

Fixing fistula

While new clinical management guidelines promise better treatment outcomes for women with obstetric fistula, more needs to be done to prevent this debilitating condition in the first place. Felicity Thompson reports from Sierra Leone.

Zainab Jabati (not her real name) gave birth for the first time at sixteen. Not unusual for a teenager in rural Sierra Leone. Growing up in a tiny village on the remote tip of a mangrove-ringed island off Sierra Leone's southern coast, Zainab was two days by boat from the nearest clinic. When she went into labour, her mother was away visiting a sick relative and local women took her to a 'sacred bush' to give birth. She was there for three days while the women tried to induce labour by sitting on her belly and pulling at the baby with their hands. Perhaps not surprisingly, the procedure failed. "When it came out, my baby was dead," Zainab remembers.

As terrible as the experience was, losing the baby was just the beginning of Zainab's problems; she suffered an obstetric fistula – a communication between the vagina and the urethra and/or the large intestine. This can result in chronic incontinence. Obstetric fistula often follows prolonged, obstructed labour and typically affects the poorest of the poor – uneducated women living in rural areas in countries where obstetric care is poor and women tend to give birth at home.

Without proper treatment, women with an obstetric fistula can face a

lifetime of suffering, unable to control the discharge of urine or fecal matter. Often abandoned by their husbands and families, they find themselves effectively ostracized from society. Girls drop out of school, women cannot work and simple things – like getting on a bus – become an ordeal because of the way the sufferer smells. "People didn't greet me," Zainab remembers. "Men didn't want me. It was very difficult – I didn't have any friends."

Reliable incidence and prevalence data on obstetric fistula are lacking, but the United Nations Population Fund (UNFPA) estimates between 2 and 4 million women suffer from obstetric fistula in low-income countries in Africa, south-east Asia and the Middle East, with another 50 000 to 100 000 women and girls developing the condition each year. Mariana Widmer from the department of Reproductive Health and Research at the World Health Organization (WHO), says the social stigma and misunderstanding that it inspires has led to significant under-reporting, making it a largely hidden condition.

The UNFPA steers the Campaign to End Fistula, as well as the International Obstetric Fistula Working Group – the decision-making body of the campaign – which comprises over 60

national and international agencies collaborating on all aspects of fistula, including prevention, treatment, social reintegration and rehabilitation. The campaign started in 2003, and according to Gillian Slinger, the campaign's coordinator at UNFPA, it has done much to raise awareness about the condition.

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Our understanding of obstetric fistula is also set to improve with the completion of a number of studies, including a literature review of worldwide fistula prevalence and incidence that is under way at the London School of Hygiene and Tropical Medicine. Meanwhile, the Johns Hopkins Bloomberg School of Public Health is leading a multi-country study to examine post-op prognosis and long-term outcomes of obstetric fistula cases following surgery. The clinical picture is also improving. US-based reproductive health non-profit, EngenderHealth, and WHO are currently coordinating a randomized controlled trial studying catheter management in post-operative fistula patients. WHO also recently developed clinical management guidelines for obstetric fistula, while the International Federation of Gynecology and Obstetrics (FIGO), the International Society of Obstetric Fistula Surgeons (ISOFS), and other partners have published the first guidelines on obstetric fistula repair surgery.

At the Aberdeen Women's Center in Freetown, Alyona Lewis, Sierra Leone's only national full-time fistula surgeon, is currently using the new Training Manual for Fistula Surgeons to



Alyona Lewis, the only obstetric fistula surgeon in Sierra Leone, chats with a young woman at the Aberdeen Women's Center in the capital, Freetown

train a second Sierra Leonean surgeon in obstetric fistula repair surgery and treatment. Lewis hopes that her trainee surgeon will take up the call. “You are not just passing on your skills,” she says. “You must allow the [trainee surgeon] to develop the compassion, the passion, the empathy – to look at the patient not just from one point of view, but ... as a human being.”

Steve Arrowsmith, a surgeon who has worked on fistula internationally for the past 25 years and currently trains surgeons in fistula surgery on board the *Africa Mercy*, a ship providing medical care in western African ports, says it is difficult to find surgeons who have both a high level of surgical expertise, but also the drive to practise in resource-poor countries. This can result, he says, in failed repairs. “Despite everyone’s hopes to the contrary, fistula repair is difficult surgery that spans the boundaries between surgical disciplines – urology, plastic surgery, colorectal surgery and gynaecology,” he says, noting that more and more women are coming forward with post-operative issues, suggesting that fistula repair is being attempted by unqualified doctors.

While it is clearly essential that women and girls have access to treatment, experts agree that the emphasis with regard to obstetric fistula policy must be on prevention. The vast majority of obstetric fistula cases occur when there is a lack of skilled birth



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Women celebrate their successful obstetric fistula repair surgery at the Aberdeen Women’s Center in the capital, Freetown

attendance and no emergency obstetric care, which is a major contributor to maternal mortality. “If you get obstetric care right, then you shouldn’t have any fistula,” says Regina Bashtaqi, Health Poverty Action’s director in Sierra Leone, who believes that obstetric fistula is one maternal condition among many that can be eradicated if the core maternal health problems are resolved. Of course, resolving those problems is no simple task and requires a concerted effort on the part of governments. And the same can be said of fistula prevention itself.

The Campaign to End Fistula is trying to get governments more involved in efforts to eradicate obstetric fistula, notably by encouraging them and, in particular, health ministries, to ensure that a national strategy is in place for obstetric fistula as part of the Sexual Reproductive Health National Plan, Slinger says. “Another key element is to ensure that a minister of health-led national task force for fistula exists, involving partner organizations working on all aspects of fistula in each affected country,” she adds. Thus far, results have been mixed. While good progress has been made in some countries such as Liberia, many governments have been slow to respond.

For Widmer one of the obstacles to progress is governments’ lack of accurate information about the scope of the problem, which prevents the integration of specific fistula initiatives into their planning. “If there is no epi-

demology, no data, it is very difficult for policy-makers and governments to implement policy,” Widmer says. There is also a tendency for countries with high obstetric fistula prevalence to be overwhelmed by many other health issues, notably high maternal and child mortality rates. Sas Kargbo, head of Reproductive Health at Sierra Leone’s Ministry of Health, agrees. “We have a plateful of problems,” he says. “We had to deal with the biggest challenge which was access [to basic health care]. After solving this problem – and we have almost achieved that – we are now focusing on other priorities like fistula.”

For Arrowsmith, tackling obstetric fistula requires the political will and the resources to right the glaring inequity between those who have access to good obstetric care and those who do not. “We need politicians to address the problems of use of resources on national scales, and to face the reality that obstetric fistula is an issue of basic human rights,” he says.

At the Aberdeen Women’s Center in Freetown, the wards are full and some women are sleeping on mattresses on the floor. Zainab, who has just undergone surgery for her condition, is all smiles as she prepares to go home. She doesn’t know if she will be able to have children again. But she is not afraid to talk about her experience. “When I go home, I will talk about this,” she says. “If I see someone with this problem I will tell them about the Center. I will not be ashamed!” ■



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Mary Sesay is from a remote village in Northern Sierra Leone. She works to raise awareness in her community about obstetric fistula