Caterpillar to butterfly: hope for women with fistula

By Veena Gokhale

A slightly different version of this article was published by WFS. I prefer this more 'human interest' oriented version that I originally submitted.

The birth of a child should be a happy event in a woman's life. For those too poor to access medical care to handle complications, however, motherhood can bring trauma.

This is the case of women who get fistula, caused by prolonged and obstructed labour. If they could access proper medical care, they would have a caesarean section. In its absence, the constant pressure of the baby's head in the birth canal causes a hole to form between the bladder and/or the rectum and vagina. As a result, urine and/or faeces leak continuously and uncontrollably. In most cases, the baby dies. The hole can be repaired, but the surgery is not widely available in hospitals in poor countries. Typically costing US$ 250, it is well beyond the reach of poor women.

The social impact of fistula is worse than its medical consequences. Women experience extreme isolation and demoralisation. The majority are abandoned by their husbands and unable to continue their former work, leading to further impoverishment.

Women's Dignity Project (WDP), a leading, Tanzania-based non-governmental organization, has been working on this issue since the mid-90s. From 2003-2005, working with local partners, WDP conducted what is likely the most in-depth study on fistula ever undertaken. The aim was to hear directly from some 150 women and girls with fistula, their family and community members and health care providers, about the causes, impact and solutions to this problem.

Located in three rural centres in Tanzania and Uganda; and one Tanzanian hospital that offers fistula repairs, the research confirms earlier findings, adds new information, particularly on the impacts and context, and suggests a way forward.

"You can cry when you go to these villages," says Atu Mwangomale, a WDP study researcher. "Some of these women have considered suicide."

The study confirmed that a key determinant is the inability of a woman in prolonged labour to reach a hospital in time. Typically, she starts labour at home, at best attended by a midwife. When she fails to deliver for a long time, she goes to the nearest dispensary. Here, she may be advised to go to the hospital, which can be quite far. She also has no money to hire the transport, or pay for the fees and supplies. The decision to go to the hospital is not hers' as much as her husband's or mother-in-law's.

Her family members may try to raise money by selling family assets – a chicken, goat or cow. A vehicle may eventually be hired and the woman may reach a hospital after

a long, bumpy ride. Given her low status, there is no guarantee of prompt attention. By then, it is usually too late – she will loose her baby and develop fistula.

“We found that women without fistula mostly got to deliver at a health care centre and these women had received antenatal care,” says Kamugumya, another researcher from WDP.

Awareness about fistula varied. Women who lived near a hospital offering fistula repairs, that had done some outreach work, were better informed. Some women knew about fistula but were unaware there was a cure. The extent of poverty mattered. In Singida, one of the research areas in remote, central Tanzania, people were poorer and there were old women who had lived with fistula for over 30 years.

Fewer than half the women interviewed believed that fistula was caused by witchcraft, bad luck or a curse by ancestors. “If a woman with fistula had this belief, then her family members had it too and vice versa,” says Kamugumya.

In Uganda, the situation was worse: some people believed hospital intervention had caused fistula: “This is because the woman starts leaking after the baby is taken out in the hospital,” says Mwangomale.

Health workers had high awareness levels, while community members were eager for information that would help them cope.

The majority of the married women were divorced after getting fistula. “My husband said he could not live with a woman who rots the mattress with urine. He threw me out. People on the street started calling me names,” says a 20-year-old woman from the Songea district in Tanzania.

Research revealed that women with fistula often isolate themselves even before the family and community can react. Their self confidence crumbles as they deal with the effects – rash, dizziness, weakness and constantly changing clothes.

“There is a loss of ordinary life, going to church or the mosque. This keeps them away from God – something they really regret,” says Kamugumya. Many deprive themselves, not drinking water in an effort to contain the leakage.

The women often return to their parents’ homes after divorce. The family members here are supportive, but they too are poor. Some husbands continue to live with the woman and they may even have more children.

Yet these women are resilient; some save money for years to get a repair. The change after surgery is dramatic. Says one community member: “They are like caterpillars after fistula, but become butterflies after surgery.” The researchers did not find the women in their homes, on their follow-up visit, because they had regained their mobility.

“One Ugandan woman started singing and dancing when she met us,” says Kamugumya. She used to brew liquor but decided to stop this work after repair.

“Women who go back to their villages after the repair are our best ambassadors,” says Mwangomale. They seek out and talk to those with fistula and bring hope to women whose first repair has failed.

The policy recommendations of the study reinforce measures that WDP is already advocating. If implemented, they could reduce the estimated yearly 1,200 – 3000 new cases of fistula in Tanzania. They have implications for the two million women living with fistula globally, and the additional 50-100,000 women who are affected each year (World Health Organization).

Health centres need more staff, training, drugs, equipment and supplies, and must be able to provide preventive measures and c-section deliveries. Each centre must have an ambulance. Each village needs radio communication so that they can call for it.

Rural road infrastructure needs to be developed. The community can play a role in road building and maintenance. They can develop a community health fund which a woman needing special care can access.

Fistula repairs must be free, with no extra costs added. More hospitals need to offer fistula repairs. People need information about the causes of fistula and where they can go for help.

Addressing corruption in the healthcare system is another anti-fistula measure. Finally, rural women need empowerment, including income-generating activities and the possibility of making important decisions about their own lives.

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