Glamour - February 2005

Shunned and scarred for life

Can the world's most helpless female outcasts be saved?

by Rachel Louise Snyder

Catheter, compress, gauze, betadine. Carol Glowacki, M.D., and Ambereen Sleemi, M.D., demand supplies from a nurse at the National Hospital of Niamey, the capital city of Niger, an impoverished country in western Africa. In 100-degree-plus heat, the visiting American surgeons are sweating under their gowns and masks as they rush to treat 14-year-old Fatimata Ataher.

A year ago Ataher, who was married at 12, developed an obstetric fistula when she tried to deliver her first child. Fistulas are a serious complication of childbirth that leave the mother physically debilitated and, often, permanently ostracized by her family and community. They develop when, because of the position of the fetus, the narrowness of the pelvis (this was the cause in Ataher's case) or other factors, a baby cannot pass through its mother's birth canal.

Ataher labored for three days before her son was stillborn, killed by the severity of her contractions. During such an extended labor, the pressure from the trapped fetus cuts off the blood supply to tissue between the mother's vagina and her bladder or rectum, causing that tissue to die away and creating a hole, or fistula. Fistulas can be prevented by cesarean delivery; in most parts of the world, in the rare cases when they do occur, fistulas can be sutured after delivery and will heal easily. But without surgery, for the rest of the woman's life urine or feces will permanently leak through the fistula and out of her vagina, a condition that often makes her an outcast, abandoned by her husband and even her parents. Surgery to repair the fistula is cheap--just $300 or so, a small price to get your life back. Yet millions of poor women in Africa can't afford it.

Ataher is hopeful that the American surgeons will be able to heal her. She watches nervously as anesthesia is administered to numb her from the waist down. Next, Dr. Sleemi swabs Ataher's vagina with betadine; urine leaks from her fistula, dripping into a metal container on the floor. Dr. Sleemi cuts away the scar tissue, then she and Dr. Glowacki make small, careful stitches to close the fistula.

In the operating room next door, Karolynn Echols, M.D., faces an even more difficult case. As she lays out her surgical instruments, a nurse tightens a broken light to stop it from flickering, and Dr. Echols hopes the few bulbs that are still working will last through the operation on her 20-year-old patient. Fati Yaou developed a double fistula five months ago, after she gave birth to a stillborn baby. The location of the holes--directly behind the pubic bone--creates a challenge. Still, Dr. Echols forges ahead; she estimates that there's only a 50 percent chance the surgery will heal Yaou. But as the girl is wheeled out of the O.R. to the post-op ward, the surgeon offers her patient a gleaming white smile and a thumbs-up. "You do what you can and afterward you just feel unsatisfied," Dr. Echols says later. "You take two steps forward and one step back every day."
A Hidden Epidemic At least 2 million women and girls around the globe, most in Africa and Southeast Asia, suffer from this devastating condition, and at least 100,000 more develop fistulas every year, according to estimates by the United Nations Population Fund (UNFPA). Niger has the highest fertility rate in sub-Saharan Africa; girls marry young (as early as nine years old in some areas), rarely by choice, and on average bear eight children. These factors, combined with a lack of access to prenatal or medical care, make fistulas a severe problem in Niger. Yet the UNFPA estimates that only six surgeons there are trained to repair them.

"When I see women with such severe fistulas, my first instinct is to run and hide," admits Dr. Glowacki, 39, director of the division of urogynecology at SUNY Downstate in Brooklyn. "But you learn to utilize emotional resources you don't necessarily know you have. How can you not try to help them?" That's why she and her colleagues--Dr. Sleemi, 35; Dr. Echols, 37; and Cynthia Hall, M.D., 38, chief of urogynecology at Cedars-Sinai Medical Center in Los Angeles--have come to Niger on a two-week trip planned by the International Organization for Women and Development (IOWD) in Rockville, New York. These doctors are determined to give at least a few Nigerien women their lives back. "There are places in the States where people are in need, but sometimes insured patients are unappreciative, and a lot of them can't accept that they are not going to be completely cured," says Dr. Echols, who heads the gynecology and pelvic reconstruction department at Louisiana State University Medical Center in Lafayette. "In Africa, they're just so happy that you're caring for them. I feel like I have a real purpose. They need you here."

Abandoned Women It's hard to imagine women more in need than those at the National Hospital of Niamey. Spurned by their husbands and communities, 40 to 50 women live behind the hospital

in a large sunken cement square known colloquially as the Fistula Village. Many are like Zeinabou Ayouba, who is 35 and has lived here on and off for nearly 20 years. She has undergone seven operations, but none have been successful. Her husband left her long ago, she says through a translator. "I am completely orphaned.... It is not my choice, but it is from God and I'm obliged to stand it." She rubs her eyes. "My only problem is the fistula; otherwise I am healthy. But I have had enough of it."
Salamatou Ibbro, a 20-year-old with doll-like features and a backward S tattooed between her eyes, traveled more than 125 miles from her village in hopes that her fistula could be treated. Ibbro's was a rare instance of marriage by choice. But because of her fistula, her husband left her. She was fortunate that her parents could pay for two surgeries, but the procedures were unsuccessful and the family could not afford a third. Ibbro worked for weeks separating beans to be able to afford the $6 ride to the hospital.

Ibbro's isn't an isolated case. When word got out that doctors were coming from America, the population of the Fistula Village swelled by a dozen a day, with women traveling hundreds of miles, even crossing the border from the neighboring countries of Mali and Burkina Faso. In the Village, dark liquid droplets are sprinkled like stars on the ground, evidence of leaking fistulas. Dusty mats are placed around the courtyard for sitting, and metal pots with boiling food sit atop charcoal fires. Sarongs are slung over walls. The area smells of urine, sweat and charcoal. Ayouba, Ibbro and the others have become surrogate family, caring for one another after surgery, cooking meals together. They have no one else to turn to.

One Patent At A Time Back in the O.R., Dr. Sleemi, a fellow in pelvic reconstructive surgery at Maimonides Medical Center in Brooklyn, is nearly finished sewing up Fatimata Ataher's fistula. Suddenly Dr. Glowacki screeches into her mask, "Another? We found another hole!" The room goes quiet with anticipation. "We have to start all over again," Dr. Glowacki says. Dr. Sleemi looks and nods, silent.

They work for one more hour; Dr. Sleemi tests the new suture line by pouring blue dye into Ataher's bladder to see where it drains. The repair looks good. "We're doing a lot of creative surgery here," Dr. Glowacki says afterward with a resigned smile.

The doctors perform three to four such surgeries each day. The procedures typically happen in two stages: the first to repair the leaking, and the second to restore continence. Success is measured on a case-by-case basis. For one patient, it may be a victory if she never leaks again; another may finally be able to return home. But even in the best cases, many of these women will never have children. "The value of a woman in Africa is her ability to bear children," says Dr. Glowacki. "So you know these women have no value anymore to their societies. When you hear about that, the spirit leaves you. I think all of us feel that way."

At the end of every day, the doctors examine new patients to add to their surgery list. Exams start after 4 P.M. and take 10 to 15 minutes each. Women are lined up by the dozens. When Aminatou Mahamadou, a 25-year-old with a four-year-old fistula, climbs onto the table, Dr. Sleemi begins her exam and gasps. "I've never seen anything like this," she whispers.

In one of Mahamadou's two previous surgeries, a doctor had sliced away excess skin from her labia and sewed it inside her vagina to try and cover the fistula hole. Now, unbelievably, there is pubic hair growing inside her, she still leaks urine and her vagina is the size of an olive.

Her chances of success are slim, but the doctors simply cannot leave her with the hack job she's been given, so Dr. Glowacki schedules Mahamadou for surgery. Another young woman, Haoua Sadou, 18, enters. She is exuberant, with high cheekbones and a Julia Roberts smile. Gold earrings dangle from her lobes. She was married at 12, got pregnant at 17, spent seven days in labor and lost her child. Another gasp, this time from Dr. Echols as she begins the exam: She can put her finger into Sadou's vagina and feel through her urethra and bladder all the way to her pubic bone, because the fistula is so large. On the exam table, Sadou's eyes gleam; she doesn't stop smiling even when Dr. Echols leans toward her and says, through a translator, that Sadou's problem is too complex for surgery this time. The doctors must choose cases with the highest chance of success or they risk jeopardizing funding for future teams. "But I promise," Dr. Echols tells Sadou, her hand on the girl's shoulder, "I'll do some research, get some experience and come back to help you." Sadou nods and winks. She will not show her disappointment.

Healing And Hope The doctors remain strong when they are treating patients, but in their guesthouse at the end of the day, the magnitude of the problem threatens to engulf them. "It

is disheartening, especially getting women who've had two, three, four surgeries--all of them unsuccessful," says Dr. Sleemi. "It's like a broken vase: You can glue it back together, but the crack will always show. Put it back together enough times and you don't have any large pieces of glass left."

Dr. Echols breaks down when she thinks of Mahamadou and her mutilated vagina. "We were there for hours," she says; it is near midnight and her voice is cracking. "I just felt like I failed her. When we first examined her it was horrible...who the hell...what kind of goddamned technique... I just don't understand it." Tears stream down her face. Mahamadou does not yet know that she cannot have children. She does not yet know that she cannot have sex.

"You know what sucks the most?" says Dr. Sleemi, throwing her arms up in frustration and anger. "This is totally preventable. All those women in the courtyard? Totally preventable if they just had C-sections. And now their lives are over."

"They are so hopeful," Dr. Echols says. "They just keep waiting and waiting. Some of them we can't operate on, but a lot of them we can. I think that is what a lot of these women have: hope."

Three days after Yaou's and Ataher's surgeries, both girls are walking and eating and neither appears to be leaking. They are among the 11 women the doctors successfully treated (out of 16) before they slid off their surgical caps and went home.

Back in the States, the doctors check in often with the IOWD office for news of their patients. Fatimata Ataher--whose father visited her frequently at the hospital--got a second surgery that enabled her to return home with him. Haunted by her condition, her father vowed that she would not be forced to go back to a husband who'd rejected her and that he won't arrange another marriage for her until she is older. Haoua Sadou, the young girl whom Dr. Echols had promised to return to help, was eventually operated on by another team of IOWD doctors. Although she could have returned home, Sadou did not want to leave her fistula sisters. She stayed on at the hospital, making rounds with the doctors and keeping up the spirits of the patients. IOWD is now training her as the hospital's first nursing assistant devoted fully to the care of the women.

The eradication of obstetric fistulas in Africa is decades away at least. But these doctors are taking crucial first steps toward that goal. "It is very rare to see a woman who has been operated on whose life hasn't changed even slightly," says Hadiza, a nurse who goes only by her first name and works with the women at the Fistula Village. "Hopefully we can eventually teach people how to prevent this, not just help them after the fact," Dr. Echols says. "I don't know how, but we'll keep trying. I'll be doing this for a lifetime."