNFPA

Cameroon

“*The traditional birth attendants say to be calm and wait it out ... and in the meantime, a complication can develop. But at the hospital ... well, they know better.*”

Woman,
Cameroon

Cameroon's population is 16.3 million and growing. Seven percent of women of reproductive age use modern contraceptives, and women have an average of five children. Slightly more than half (54%) of deliveries occur in a health facility. Among those women who give birth at home, most are assisted by a traditional birth attendant. The estimated maternal mortality ratio ranges from 430 to 1,100 deaths per 100,000 live births.

In 2004, a descriptive exploratory survey was conducted on obstetric fistula in 50 health facilities in two provinces of northern Cameroon. Women living with fistula (63) and traditional birth attendants (101) were interviewed, and focus groups (22) were conducted with men and women of reproductive age. Most women who developed fistula had been in labour, at home, for more than 24 hours with only a traditional birth attendant.

Reluctance to seek health care

Among women who were living with or had lived with fistula, use of antenatal care was limited. Reluctance to seek out health care services was due to lack of money, distance from the health facility, and refusal of the husband. In general, women living with fistula and community members noted that emergency obstetric services were not available in their region. Community members felt that health facilities offered limited emergency services and did not have proper equipment or adequate care for mothers and newborns. Women relied on traditional birth attendants during delivery and sought out professional maternity care only for complications.

Interestingly, health facilities had greater resources than was perceived by the community. A review of health facilities found that district and provincial

hospitals had functional operating theatres with the necessary equipment to handle surgery, including Caesarean-sections. The majority of health facilities (78%) had a referral system with appropriate logistics including either a vehicle or easy access to hired transportation.

Use of traditional birth attendants

Most traditional birth attendants were elder women who had resided in the community for at least 20 years. In general, these women were illiterate, and only half had received any type of formal training. The traditional birth attendants interviewed believed that they were highly solicited due to their quality services, their good childbirth skills, and their low-cost or free services. During the course of discussion with the traditional birth attendants, nearly all affirmed that they referred their patients to a health facility, be it a health centre or a district hospital, if they were experiencing a difficult labour. When questioned about the nature of a difficult labour, the traditional birth attendants cited prolonged labour, maternal exhaustion, and abnormal presentation of the foetus.

Community members highlighted reasons for using a traditional birth attendant. Lack of money and the long distance made health facility access difficult. The traditional birth attendant was often known to the family. Some community members stated that health facilities did not have proper equipment for women in labour and that health providers needed improved communication skills. Some husbands objected to male health providers seeing their spouses unclothed.

Conversely, some community members accused the traditional birth attendants of being responsible for certain avoidable complications. Interviewees indicated that traditional birth attendants did not easily accept that a labour complication might need professional assistance. Nevertheless, traditional birth attendants hold a place of prominence in the community with regard to pregnancy and childbirth.

Democratic Republic of Congo

“In 2000, most people did not want to hear about vaginal repair.... Now women understand that if they do not talk about it, they could be marginalised ... and may die of fistula. It is better to talk about it so they can be helped.”

*Dr. Mukwege,
Panzi Hospital, DRC*

The Democratic Republic of Congo (DRC) has a wealth of natural resources, yet its people are among the poorest in the world. From 1998 to 2003, the DRC was in a state of civil conflict and violence that destroyed the country's social and economic infrastructures. This period was characterised by the massive and systematic rape of girls and women as a weapon of war. Maternal mortality (930–3,000 per 100,000 live births, depending on the region), infant mortality (115 per 1,000 live births), child mortality (204 per 1,000 live births), and sexual violence are on the rise, especially in war-torn areas.

A study conducted by the Ministry of Health and UNFPA in six provinces found that fistula is not well known. Approximately half of the female focus group participants were aware of fistula compared to 25% of the men. Men stated that sociocultural barriers prevented them from being involved in their spouses' health matters even though they were responsible for the social welfare of their families. It is local custom that men do not communicate often with their spouses. According to one man interviewed, “when they see you chatting with your wife, everyone comes around to stare at you.” Pregnancy and childbirth are managed primarily by elder women. Men are consulted when there are complications, but admitted to being ignorant on maternal health matters and unable to recognise dangerous complications in pregnancy and labour.

Traumatic fistula

Fourteen percent of the 432 fistula cases found in six provinces were the result of traumatic causes. Traumatic fistula is caused by direct gynaecologic trauma, such as violent rape, mass rape, and the insertion of objects into a woman's vagina (gun barrels, bottles, sticks). Girls and women of all ages can be affected. Eighty percent of the 61 traumatic cases identified in this study were raped at least three times during the same episode by as many as four aggressors, mainly men in uniform. In some cases, objects such as iron batons, bayonets, and sticks were used to rape the women. In a few cases, guns were fired into the vagina. Many women with traumatic fistula do not report the incident for fear of reprisals from their aggressors and stigma within the community.

Panzi Hospital in Bakuvu received 10,624 rape survivors from 1999 to 2006, 1,225 of whom received fistula surgery.¹⁷ HEAL Africa Hospital in Goma has received over 3,550 rape survivors and performed 600 fistula surgeries (68% for traumatic fistula) since its inception in 2003. Administrators at both hospitals acknowledge that women with traumatic fistula need comprehensive psychological treatment and job skills training in addition to surgical care, but are challenged by the time required.



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Treatment and psychosocial care

The HEAL Africa Hospital, formerly Doctors on Call for Service (DOCS), identifies women and girls who have been raped or who have fistula, and offers medical treatment and psychosocial care. A network of local counsellors refers them to appropriate care. The goal of the programme is to enable the women and girls to enter into a healing process, and support them as they re-enter society as productive and healed people.

Women who have "graduated" from the organisation's Heal My People programme have received counselling as well as training in family mediation, and have learned facilitation techniques to promote peace with women from various ethnic groups, often from the group that committed the sexual violence. This is an important first step in the process of conflict resolution. They have learned new skills, which they bring back to their villages and may have taught their skills to other women.

Eritrea

"I sleep in a separate bed from my husband. My husband does not complain. I don't feel comfortable having sex. I refuse my husband sometimes."

32-year-old woman, mother of two, living with fistula for 17 years, Eritrea

After years of conflict over the border with Ethiopia, severe draught, and food shortages, Eritrea struggles to reconstruct social services and economic stability and to reintegrate displaced populations. With a population of 4.4 million, Eritrea has a modern contraceptive prevalence of 5.1%. The total fertility rate has declined to 5.4, though the ideal family size is slightly higher (5.8). Maternal mortality is one of the highest globally (890 deaths per 100,000 live births), with 49% of pregnant women seeking antenatal care and 21% of births attended by a skilled attendant.

A 2003 study supported by the Eritrean Ministry of Health and UNFPA documented the state of obstetric fistula in six regions. Eighty women living with fistula were recruited through the radio and interviewed. Seven focus groups were conducted with 78 traditional birth attendants, community leaders, religious leaders, and health workers. A second study conducted with Stanford University interviewed new (11) and returning (15) fistula patients and their family members at Massawa Hospital during a surgical mission in late 2004.

The majority (56%) of fistula patients interviewed were 20 years old or younger when the fistula occurred. Most women had a healthy pregnancy before the birth that led to the fistula. The majority of interviewees lived in remote villages several hours' walking distance from the nearest health facility. As a result, they had difficulty accessing antenatal care, skilled care at delivery, emergency obstetric care, and fistula treatment. Many of the women were still married, though some had lost their husbands in the war. In most cases in which husbands stayed with the woman living with fistula, researchers found that the couple had living children prior to the onset of fistula.

Home deliveries

Tigre and Tigrigna tradition promote delivery of the first baby at the home of the woman's mother. Health facilities are perceived as unlucky and filled with evil spirits. As a result, most of the women laboured at home with assistance from older female relatives, neighbours, and in some cases traditional birth attendants. Even women who lived in urban areas travelled back to their home villages to give birth.

In several cases, older female relatives and neighbours who were present during labour delayed seeking medical help anywhere from 24 hours to 5 days after complications began. Distances from the village to a health facility were often long and difficult. By the time most women reached the hospital, it was too late to save the baby, and the damage leading to the fistula had already occurred. Many women interviewed in 2003 said they were



Photo credit: Lucian Read/WpN/On behalf of UNFPA

the unlucky ones and blamed the traditional birth attendant for delaying the referral and/or forcing the delivery.

Experiences after treatment

In 2004, a team of foreign surgeons performed fistula surgeries for 64 women. Eleven patients who returned for additional treatment and four of their family members were interviewed in late 2004. In general, problems with incontinence had improved for all women. Some described more autonomy since the surgery, though many noted that their social situation had not changed markedly since the surgery and said they still felt isolated. This may be due to the fact that women who had continuing problems were more likely to return for follow-up care. The majority of interviewees were not working at the time and were receiving financial support from their husbands and/or family members.

Hopes for the future

When asked about the future, all hoped to be fully healed from the effects of obstetric fistula. They longed to join in social activities, go to church,

work, and raise a family. Many women expressed the desire to study or start a business. Those with no children hoped to get pregnant. A 32-year-old woman living with fistula for 17 years said, "I want to start a new life. I want to have friends. I want to share my story. I know that there are other women with the same problem. They don't know that they can be healed."

Sudan

“My parents sent me out as they said that I have disgraced the family by being unable to reproduce and the smell from me is just too much.”

*Woman,
Southern Sudan*

Since gaining independence from Britain in 1956, Sudan has faced two prolonged civil wars. Over the past two decades, more than 4 million people have been displaced, 2 million have died, and refugees have fled to neighbouring countries. Despite a peace treaty in the south in 2005, a separate conflict in

Darfur continues. There some 200,000 have died, and an estimated 2 million have been displaced within Sudan and to neighbouring countries. These political and humanitarian crises have undermined the health sector's ability to address basic social, economic, and health needs.

Early marriage and early pregnancy are common across all of Sudan; more than 40% of girls are married by the age of 18. Use of any contraceptive method is low across the country—around 8% and even less for modern methods. There are also wide variations in contraceptive use throughout the country, with some states having rates of less than 1%. Obstructed labour is considered a major health problem leading to maternal morbidity and mortality in Sudan, especially in regions of civil conflict.

Accessing sexual and reproductive health care in conflict-torn regions

Civil conflict has created major barriers to accessing sexual and reproductive health care in the Darfur region. Nearly 700,000 people have been displaced in West Darfur, 25% of whom are women of reproductive age. The risk of violence en route to health facilities, terrible roads, long distances, and high health care costs are obstacles to accessing appropriate health care in this war-torn region. In West Darfur, home delivery with traditional birth attendants, midwives, or family members is common (85%) and obstructed labour is prevalent because of the lack of available, accessible, and affordable emergency obstetric services.¹⁸ Transportation to care is hindered by the security situation and impassable roads during the rainy season. Internally displaced people (IDPs) face curfews imposed by local authorities and even physical barriers surrounding camps, particularly at night. In a setting in which outsiders are distrusted, those entering camps to offer health care may also be targets of distrust or even violence.

Within the national health care structure, there are several hospitals in the Darfur region with facilities and trained personnel offering fistula surgical services. Zalingei Hospital in West Darfur opened a Fistula Centre in May 2006 with support from

UNFPA. The annual surgical campaigns begun there in 2006 provided free fistula surgery; however, poverty and civil conflict hinder the ability of patients to travel for treatment. Despite these challenges, some 107 cases of obstetric fistula were treated at the centre in 2006.¹⁹ Midwives and nurses at the centre counsel women about fistula, reintegration, and family planning as part of the recovery process. Zalingei Hospital tries to restore hope and a semblance of normalcy in an environment in which life is disrupted and unpredictable.

Rebuilding services after decades of conflict

Decades of civil conflict in South Sudan wreaked havoc on the health system and infrastructure, resulting in some of the poorest health indicators globally. Of the estimated 11 million population, only 25% have access to health services, some 20% are considered IDPs, and many more are repatriating from other countries. Recent data shows that South Sudan may have the highest maternal mortality ratio in the world (2,037 per 100,000 live births) with few births attended by skilled personnel (5%). The extent of fistula is unknown but is suspected to be high considering the presence of many risk factors. Reports from neighbouring countries that are seeing cases of fistula from South Sudan indicate that a potentially significant number of women are hidden and not coming forward due to unavailability of care.

With the signing of the Consolidated Peace Agreement in January 2005, efforts began to rebuild the health system—although the newly established Government of South Sudan faces many challenges ahead. One complex and difficult area will be ensuring skilled attendance at birth. Very few personnel with midwifery skills are available in the region (an estimated eight midwives in South Sudan). Finding qualified women to train will also be difficult as the majority of states in the South have a primary school enrolment of less than 10% and a completion rate below 5%. Efforts have also begun to help women living with fistula. In 2006, nearly 20 women received care at a fistula treatment event in Juba.



Photo credit: Lucian Read/WpN/On behalf of UNFPA

PROMISING PRACTICES



I tell them they need to give birth in good conditions and avoid a long labour. I tell them what I have been through so they don't have to suffer like I have.

Kouboura Moutari, survivor of fistula repair and educator with Solidarité, Niger



A rapid assessment of experiences in the prevention and treatment of obstetric fistula has revealed some promising practices worth examining further. It is important to note that these practices have not been evaluated rigorously, nor have they been applied in different settings. Evaluation of the applicability in other settings is key.

Eritrea: Reintegration and Counselling

In Eritrea, a dedicated fistula centre provides treatment and reintegration services for women. To assist patients to heal emotionally, staff at the hospital have been trained in counselling specific to fistula patients and regularly provide this service for the women in their care. The women who received counselling felt that postoperative counselling sessions had helped them to learn more about family planning and birth spacing. In turn, patients with successful treatment and their families reported advising community members about safe motherhood practices and preventing obstetric complications. Others encouraged pregnant women in their communities to seek antenatal care. These findings pointed to the need for increased counselling post-treatment on the causes of fistula, the treatment process, and recovery, as well as sexual and reproductive health education.

Ethiopia: Model Fistula Hospital

The Addis Ababa Fistula Hospital provides physical, social, and spiritual assistance to fistula patients and raises international awareness on obstetric

fistula and other maternal morbidities. The Fistula Hospital has developed a model programme that includes free fistula treatment and long-term care for women who cannot return to their villages. Creating a supportive and caring environment has been critical to their success. Many nursing aides at the hospital are former patients and promote a friendly environment. The Fistula Hospital has set the standard to provide services for those suffering from childbirth and related injuries, and to rehabilitate women so they can integrate back into their society with dignity and a sense of self-worth. Hundreds of health professionals have been trained at the Fistula Hospital in the management of obstetric fistula. Hospital staff have shared their experiences with facilities across Africa and Asia.

Malawi: Community Empowerment to Strengthen Health Care Provision

In 232 villages in Dedza, Mchinji, and Nkhatabay, local structures for promoting community involvement in reproductive health and safe motherhood were strengthened. Community leaders, traditional authorities, and village heads were trained in safe motherhood, pregnancy-related complications, and the importance of delivering at a health facility. Trainees later enforced community safe motherhood bylaws and established task forces to follow pregnancy outcomes and record maternal deaths. The bylaws stated that all untrained traditional birth attendants should not conduct deliveries, and that first pregnancies should be delivered at a health facility. Penalties were established for those who break the bylaws, with severe penalties for maternal death.

Local Village Health Committees spread messages encouraging women to deliver at health facilities, including writing the important messages on the walls of houses, as well as presenting them through dramas, poems, and songs. Trained Committees recorded pregnancies and maternal deaths, monitored the activities of traditional birth attendants, and secured reliable transport for obstetric emergencies. The experience showed that community leaders are gatekeepers to community beliefs and cultural values, and that communities can achieve positive health outcomes through information and support.

Niger: Social Rehabilitation and Reintegration

Two NGOs, DIMOL and Solidarité, have created a community-based advocacy strategy for the social reintegration of women who received fistula treatment. This non-hospital-based strategy consists of a 3- to 6-month training for women in income-generating activities, postoperative care, and social reintegration. After the training, a practitioner, a social worker, and an NGO representative accompany and support women in their return to their village. In addition, the NGOs and community leaders conduct educational outreach on early marriage, the importance of antenatal care consultations and assisted childbirth, girls' education, postoperative care, STIs, HIV and AIDS, and the causes and consequences of obstetric fistula.

Initial findings revealed that this strategy has relieved overcrowding health centres where women had remained due to fear of returning home after years of stigma. Community health promoters and treated women have participated in community-based education, prevention, and reintegration activities. Close accompaniment at the community level has helped women to follow postoperative care instructions. Income generation skills have helped women meet their basic financial needs. Women feel accepted by the community, and community members talk more openly about fistula.

Sudan: Midwifery School System

Midwifery schools in Sudan started in 1921 to ensure a midwife in every village. Village midwives filled a gap in female providers, which were preferred, and brought services to the community. They were the front line of birthing care and prevention of obstetric fistula in Sudan – providing care for normal deliveries and referrals in the case of complications. Sudan currently has three teaching hospitals and four midwifery schools, which are competency-based with hands-on training. The basic skills acquired at midwifery school include 15 normal deliveries and 5 difficult deliveries under the supervision of an obstetrician, administration of injections, recognition of risk signs, timely referral, and measurement of blood pressure. In one region,

women who have been treated for fistula have been trained as village midwives. Scholarships are available for many of the students.



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OBSTETRIC FISTULA: STRATEGIC RECOMMENDATIONS



[Obstetric fistula] occurs due to obstructed delivery and improper handling during delivery. To avoid these kinds of problems, the first [priority] is to conduct delivery by trained personnel.

36-year-old rural
medical practitioner,
Bangladesh



Country-level needs assessments highlighted the following recommendations for policy makers, programme managers, and researchers for appropriate and comprehensive prevention, treatment, and reintegration programmes.

1. Promote legislation and policies to reduce maternal mortality and morbidity, and address underlying sociocultural factors

It is vital to develop supportive legislation that addresses the social, cultural, economic, and political contexts of maternal death and illness, including obstetric fistula. In particular, existing customary law has been seen as an entry point at community levels for advocacy and education around fistula. Model health policies and programmes in affected countries should address equitable access to reproductive health services and specialised equipment and supplies for fistula treatment. Clinical and contextual determinants of maternal health must be considered. Strategic policy planning should raise the visibility of underlying and indirect causes of maternal mortality and morbidities, including poverty, gender inequality, harmful practices, lack of girls' education, early marriage, and women's low status. Disaggregation of indicators by age, economic status, and geographic location could help target these issues. Such indicators could help programmes focus on vulnerable groups and key needs.

2. Strengthen health system capacity to provide skilled maternity care that is accessible, affordable, and culturally acceptable

It is critical that governments implement services at local levels to ensure that women and adolescent girls receive skilled maternity care throughout pregnancy, childbirth, and the early postnatal period. All women and adolescent girls must have access to emergency obstetric care. Governments must ensure that quality reproductive health services are accessible, affordable, and acceptable to the community. Furthermore, governments should develop, disseminate, and implement national guidelines and service standards to prevent, detect, and treat obstetric fistula in a compassionate manner. The mobilisation of funds is crucial to make treatment and reintegration programmes available to all women with obstetric fistula.

3. Strengthen health system capacity to manage obstetric fistula sensitively, ensuring that care and treatment are subsidised and accessible

Fistula management and the prevalence of skilled birth attendants in district and national health facilities must be improved. It is critical to strengthen mechanisms to identify, refer, and transport fistula patients. All needs assessments highlight transportation difficulties as a great obstacle to accessing emergency obstetric care and subsequent fistula treatment. Training curricula for doctors and nurses in the management of fistula should include prevention, detection, treatment, and reintegration. Sensitive communication skills and attitudinal changes are critical to improve the behaviour of all staff towards fistula patients. Providers need training in compassionate counselling to help women cope with their injury, and all staff needs sensitivity training. Treated

women should be informed about family planning and risks in pregnancy and delivery. Enhanced health facility counselling services will foster trust between women and health personnel.

4. Raise awareness on sexual and reproductive health and reproductive rights to address obstetric fistula

Increasing knowledge about obstetric fistula requires clear and effective messages on sexual and reproductive health targeted at key audiences, such as pregnant women, husbands, community leaders, community members, religious leaders, health care providers, and traditional birth attendants. It is vital to raise the awareness of husbands and elders regarding pregnancy and childbirth as they play a critical role in decision making. Informative and educational messages can be conveyed through radio programmes, television, local theatre groups, newspapers, magazines, the Internet, and other means.

Educational and rights-based messages need to promote affordable and accessible skilled maternity care, including emergency obstetric care. Messages should emphasise the potential harm of child marriage and traditional practices such as unattended home deliveries. It is critical that messages demystify the root causes of delivery complications, describe the signs of obstructed labour, underscore the consequences of delaying seeking medical care when complications arise, and reduce the stigma of fistula. Messages on treatment options and social reintegration for women who have been treated are vital to reach women who may be living in shame and hidden from the community.

5. Promote the empowerment and reintegration of women into communities post-surgery

Healing from obstetric fistula is both physical and psychological in nature. Surgery to close the fistula is medical care for physical healing, yet the social, economic, and psychological scars require rehabilitative care. A number of community-based and public organisations have striven to create reintegration programmes despite limited resources. It is important that women living with fistula are

involved in defining the meaning of reintegration and participate in the development of such programmes.

Knowledge building is critical to women's empowerment. Strategies for rehabilitation and reintegration have included training in literacy and income-generating skills, loans and grants for microbusinesses, reproductive health education, and counselling. Such programmes need further evaluation to understand what impact they have had upon women's lives. Programmes should also strive not to further segregate or isolate women. Income generation can help to improve the socioeconomic situation of women and in turn alleviate their financial dependency on others. Counselling should include education on family planning, future pregnancies, and deliveries. Finally, women with cured fistula can play an important role in community outreach. While women speak with



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community members about obstetric fistula and reproductive health, women become empowered and reconnected with the community.

6. Involve women who have lived with fistula as equal participants in maternal health programme planning, implementation, and evaluation

Women living with fistula or post-surgery have an important role to play in sensitising communities regarding the continuum of maternal health care, including the risks that arise during pregnancy and delivery. They can assist in identifying messaging that will resonate in communities and the channels for spreading these messages. Their voices can also be

raised to higher levels to highlight the consequences of failing to provide affordable and accessible reproductive health services – particularly those related to pregnancy and delivery. Additionally, women who have lived with fistula can help to identify solutions for overcoming the barriers to reproductive health care and to evaluate the services that are provided. This would directly contribute to improving the accessibility and quality of maternal health care, including treatment for fistula. In the area of reintegration where the least is known, women's own voices, needs and priorities should drive the development of programmes. Lessons for empowering women's participation can be drawn from existing experiences, such as the participation of people living with HIV and AIDS.

7. Promote partnerships to share key lessons and to catalyse collective action

Partnerships among all players in fistula management are important in raising the visibility of obstetric fistula and addressing its social and health aspects. Potential partners include women living with fistula, medical training institutions, medical practitioners, counselling and social support programmes, institutions that promote income-generating activities, NGOs, and community-based organisations. Building local and South-to-South partnerships is an essential strategy as the majority of expertise resides in developing countries, where fistula is most common. For example, when fistula treatment centres were established in Chad, surgeons were trained at the Addis Ababa Fistula Hospital in Ethiopia.

Increased collaboration between institutions promotes expanded treatment and reintegration and improved communication with providers in different regions and countries. Partners can share experiences in strategic planning, protocol development, awareness-raising approaches, and advocacy. Information sharing is worthwhile in highlighting potential obstacles to prevention, treatment, and reintegration. Partnerships—whether local, regional, or international—should be based on mutual respect, with cultural and gender sensitivity.



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8. Support research on obstetric fistula to improve understanding of the impact of maternal morbidity and barriers to accessing vital reproductive health services

More research is needed on the social, cultural, economic, and political factors surrounding maternal health, including obstetric fistula. Research on obstetric fistula can provide a key contribution to the knowledge base on maternal health. It is critical to:

1. Conduct in-depth interviews with obstetric fistula patients as a source of information to improve maternal health programming and services. These interviews can help shed greater light on the "three delays" (see sidebar, page 12) and provide women's perspectives on the barriers to utilisation of health care;
2. Gather data on women with repaired fistula, including reintegration and how they handle family planning, future pregnancies, and delivery of children;
3. Gather data on health care provider attitudes and practices towards fistula patients;
4. Document models of reintegration support services; and
5. Document the social and economic costs of fistula to families, communities, and economies in terms of lost productive time, as well as the cost to the health system in terms of treating fistula and related morbidities.

CONCLUSIONS

The Campaign to End Fistula has been shaped by the findings from these needs assessments. The assessments have proved useful in identifying key institutions and individuals working in fistula prevention, treatment, and reintegration. In the majority of these countries, the Campaign's efforts represent the first research on fistula. Visibility has been raised, and national plans have been developed to eliminate the condition.

Research findings show that obstetric fistula is excessively high where women lack education, economic autonomy, decision-making power, and access to appropriate reproductive health services, including emergency obstetric care. Furthermore, maternal health is closely linked to social context and cultural norms and behaviours.

Campaign partners recognise that obstetric fistula is a complex health problem, caused by a broad range of interlinked social, cultural, economic, and systemic factors that affect the availability, quality, and utilisation of maternal health services. These same factors are at the root of maternal death and disability. While further research is needed to explore and better understand these factors, the social and economic costs to women, communities, and health systems are too great to delay action. Too many of the world's most disadvantaged and vulnerable women have suffered this preventable and treatable condition in silence. Too many women are dying in childbirth needlessly. It is time to put an end to maternal death and disability.

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Living Testimony: Obstetric Fistula and Inequities in Maternal Health brings together the voices of women from 29 countries in Africa, the Arab States, and Asia regarding life with obstetric fistula. Their families, community members, and health care providers share knowledge, attitudes, and perspectives on pregnancy, delivery, and fistula. This advocacy publication presents promising practices and strategic recommendations for policy makers, programmers, and researchers seeking to improve access to vital maternal health services and strengthen fistula prevention and treatment programmes in affected countries.

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