After A Decade Of Achievement, It's Time To Move Beyond Fistula

Commentary by Iain Guest

This Thursday, May 23, the world will celebrate ten years of fighting fistula, a foul condition that affects up to 3 million women and girls in the Global South and causes incontinence and sometimes even death. The Campaign to End Fistula has been something of a triumph. Over the past ten years, the UN Population Fund (UNFPA) alone has supported over 34,000 fistula surgeries. At last count, 238 facilities around the world were treating the condition.

But with success have come questions. Last year, political infighting in Washington produced two bills before the US Congress with differing visions about how best to treat fistula. That battle appears to be far from over. Beyond that, there is growing concern that a single-minded focus on fistula has produced a privileged aid "silo" which excludes other damaging conditions caused by child-birth, notably uterine prolapse and incontinence. While next week will be cause for celebration, it should also be an opportunity for a rethink.

The fistula campaign began in 2003 and drew inspiration from the work of Catherine Hamlin, an Australian surgeon, at the fistula hospital in Ethiopia. Its message was simple and powerful. Obstetric fistula results from obstructed child-birth. It occurs when the foetus becomes wedged in the mother's pelvis, creating a hole in her birth canal. If untreated, the mother either dies or survives to leak feces and urine, which turns her into a social outcast. In the Congo, women have also suffered traumatic fistulas as a result of having bayonets and sticks thrust into their vaginas.

Once the yuck factor was overcome, the dam broke. UNFPA led the charge, with help from celebrities like Oprah Winfrey and Richard Branson. The Fistula Foundation funded surgeries. The New York Times columnist Nicholas Kristof stiffened nerves with his reports, including one of a fistula-sufferer who smelled so foul that she was left to lie in
her waste to be eaten by hyenas. A fine documentary, Walk to Beautiful, won prizes. The US Agency for International Development (USAID) and EngenderHealth, its NGO partner, set up country programs. Somewhat remarkably, fistula had captured hearts, imaginations and aid budgets.

These pioneers deserve special credit because they were venturing beyond maternal mortality, which has long held the development community in thrall, and taking on a morbidly which may not pose an immediate threat of death but which certainly ruins lives. This represented a bold shift. As UNFPA points out, for every woman who dies in childbirth, 20 more are disabled.

The question is - where does it go now? Last year's squabble in the US Congress suggested that it may not be smooth sailing. Ironically, the two competing bills were sponsored by Democrats from the liberal northeast. Both called for fistula to be treated, but Representative Carolyn Maloney also stressed the importance of prevention to include family planning. The rival bill from Representative Rosa DeLauro, was reportedly inspired by another Kristof column and proposed fistula centers of excellence to be serviced by visiting American surgeons. The DeLauro bill made no mention of family planning, presumably in the hope of appealing to conservatives.

In the event, neither bill was put to a vote, but Congresswoman DeLauro is reportedly preparing to try again. Many experts in reproductive health feel this would be a big mistake. For one thing, there are very few American fistula specialists because fistula is so uncommon in the US. On the other hand, ten years of work on fistula has produced a network of skilled African and Asian surgeons, and critics of DeLauro say that any US money should go to building up their local support systems. Contacted in the Congo, where she is working at the famed Panzi hospital, Lauri Romanzi, a prominent American urogynecologist, called the DeLauro proposal "daft."

The larger question is whether the focus on fistula is blocking action on other conditions, particularly uterine prolapse, or fallen womb. According to the Women's Reproductive Rights Program (WRRP), an AP partner in Nepal, prolapse is caused by a perfect storm of pressures which bear down on poor women. These include early marriage, untrained birth attendants, poor nutrition, work, heavy lifting, domestic violence, and even cultural taboos. According to the UNFPA, around 200,000 women in Nepal suffer from the condition. One doctor told me: "It's very difficult to convey the sheer misery of living for years with one's private parts hanging between your legs."

As with fistula, women with severe prolapse are likely to be ostracized. Younger women have difficulty finding a husband. Older sufferers may be divorced, rejected by their families, and end up working as servants for their former husbands. It is perhaps no coincidence that a UNFPA study found suicide to be the leading killer of women of reproductive age in Nepal.
Why not expand the fistula campaign to prolapse? Gillian Slinger, who heads the fistula program at UNFPA, argues that the battle against fistula is far from won and that fistula should have first call on limited health budgets. One hears the same from USAID. Both agencies also appear worried about taking the focus away from maternal mortality, even though their work on fistula is presumably helping to bring down maternal mortality (which, like fistula, can be caused by obstructed labour). In spite of this, donors are dead set against taking on prolapse - so much so that women with prolapse are reportedly being turned away from fistula camps in Africa.

These reports frustrate Sinan Khaddaj, a surgeon who runs the Women and Health Alliance (WAHA) from Paris. Dr Khaddaj also says that many of the women arriving at WAHA hospitals in Africa are suffering from severe incontinence caused by years of child-bearing, but not necessarily fistula. He said it was inhuman and unethical to only treat one post-obstetric condition, like fistula, and ignore others.

Dr Khaddaj is one of a number of experts who call for an integrated approach to treating all pelvic floor disorders, under the broad rubric of maternal health. This could start in villages, where health workers and midwives would be trained to diagnose and provide basic treatment. Women needing surgery would be referred to hospitals, where doctors would be trained and helped by international specialists as appropriate. At least one African hospital - Aberdeen in Sierra Leone - has developed integrated training. "Not only does it make sense, it's what African doctors want and what African women need," said Lauri Romanzi.

Dr Romanzi made a strong argument for the integrated approach at a UNFPA-sponsored meeting in Washington last year, and she would like to see it tested in pilot projects. This might alarm some fistula fans, but can they really deny any woman the chance of a healthy life? Let's get ready for another, longer, walk to beautiful.

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