



Operations of Compassion

Traveling doctors go to Africa and Asia to repair fistulas: avoidable childbirth injuries, little known in the U.S., that can destroy a mother's reasons for living.

By Mariana Minaya

When Dr. Marcella L. Roenneburg first decided to take her daughter to work two years ago, it was more than the usual trip downtown to mom's office at Mercy Medical Center in Baltimore.

The two crammed their suitcases with surgical gloves, sutures and soap and flew 5,000 miles to a primitive operating room in the impoverished West African country of Niger. Last fall, the destination was Bangladesh.

Clad in surgical masks and scrubs, mother and 16-year-old daughter tended to girls who have suffered devastating wounds of pregnancy - wounds that can turn them into social outcasts.

"There's a saying in one of those countries, 'To be pregnant is to have one foot in the grave,'" Roenneburg explained. Even if the girl survives labor, she may be left with a vesicovaginal fistula - a hole in the tissue separating the bladder from the vaginal canal.

Because of the fistula the victims constantly leak urine, and because of their foul smell - which one of Roenneburg's patients described as being like "walking death." Frequently, the girls are abandoned by their husbands, families or entire villages.

Although usually forestalled by cesarean section in the developed world, fistulas affect about 2 million women in sub-Saharan Africa and parts of South Asia, where adequate health care is often unavailable for women in labor, according to estimates by the World Health Organization.

Few doctors in these countries are capable of repairing the holes, which leads surgeons like Roenneburg, 51, to travel to different countries for weeks at a time to cure as many women as possible.

Roenneburg's November trip to Bangladesh was her third surgical mission, and the second for her daughter, Rachel Rabinowitz. At Mercy, Rachel was never allowed to watch her mother - a specialist in women's urinary and gynecological problems.

"I know what she did, but I didn't really see the full scale of what she did until then," Rachel said.

For a specialist like Roenneburg, it was a familiar problem in an unfamiliar setting. But few doctors outside her specialty have ever seen a fistula caused by pregnancy because cesareans are so widely available here.

"It's not a Western, educated female problem," said Dr. Clifford R. Wheelless Jr., an associate professor of gynecology and obstetrics at the Johns Hopkins School of Medicine. Wheelless has operated on about 500 women in four different countries - including making trips to Niger and Bangladesh with Roenneburg.

"It's just repeated all over sub-Saharan Africa," Roenneburg added. "These are really the hidden dregs of society."

The problem occurs during labor, when the fetus is stuck in the birth canal for too long and the continued pressure against the pubic bone cuts off blood flow to the surrounding tissue. Without blood, the tissue between the vagina and the bladder dies, resulting in a hole called a fistula.

All women are at risk for the problem, but young or malnourished women with small, underdeveloped pelvises are especially susceptible.

Girls typically marry between the ages of 10 and 15 in rural areas of many developing countries, according to the United Nations Population Fund. A majority of women with fistulas who do get care are younger than 25, a 2005 review of studies from different countries conducted by the International Continence Society shows. At least 30 percent are younger than 20.

"The basic problem is babies having babies," Wheelless said.

If the women could reach a doctor to perform a timely cesarean, they wouldn't develop a fistula. However, clinics are often so far from rural villages that walking is out of the question, and cars are too expensive to hire for the trip.

"As one doctor has said, it's a matter of obstructed transport as much as it's a matter of obstructed labor," said Kate Ramsey, a technical specialist at the Population Fund's Campaign to End Fistula. "You can't just call a taxi, and even if you could you don't have the money."

Even if the women reach a clinic, no doctor may be available. "The government has no money to pay doctors to be at every outpost," Roenneburg said. If there is a doctor at a clinic or hospital, women may have to buy their own supplies and antibiotics for surgery, which many can't afford.

As a result, women usually turn to a relative or neighbor with no professional training to help them deliver the baby, Ramsey said.

In Niger, only 16 percent of births occur with skilled attendants, according to a 2003

U.N. report. Often, those helping a woman deliver don't realize she needs professional medical help until it's too late to prevent a fistula or save the baby. Roenneburg said she has heard of unskilled attendants in Niger burning the women if labor stalls - to drive out the devil they believe is causing the problem.

In addition to the constant leaking of urine, it may be very difficult for women to bear children or even have intercourse again because of the fistula.

"She gets disenfranchised by society," Wheelless said. "The husband divorces her, the family asks her to leave the little hut, and the chief asks her to leave the village, all because she smells bad."

"A woman's worth in Africa is measured by the number of children she produces," he added. "Their life is sort of over at age 16."

Some young women with fistulas try desperately to reach maternity wards in hospitals. If they're not killed by wild animals or don't die from other causes on the journey, they may spend years waiting for the arrival of doctors who can perform the operation, Wheelless said.

In Niger there are a half-dozen doctors who can repair basic fistulas, according to the U.N. It is also hard to attract doctors to work in such poor, isolated areas, Ramsey said.

In those cases, an area in or near the hospital becomes a makeshift "fistula village" - an oasis for women who are not allowed into restaurants or hotels. Because of the smell, bus drivers won't let the women ride with other customers, forcing the girls to sit on top with the luggage, Wheelless said.

About 20 women spend their days doing beadwork or embroidery in the outdoor courtyard of one such Nigerien ward, Roenneburg said. Some of the women's children live there, sleeping on the same urine-soaked mattresses that they lay out in the sun to dry every morning.

"They remind me of some of the leper colonies you would see over in Africa," Wheelless said. "They almost form a little sorority."

Roenneburg said some women develop such close bonds that they refuse to leave the ward even after they are cured. They prefer to stay with the women who have become like their sisters instead of returning to a family and village that scorned them, Roenneburg said.

"The strong girls will help the weak girls," said Rachel, who sensed a mix of hope and desperation among the patients in the National Hospital in Niger.

Even more women journey to the wards from miles around when word gets out that a medical team is arriving to repair fistulas. Wheelless said his team of five doctors

performs from 70 to 100 surgeries in a two-week trip. Even so, they have to leave behind some women who are desperate for the surgery.

"They'll be at the gate beating with metal pots and pans asking you to stay and do more," he said.

The doctors treat fistulas of varying severity. Some women experience tissue damage so bad that they leak feces as well, requiring more complex surgery.

There is also some debate over the success rates for the operation. Small fistulas are repaired relatively easily during a 1 1/2 -hour surgery, but it may take more than one operation to fix large fistulas and restore a woman's continence, Roenneburg said.

Women with fistulas may experience the blockage or loss of a kidney. The prolonged labor may also cause nerve damage that results in a "foot drop," which prevents a woman from walking properly, Wheelless said.

Like many medical problems, this one is easier and cheaper to prevent than to fix, the U.N.'s Ramsey said. While a cesarean costs about \$60 in developing countries, repairing a fistula costs about \$300.

In the United States, only about 50 doctors are qualified to do the job, Wheelless said, because very few have actually seen fistulas. It was Wheelless, 67, who trained Roenneburg during her residency at Union Memorial Hospital and eventually recruited her for the project.

Roenneburg said she got interested in international medicine after her husband died seven years ago and she wanted a place for her family to direct its energies.

"We have a lot to share," she said, so she contacted the International Organization for the Development of Women, a group devoted to curing fistulas. She first traveled to Niger in 2004 - paying for her airfare, food and transportation. On the next trip, she asked Rachel to join her.

Her daughter, who took a week off from classes at Beth Tfiloh Dahan Community High School, said she got more than she bargained for when she was put to work in the hospital, helping the doctors and playing with the children who had practically grown up in the fistula village. And it was sobering to meet girls her age in the clinic.

"I can't imagine myself or my friends being married with kids," said Rachel, a sophomore. "They're not mature enough both physically and mentally to be at that level yet."