

## Preempting the Need to Repair: Toward a Comprehensive U.S. Policy on Obstetric Fistula

By Sneha Barot

After decades of taking a backseat to other more visible global health problems, the issue of maternal health has finally captured the attention of the world's policymakers. A major breakthrough came in 2000, when 189 countries adopted eight Millennium Development Goals (MDGs) designed to reduce global poverty and support development. Improving maternal health was designated as MDG 5, and it includes the specific targets of reducing the maternal mortality ratio by three-fourths and achieving universal access to reproductive health by 2015.

It was not until this year, however, that serious focus on and commitments to maternal health have taken a center stage in actual global health efforts. In June, leaders of the richest countries decided at the G-8 summit in Canada to prioritize investments in maternal, newborn and child health in the group's development agenda. The G-8 countries committed \$5 billion over the next five years to these efforts, complemented by another \$2.3 billion pledge by private foundations led by the Bill & Melinda Gates Foundation and other nations not in the G-8.

Earlier in June, the Women Deliver conference in Washington, DC, brought together more than 3,400 advocates, high-level government officials, donors, journalists and health professionals to strengthen global initiatives to reduce maternal deaths and illnesses. And also this year, the United Nations (UN) Secretary-General highlighted his desire to raise the profile of MDG 5, by launching a Joint Action Plan to accelerate progress on maternal and child health.

The Obama administration has also expressed its interest in prioritizing this issue. Maternal and child health is a key pillar in its Global Health Initiative, and a "woman- and girl-centered approach" is one of the initiative's seven principles. Although such attention and resources are overdue and welcome, and although recent data show some progress in lowering rates of maternal mortality, the fact remains that rates of pregnancy-related deaths are unacceptably high. The world is far behind in meeting the MDG 5 targets.

Within the field of maternal health, moreover, there are specific pregnancy-related disabilities that themselves have been overlooked through the years. Prominent among these is obstetric fistula, long an unspoken problem, but now finally also garnering some well-deserved awareness. Obstetric fistula is caused by prolonged, obstructed labor without access to emergency obstetric care, leaving a hole, otherwise known as a fistula, between a woman's vagina and her bladder, rectum or both. Unless they can get surgical treatment, women with fistula live with urinary or fecal incontinence, and likely face shame, stigma and despair.

Because this condition generates such deep sympathy, a diversity of actors in the advocacy, media and policy communities—including those who sit at opposite poles of the political spectrum—are taking an interest in it. One consequence of this broad-based acknowledgment of the problem, however, is that ideological divisions seem to be forming over how to actually address it. As with HIV over the last decade in the context of the President's Emergency Plan for AIDS Relief (PEPFAR), one of the major develop-

ing fault lines is over the level of emphasis that should be placed on prevention efforts, which would include family planning, versus less ideologically fraught treatment efforts. Experts in the field overwhelmingly agree, however, that as advocates and policymakers consider efforts to develop new initiatives on obstetric fistula, it is imperative that such policies be grounded in an evidence-based, which is to say comprehensive, approach.

### Understanding the Problem

Although there is widespread agreement that the existing data are incomplete and likely underestimate the problem, according to the World Health Organization (WHO), there are at least two million women worldwide who have obstetric fistula. Another estimated 50,000–100,000 new cases of fistula occur each year, though some say the incidence is higher.

There may be no more heart-wrenching portrait than a woman enduring obstetric fistula. She is typically young, often as young as 13. She is usually from a poor family in a poor community in a poor country, probably in Sub-Saharan Africa or South Asia, because obstetric fistula has almost disappeared from the developed world. She may have a weak, stunted or undeveloped pelvis, which could be due to malnutrition, childhood illness or young age. Often married as an adolescent, she does not or is not allowed to practice contraception and becomes pregnant. During prolonged, obstructed labor, her fetus is too large to pass through the birth canal, and pushes against the tissues of her vagina, bladder and rectum for days, which leads to a fistula. Access to emergency obstetric intervention, in particular a cesarean section, could prevent a fistula from occurring, but is generally unavailable.

Most of the time, such a woman delivers a still-born baby. If she herself survives the labor, which can last up to a week, fistula causes an involuntary leaking of urine or feces, which is horrifying to her and those around her. The physical effects can include a strong stench, bladder or kidney infection, infertility, painful ulcerations, and nerve damage and paralysis in the legs. The

overpowering smell and her physical condition often lead her to be divorced by her husband, abandoned by her family and ostracized by her community. A woman with fistula may have little or no access to resources to get appropriate physical and mental health care or to economic opportunities to earn a livelihood, pushing her into further poverty and depression, and sometimes suicide. A woman may live with this condition for the rest of her life, if unable to access treatment. The physical, psychological, social and economic consequences are utterly debilitating.

### The Three Prongs

There is widespread consensus among fistula experts that a comprehensive approach to addressing the problem encompasses three prongs: prevention, treatment and rehabilitation. As with many other global health issues, however, prevention may be key to solving the problem, but it is often the most difficult area in which to make progress and demonstrate success.

In the case of obstetric fistula, prevention means providing universal access to adequate reproductive and maternal health care, as well as addressing the underlying systemic conditions that lead to the condition. At the most proximate level, prevention measures include the availability of skilled birth attendants and emergency obstetric care, including access to a cesarean section. Another essential prevention strategy, however, is access to family planning services that help women delay too-early pregnancies, have only the pregnancies they want and space them appropriately to maximize their own health during pregnancy and the health of their babies.

Equally important to preventing fistula are interventions to combat the other, often interlocking, social and economic inequities that contribute to this particular maternal morbidity: low status of women, lack of education for girls, early marriage and pregnancy, malnutrition, poverty, inadequate health and transportation infrastructure and harmful traditional practices such as female genital mutilation. Failure to aggressively take on these persistent, root causes of fistula—and indeed of most other poor maternal health outcomes—will only ensure that the problem endures.

Treatment for obstetric fistula usually consists of surgical repair. There are many different forms of fistula, from the simple to the complex. Some 90% of uncomplicated cases can be successfully repaired; the average cost of fistula treatment, however, is about \$300. For complex cases, repair may not be possible at all, but if it is, incontinence may continue regardless. Some fistulas can be extremely complicated, involving damage to other bodily systems and requiring multiple, expensive surgeries to treat. A holistic model of treatment also requires attention to infrastructure and local capacity, including the training of indigenous health professionals, provision of postoperative care, and equipping and upgrading health facilities.

Moreover, surgical repair of fistula is often only the first step for women to heal from this condition. Years and sometimes decades of living with fistula leave many women socially, psychologically and financially unable to function in their communities. Accordingly, the last prong of a comprehensive approach to fistula includes services that help fistula patients reintegrate into society through the provision of counseling, skills training, literacy classes and other support, to restore their dignity, self-confidence and self-sufficiency.

A variety of contingencies can arise even after a repair, including later complications, subsequent pregnancies (if possible) that require cesarean section, or recurrent fistulas (which can reoccur even with prior uncomplicated cases). Because of these factors and the devastation to women affected and those around them, it is crucial that prevention efforts be strengthened and emphasized in tandem with those around treatment and repair. Moreover, because obstetric fistula shares the same underlying causes that lead to other types of maternal morbidity, and to maternal and newborn deaths, it is not surprising that WHO and other leading global health professionals recommend that fistula prevention and treatment programs be integrated into a country's overall plan to lower maternal and infant deaths. By pursuing a coordinated approach, fistula programs themselves will be stronger, more effective and

more sustainable, along with the broader safe motherhood initiatives in which they are located.

### Ongoing Fistula Initiatives

International aid efforts to tackle fistula have gained steam over the last few years. The global development agency that has led the charge against obstetric fistula is the United Nations Population Fund (UNFPA), which founded the first global campaign around fistula in 2003. The Campaign to End Fistula has embraced a comprehensive framework to eliminate fistula and assists countries in conducting assessment surveys, developing national plans and implementing those plans through interventions to prevent and treat fistula, and to provide reintegration services. It is working in 49 countries, and UNFPA has raised \$37 million to support the campaign (see map). Additionally, UNFPA acts as Secretariat for the International Obstetric Fistula Working Group, which coordinates activities to eliminate fistula and whose membership includes leading individuals and organizations dedicated to fistula prevention, treatment and recovery.

The U.S. government's financial and technical contribution to international fistula efforts is implemented through the U.S. Agency for International Development's (USAID) maternal health program as well as its population and reproductive health program. USAID's FY 2010 allocation for fistula is more than \$11 million, and the agency has programmed \$59 million since it began implementation in 2005. It currently provides assistance to 34 fistula repair centers in 11 countries, as well as an additional 39 facilities for prevention services such as family planning and maternity care. The bulk of USAID fistula funding is funneled through the Fistula Care Project, a five-year cooperative agreement with EngenderHealth, a nongovernmental organization working on reproductive health. The project implements the majority of USAID's prevention and repair programs, and manages the data for all of USAID's fistula programs. In addition, USAID is a member of the Campaign to End Fistula, as well as of the International Obstetric Fistula Working Group.

## New Directions

In Congress, interest in fistula spans the ideological spectrum. Congresswoman Carolyn Maloney (D-NY), a staunch ally of reproductive rights who has a long record of supporting fistula programs, has most recently introduced a bipartisan bill with Rep. Mike Castle (R-DE). The bill emphasizes both prevention—including access to sexual and reproductive health services—and treatment, along with activities that build country capacity, such as promoting “south-to-south” training from one developing country to another. Rep. Rosa DeLauro (D-CT), another champion of women’s reproductive rights, is also in the process of developing new fistula legislation. DeLauro has previously worked with those on the other side of the aisle to find common ground on divisive issues, notably around legislation to reduce the need for abortion, which she introduced with antiabortion Rep. Tim Ryan (D-OH) last year.

Socially conservative legislators also have taken action on this issue. Rep. Chris Smith (R-NJ), a vehement opponent of comprehensive sexual

and reproductive health services, has long promoted obstetric fistula programs. His philosophical approach was apparent during consideration of the FY 2006–2007 State Department reauthorization bill, to which he added funding for fistula repair activities, yet also successfully introduced an amendment that weakened language on fistula prevention and removed reference to contraceptive services.

Given the current political climate and the anti-family planning stance of many socially conservative lawmakers, there is growing concern among fistula advocates that a strong commitment to fistula prevention, particularly with regard to family planning, could be dropped in any legislative effort that seeks to attract broad bipartisan support and conservative evangelical participation. Such a concern has been heightened by the arrival of a new fistula-focused coalition on the scene. The coalition is being led by L. Lewis Wall, the founder and president of the Worldwide Fistula Fund, and a surgeon and professor of obstetrics and gynecology who has written extensively on the issue of obstetric fis-

## CAMPAIGN TO END FISTULA

The UNFPA-led campaign is active primarily in Africa and South Asia.



Source: UNFPA, 2010.

tula. He has partnered with Michael Horowitz, a former Reagan administration official currently at the Hudson Institute who brandishes his experience in bringing together left-right and secular-religious coalitions on a variety of social causes.

Together, Wall and Horowitz are spearheading an effort to seek U.S. foreign assistance funds for the creation of a new fistula initiative. Their proposal has been highlighted in the media and most prominently promoted by New York Times columnist Nicholas Kristof, who himself has championed reproductive and maternal health issues. Although an updated draft of the proposal has not been widely shared with the fistula community, a public draft made available through Kristof's column late last year outlined a heavily treatment-focused plan that would span more than 10 years and cost over \$1 billion to, among other things, construct stand-alone fistula centers to offer surgical repair throughout Africa.

A critical and defining strategy of the coalition has been to actively recruit religious and conservative advocates to the cause, with the hopes of replicating the political success of the PEPFAR program, first enacted into law in 2003 and reauthorized in 2008 with a \$48 billion spending level. Credit for the original passage of PEPFAR against odds considered long at the time, as well as for the high level of funding the program has been able to maintain, is widely given to the ideological diversity of the key actors who have provided their support, including both liberal and conservative lawmakers and highly visible representatives of the conservative faith-based community.

It appears that Wall and Horowitz believe that obstetric fistula can have even more resonance among a similarly wide constituency. Their publicly circulated proposal notes, "Religious leaders—of right and left—have shown by their efforts on behalf of the PEPFAR Initiative that they can be engaged in an initiative to save millions of vulnerable and afflicted victims from a condition easier and far less costly to treat and eliminate than AIDS."

The PEPFAR parallel raises alarm bells for advocates of sexual and reproductive health working

on fistula issues. Their concerns stem from the experiences of advocates during the original PEPFAR authorization process, as well as the reauthorization process in 2008, in which the price paid for holding together a coalition that included religious and social conservatives was steep. Both times, evidence-based prevention policies were sacrificed in favor of abstinence promotion, devaluation of prevention efforts generally, and a failure to recognize the value of better integration between contraceptive services programs and HIV prevention and treatment programs.

With respect to maternal health policies, the MDG framework clearly sets forth the importance of universal access to reproductive health care to the achievement of better maternal health. This interrelationship has been repeatedly affirmed by evidence, and supported by key implementers and donors alike. As the recent G-8 declaration stated, many pregnancy-related deaths and injuries could be prevented with "better access to strengthened health systems, and sexual and reproductive health care and services, including voluntary family planning." With specific regard to fistula, the 2008 report of the UN Secretary-General on "Supporting Efforts to End Obstetric Fistula" states that "optimal maternal health, including elimination of obstetric fistula, will ultimately be achieved through universal access to reproductive health." Policies and programs to eradicate obstetric fistula cannot succeed without a robust family planning component.

Sexual and reproductive health advocates working on fistula are anxiously monitoring the development of fistula legislation in Congress. As the process moves forward, they are determined to ensure that, this time, comprehensive and evidence-based policies are not sacrificed to accommodate an ideologically diverse constituency. Even as advocates continue, years later, an uphill battle to repair some of the shortcomings of PEPFAR, the lesson and their message to policymakers has become clear: Do it right the first time, so you don't have to fix it later. [www.gutmacher.org](http://www.gutmacher.org)