Finding a balance in the treatment and prevention of obstetric fistula

With curly lashes and soft, full eyebrows, Almaz looks younger than her 20 years, even more so when she starts to cry. "I'm scared," she says in Amharic, digging her nails into the palms of her hands. "I don't want to die."

She is about to undergo surgery in the sleek, gleaming white operating theatre of Addis Ababa's Fistula Hospital, the world's most renowned centre for treating obstetric fistula, a term used to describe vesicovaginal or rectorvaginal fistula occurring after failed or obstructed labour.

Almaz (not her real name) is 1 of 2300 patients treated annually by the hospital's 6 doctors and, like many who arrive, is frightened and suspicious. She is also wary after spending a year alone in a hut, her husband having left her when she gave birth to a stillborn. She's been incontinent since, and rarely visited, except by her sister and friends dropping off food.

Almaz hopes to join the ranks of the 93% to 95% of women whose obstetric fistulas are successfully closed at the facility that has become a haven for Ethiopian fistula sufferers since being established in 1974 by Australian surgeon Catherine Hamlin and her late husband.

Fistula Hospital Chief Executive Officer Mark Bennett says that about 20% of patients continue to battle incontinence and other complications post surgery, because what's left of their bladder is too small to hold much urine. In rare cases, where the bladder has been completely sloughed out through the vagina and cannot be repaired, stoma surgeries are performed, explains Dr. Hailegiorgis Aytenfisu. For most women, though, surgery means "they can urinate normally. They can get married. They can even have another baby."

Wendy Glauser

Patients with fistula wrapped in colour-block blankets knitted by women in Australia and Europe. Because of the elevation, it can be cool in Addis Ababa.

It is a welcome outcome for women in Ethiopia, where obstetric fistula is so prevalent that a foundation established by Hamlin — who continues to perform surgery at age 84 — is in the process of building 5 more treatment hospitals. Three are already operational.

Skeptics wonder if the focus would better be placed on educational measures, given that obstetric fistula is essentially preventable with a cesarean section. But it's difficult to shift the focus when demand for treatment continues to rise.

It's a function of cultural, political and economic factors, Bennett says. Ethiopian women become susceptible to obstructed labour at a young age. Growing up in poverty, they're made to

fetch water and till soil, and they don't get enough nutrients to satisfy the needs of their young bodies. "And a higher proportion of women in Ethiopia are small."

But the clincher is that 85% of the population live in rural areas, often more than a day's journey — by foot, bus or ride from a stranger — from the nearest hospital. Roughly 95% of Ethiopian women give birth at home. "It's considered normal to give birth at home and it's probably considered normal that a certain percentage of women die giving birth," says Bennett.

Another young woman, Werkenish (again, because of hospital policy, not her real name) surveys the garden that Hamlin built at The Fistula Hospital, which was featured on *The Oprah Winfrey Show*, and a smirk comes over her tribal-tattooed face as she reminisces about her life. She was betrothed at 10 and taken to her mother-in-law's to learn how to cook njera (an Ethiopian bread) and roast coffee beans.

She eventually developed a severe vesicovaginal fistula after 5 days of labour and spent a year seeming to constantly launder her sheets and clothing. One day, she told her husband to find another woman because she was no longer fit to be a wife. "My husband was disappointed but what could he do?" asks Werkenish, who now lives with her parents.

Wendy Glauser

Fistula Hospital officer Bethela Amanuel demonstrates how a fistula occurs.

Eliana Aponte/REUTERS

An Ethiopian woman carries a bucket of urine inside a clinic at the Addis Ababa Fistula Hospital, which has performed more than 32 000 free operations on women suffering from the humiliating injury that typically results in a constant leak of urine. A fistula is caused by a tear in the tissue between the vagina and adjoining organs due to prolonged labour, particularly in young, undernourished women.

Most women with obstetric fistulas are ostracized by their husbands and, sometimes, even by their families. "Usually the first thing women will notice is that they're not invited for the coffee ceremony," a daily ritual in Ethiopia, explains Bethela Amanuel, public relations officer at the hospital. The smell of stale urine and feces can be offensive, and with little understanding of conventional medicine, rural Ethiopians often see fistulas as a curse or the fault of the woman.

In reality, fistula happens because women don't have access to cesarean sections, and critics of Hamlin's well-funded organization say focus would more properly be placed on improving access to cesarean sections rather than surgical repair of fistulas.

"It's shameful that more fistula hospitals are being built when fistula is 100% preventable," says Dr. Ronald Lett, the Addis Ababa-based director of the Canadian Network for International Surgery.

Dr. Yifru Berhan, an Ethiopian gynecologist and head of a medical school in the town of Hawassa, agrees. "It's unfortunate that we have hospitals to manage the complication but not to prevent the complication."

There are signs, however, that management at the hospital are finally heeding such calls. "It seems a futile task if you keep sewing up women if you're not reducing the numbers coming," says Bennett, noting that Ethiopia's expanding population is increasing the demand for fistula surgery.

In hopes of easing that pressure, the Hamlin Foundation is building 25 prevention clinics in addition to 5 treatment hospitals. Each clinic will be staffed by 2 midwives, who will encourage women to seek antenatal care. The foundation has also hired advocacy officers in recent years to speak at churches, markets and schools about the causes of fistula and how to prevent it. "It's important we teach the whole community," says Amanuel, "because a woman might say 'I need to go to the hospital,' but unless her husband agrees with her, she won't go." The advocacy officers target traditional birth attendants (women who have experience cutting umbilical cords but no professional medical background), teaching them to recognize obstructed labour and identify women who shouldn't give birth vaginally.

But Amanuel predicts prevention will be a long and arduous task. "You

have to make sure that people have transport to get to the hospital; you have to have good roads; you need antenatal clinics that are close enough for women to get to for a check up. You have to make sure there are schools so there is a choice for the girls. You have to make sure the nutrition value is different. You have to change the culture of early marriage."

Women prone to fistulas are poor, rural and barely educated, living as they do in a culture which sees the schooling of girls as a "waste," adds Amanuel, who grew up in Ethiopia's taxi-jammed capital. "They're the most voiceless members of our society." — Wendy Glauser, Addis Ababa, Ethiopia

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Medical whistle-blower protection lacking

Whistle-blowing doctors who take stands on behalf of their patients typically have few protections against retaliation.

But that's begun to change in some countries and states, like California, in which hospitals can be fined for reprisals. Some argue such protections should be systematic throughout Canadian medicine.

Their arguments are being bolstered by the experience of Alberta family physician Dr. John O'Connor, who over the past 2 years has found himself embroiled in controversy after publicly surmising that the development of the tar sands was linked to higher rates of cancer in the Northern Alberta town of Fort Chipewyan in which he works.

O'Connor's concerns drew international media attention and have since spawned a pair of investigations.

His statements also prompted an assault on his medical licence, led by 3 physicians who work for Health Canada and who filed complaints about O'Connor with the College of Physicians and Surgeons of Alberta in 2007.

One of those, Dr. Hakique Virani, says the Health Canada trio are concerned about O'Connor's practice and conduct, primarily because he failed, they say, when requested by the province, to produce records for the patients he'd claimed had cancer.

Howard May, a spokesperson for Alberta Health and Wellness, says his agency "went out of our way to get Dr. O'Connor to come forward with information, and he didn't do it."

O'Connor disputes this, saying that when he was asked to provide the names of people he knew had specific tumours or cancers, he did.

"I was asked for direct input and I gave them the information."

O'Connor adds that he was accused of causing "undue alarm," but members of the community have told him they are concerned, not alarmed.

He believes his advocacy "has given them the encouragement and the motivation to go ahead." One complaint against O'Connor remains unresolved. (The College declined to investigate another and closed the case on the third).

Spurred by the O'Connor case, the general council of the Canadian Medical Association passed a resolution in 2007 urging that doctors be protected from "reprisal and retaliation" when they speak out as community advocates.

Pressure to protect whistle-blowing doctors and nurses in Canada has also come from public health and legal experts, including the SARS Commission, which concluded in 2006 that health care workers in Ontario need whistle-blower protection to ensure they report public health risks promptly and "without fear of consequences."

Manitoba is the only jurisdiction in Canada that now enforces such protection.

It emerged after a 1994 dispute in which anesthesiologists at the Winnipeg Health Sciences Centre boycotted the hospital's cardiac surgery program and asked administrators to review its safety. The doctors were forced back to work under threat of losing their jobs.

A subsequent pediatric cardiac surgery inquest found that several deaths in the program could have been prevented and led, in turn, to Manitoba Regulation 64/2007, which protects healthcare professionals from reprisals when they make complaints about the quality of clinical care.

Similar protections are more widespread in the United States, where the Joint Commission on the Accreditation of Hospitals prohibits retaliatory action.

California has gone a step further, mandating that once a complaint is made, reprisals within 4 months are presumed to be retaliation, and the hospitals can be fined up to US$25 000. — Miriam Shuchman MD, Toronto, Ont.

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The Athabasca tar sands have been linked by Dr. John O'Connor to "clusters of diseases" among his patients in Fort Chipewyan, Alberta. O'Connor was accused by Health Canada of "causing undue alarm" and "blocking access to data" in his patient files.