Women in Uganda dismantle stigma of fistula

Treatment for the debilitating obstetric injury has been scarce in Uganda, but organisations are helping to fill the gap, writes Mara Kardas-Nelson.

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Loy Tumusiime's back is erect, her arms gesticulating wildly, as she speaks at length to a small cluster of men, who occupy the few benches available in a small plot of dusty land, and a larger group of women seated on the grass a few feet away, at a community meeting in Bukaigo, Uganda. The topic being discussed is one that she is passionate about: obstetric fistula.

Obstetric fistula is a medical condition in which a hole develops either between the rectum and

the vagina (rectovaginal fistula), or between the bladder and the vagina (vesicovaginal fistula), as a result of obstructed labour in areas with limited medical care. Without being able to get a C-section or receive other medical support, the lives of both mother and baby are put at risk.

In Uganda, 6 000 women die in childbirth every year, and those who do make it through may face chronic medical issues, such as fistula, which results in the leaking of urine and/or faeces. This incontinence can lead to social isolation and further medical problems such as infections and infertility.

Obstetric fistula is rare in relatively developed South Africa. But it is a different story in a country like Uganda, where fistulas are a very real risk for women of childbearing age, especially those living in rural areas where medical care is scarce. According to World Health Organisation figures for this year, Uganda has 14.3 health professionals (doctors, nurses, and midwives) per 10 000 people. This is well below the recommended 23 health professionals per 10 000.

The health ministry estimates that anywhere from 140 000 to 200 000 Ugandan women currently have a fistula, with 1 900 new cases occurring each year.

Tumusiime is well acquainted with these issues. In 2010, despite receiving a C-section to ease obstructed labour, she lost her baby. Tumusiime soon realised that something else was wrong when she began "leaking". Her husband subsequently divorced her, complaining that the smell of urine in the house was too strong.

Tumusiime soon met members of the Uganda Village Project, an organisation based in Iganga district in South Eastern Uganda and, after receiving two operations, finally had her fistula repaired. She now devotes her time to working with the project on education and outreach, teaching communities about the importance of birthing at health facilities and offering women the chance of recovery through "fistula camps" at the nearby Kamuli Mission Hospital.

Hardly a social outcast, as is often the case with women who have experienced a fistula, Tumusiime proudly confronts stigma and openly speaks about the simple things men and women can do to prevent it.

Fistula can be prevented through regular antenatal care and hospital deliveries and repaired through surgery. But resources are limited.

Only gynaecologists and surgeons who receive specialised training can repair fistulas. Although a training programme is offered through Mulago Hospital in the capital, Kampala, interest is low, because of the stigma attached to the injury, limited focus on fistulas in medical school, and the perception that fistula repair is difficult.

In this country of 34.5-million people, the health ministry says that there are only 24 surgeons who can repair fistulas. Only 1 000 to 1 500 repairs are done annually.

Many hospitals rely on visiting surgeons who come for a short period of time and are responsible for a slew of tasks, fistulas being just one of them.

As such, women primarily attend temporary fistula camps for treatment, run by the government, the United Nations Population Fund (UNFPA) or nonprofit organisations, or they go to Mulago Hospital.

But sometimes the distance is too far and the cost of travel too great, or women simply don't know about services.

Rose Mukisa of EngenderHealth, an organisation supporting the Ugandan government's fistula efforts, says that most women have fistulas for 15-20 years before they are able to have them repaired. Twenty-three percent of the Uganda Village Project's fistula patients wait more than 20 years for treatment.

But, with the support of the UNFPA, the health ministry has set up a fistula-repair training programme for surgeons and gynaecologists. The ministry hopes that, as training increases, fistula treatment will not only occur at national and regional referral hospitals, but also at health centres, or "mini hospitals", situated across the country.

Better training could help to prevent fistulas: according to the Uganda Village Project's Maureen Nakolinzi, 21% of the country's cases are the result of human error, often occurring during C-sections (a dark irony, given that C-sections are also needed to help prevent fistulas).

But the health ministry's Peter Kivunike says this rate is hard to quantify, as women may realise they have a fistula only after they receive medical care as a result of obstructed labour. The fistula therefore could have occurred from the difficult labour, or from the C-section conducted to assist mother and child.

Better training of surgeons and gynaecologists is only part of the answer. The health ministry and its Fistula Technical Working Group, made up of the government, the UNFPA and nongovernmental organisations, is teaching a range of healthcare workers such as nurses and midwives how to identify obstructed labour so that women can be properly referred for C-sections in time.

And, although the health ministry warns against using traditional birth attendants, they are now also being trained in fistula prevention and education to spread the word at community level.

Groups such as EngenderHealth and the Uganda Village Project are also trying to involve men in

the process. Both not only pay for transport and food for women undergoing fistula treatment, but also feed and transport attending family members, such as husbands.

"These women are entirely economically dependent on the man, so if the man doesn't appreciate the need for delivery at hospital or the need for prenatal care or the need for fistula repair, then we won't achieve what we want to," says EngenderHealth's Mukisa.

She hopes that the men they support will help to encourage behaviour change among others in their communities.

But Nakolinzi says that outreach activities need to be tailored to women. The health ministry uses radio adverts to spread the news about fistula camps, but she says the message won't reach those who need to hear it most.

"We asked a woman who had a fistula for 13 years and was fixed when she was 78 years old why she hadn't heard about it on the radio, and she said, 'Who listens to the radio? Men listen to the radio'," says Nakolinzi.

"Most people think they were cursed or bewitched or it was God's will. People have never heard that it was [through] child birthing, they don't know there is treatment ... We ask women who have had fistulas for 30 to 40 years and they say they didn't know at all that [repair] was happening. You need to reach down and send people there."

In the absence of adequate information, organisations such as the Uganda Village Project make use of the ministry's village health teams, or volunteer community health workers, to spread the word about education programmes and to find women in need of treatment.

Since 2009, the project has connected 225 women to the fistula repair camps at Kamuli.

They have Tumusiime at their side throughout the surgery and recovery. She also follows up on their progress when they're back home and asks them to find other patients in need.

At the end of her session in Bukaigo, Tumusiime hands out her phone number to everyone at the session, telling them to call her with any questions about fistulas or childbirth.

Her efforts do not go unanswered. She says she has to turn her phone off every evening at 11pm to keep it from ringing through the night. A few women stay quietly behind to speak to Tumusiime about a leak that they have, or a woman they know of down the road with the same problem.

Already she's planning the next trip to Kamuli to help others to receive the treatment she has received.

"It's like a new life," she says.

Watch the slideshow here.

Mara Kardas-Nelson is a journalist at the M&G Centre for Health Journalism. Her stories are produced with the support of the Open Society Foundation but are editorially independent of any sponsorship