



Today Uganda joins the rest of the World to commemorate the International Fistula Day under theme: *End fistula now, reach everyone*. The commemoration aims at raising awareness, visibility of obstetric fistula and identify actions towards ending the condition in Uganda and world over. Agnes Kyotalengerire explores what the Government is doing to eliminate the backlog of 75,000 to 100,000 patients who are not treated.



A midwife examining a mother in labour. Prolonged labour increases risk of fistula

26

The total number of 26 fistula surgeons in Uganda

100,000

Uganda is grappling with a backlog of about 75,000-100,000 cases of fistula

Fistula: What Uganda needs

Jane Alupo has battled with obstetric fistula for 20 years. She has a *lesu* wrapped around her. She is withdrawn, isolated, and unhappy. She does not join the family members for meals and neither does she attend any social gathering. Her best companion is a small jackfruit tree in the backyard where she spends most of day.

I only bump into her after I have excused myself to use the toilet. She only opens up after about five minutes of coaxing.

"My dress or skirts are always soaked in urine, a nasty state I have endured for the last 20 years. I regret the day I became pregnant because I smell like a animal. Even my own child smells me," Alupo, 38, narrates her ordeal as she struggles to hold back tears.

Alupo says it all started in 1998 after she experienced prolonged, obstructed labour that left her with a torn bladder and leaking urine.

"When labour started, I went to a traditional birth attendant in the neighbourhood. But after realising that she could not manage to deliver me, she referred me to Soroti general hospital where I was delivered through Caesarean section. To my surprise, when the doctors removed the catheter after five days, I noticed urine was leaking," Alupo is resident of Amulisa explains.

She was examined and the doctors diagnosed her with obstetric fistula. Alupo is one among thousands of women in child bearing age who have been battling with obstetric fistula for years.

The statistics
Globally, the United Nations Population Fund (UNFPA) reports that there are approximately 3.5 million cases of fistula with up to 100,000 new cases annually with majority being in Sub-Saharan Africa and Asia.

In Uganda, obstetric fistula still remains a major public health problem that is depriving women and young girls a right to lead dignified lives.

Currently, the country is grappling with a backlog of 75,000-100,000; that is approximately 1% of women in the reproductive age living with fistula, according to the Uganda Demographic and Health Survey (UDHS) 2010.

UNFPA reports indicate that every year, there are about 1,900 new cases



Doctors carrying out surgery during a recent fistula camp at Adjumani Hospital. Photos by Agnes Kyotalengerire

of the condition. Data from the health ministry estimates that only 2,000 repairs are done every year, which implies that a good proportion of women affected by the condition are not receiving the required fistula treatment. This creates a backlog in the communities.

What is obstetric fistula?
Dr Emmanuel Odar, a fistula surgeon and senior consultant gynaecologist at Arua Regional Referral Hospital, describes obstetric fistula as a tear that occurs during childbirth between the vagina and the bladder causing the urine to leak continuously.

Odar who also terms the condition as vesicovaginal fistula explains that when a woman gets obstructed prolonged labour, the tissue in between the birth canal and the urinary tract gets injured and undergoes decay within 5-7 days creating a hole which results in urinary fistula.

In the worst cases, some women

Where to access treatment

Some women who have stayed with the condition without treatment, have confessed not knowing where to get the services. There are many health facilities across the country offering fistula surgery/repair free of charge. These include: Mulago National Referral Hospital, Arua Hospital, Fort Portal Hospital, Gulu Hospital, Hoima Hospital, Jinja Hospital, Kabale Hospital, Lira Hospital, Masaka Hospital, Mbale Hospital, Mbarara Hospital, Moroto Hospital, Mubende Hospital and Soroti Hospital. Also some few private not for profit hospital for example Kisli Hospital, Kitovu Hospital, Kagando Hospital, Kamuli Hospital, Virika Hospital, Kumi and Lacor hospital carry out surgery.

end up with faecal fistula, especially if the pressure forced the tear backwards.

Odar says most cases of fistula due to obstructed labour result into babies dying.

"When you see a mother with fistula carrying a baby, then the fistula was due to surgery, especially if the surgeon was junior and

accidentally stitched the bladder together with the uterus," he explains.

Why the backlog
Explaining why there are many untreated cases of fistula, Dr Jackson Amone who is the commissioner

Curative Services at the health ministry says the intervention on

fistula, started in 2004.

Amone says the issue of fistula was not known to the country until UNFPA together with the health ministry started bringing it up.

However, there were mothers who were already grappling with the condition.

Some women have had the condition for over 10 years and have not sought treatment because they think it is a curse or they are bewitched.

Cases reducing
However, not all hope is lost. There is light at the end of the tunnel as data from Uganda Demographic Health Survey reports indicate that the number of cases affected by fistula have been reducing over the last 10 years.

For instance, in 2006 we had a prevalence of 2.6% (about 200,000 women) of women of reproductive age (15 to 49) getting obstetric fistula. In 2011, the figures dropped to 2%,

1.4m

One obstetric fistula repair costs between \$300-500 (about \$20-\$30) this includes surgery, nursing care and treatment

2,000

The number of fistula repairs done every year

to end the condition

which was about 140,000 and in 2011, the number has reduced to 1% which translates to about 75,000-100,000 women with obstetric fistula. However, Amone laments that as the surgeons try to repair the old patients, new cases keep coming up.

Dr Peter Mukasa, a fistula specialist in Kampala, blames the limited working unprepared cases to the limited number of fistula surgeons. The health ministry has only 26 fistula surgeons nationwide with inadequate funding coupled with inadequate funding to support the repairs across the country.

What government is doing?
The health ministry, according to Amone has formed a technical working group bringing all the concerned parties on board to sensitize the public about the condition.

The group is also used as an advocacy tool, to make government and other bodies aware of the plight of fistula patients. Additionally, a lot of training has been done. A total of 26 fistula surgeons who are either urologists or gynaecologists have also been trained, trained to look after the patients, counsellors to ensure the and anaesthetists to ensure the surgery outcome is good, Amone explains.

Community Health Extension Workers (CHEWS) have been trained to enhance community mobilisation for skilled delivery attendance. Capacity building across the country health facilities across the country in emergency obstetric care and management including use of partogram is to detect deviation from normal labour has been conducted, he explains.

Usually women with fistula tend to stay away from hospital because of the stigma. In addition, they are neglected and humiliated which makes them to keep away from family and social gathering.

Is there a budget?
Amone says since management of fistula is programme in the Ministry of Health, there is not specific budget (or ring fence money) for fistula activities.

Money is obtained from the curative services department and during such international commemoration activities to support supervision.

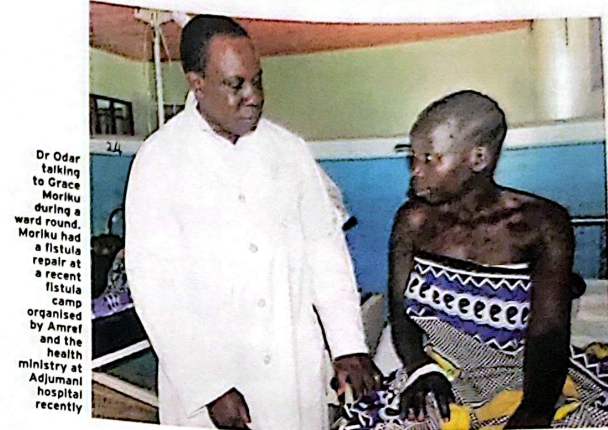
Who is at risk?
Dr Charles Olara, the is the director clinical and community services at the health ministry, says any woman is at risk of fistula during delivery. If she is not assisted by a skilled health worker.

The role of the skilled health worker is to recognise complications quickly and take action. However, women who give birth before the age of 20 are at an increased risk of obstetric fistula.

"Their bones surrounding the birth canal are not fully developed so their baby may not be able to navigate through the canal," Olara explains. Poor nutrition during childhood can also cause stunted growth and increase a woman's risk of fistula.



Teenage mothers attending post-natal clinic at Nabbi Hospital. Teen mothers are at high risk of fistula



Dr Odar talking to Grace Moriku during a ward round. Moriku had a fistula repair at a recent fistula camp organised by Amref and the health ministry at Adjumani hospital recently

"My skirts are always soaked in urine, a nasty state I have endured for the last 20 years. I regret the day I became pregnant."

by creating awareness about health hazards the complication causes to the victims.

It is for this reason that last Saturday over 1,000 people in Kampala took part in a fistula walk that was organised by Halima Namakula a renowned local singer and founder of Women at Work International.

In addition, Amone thinks it starts with keeping girls in school to avoid early pregnancies and marriages. Pregnant women should also be sensitised to attend antenatal care early and make sure they deliver at health facilities with a skilled attendant.

Skilled health workers will detect complication and refer one to another health facility where a caesarean section will be conducted and fistula avoided.

Mukasa explains that a pregnant woman can know that she has obstructed labour, if the labours for more than 24 hours.

"Ideally, the sun should not set when you are in labour," Mukasa cautions.

Is obstetric fistula preventable?
In line with this year's theme: *End Fistula reaches every one* Mukasa says obstetric fistula can be eradicated

Dr Edson Muhwezi, who is the assistant representative at the world's Sustainable Development Goals by 2050.

"We are all working to achieve the vision of the campaign to end fistula, which is *End fistula ending Generation*, no new fistula by 204

Besides, the ministry rides on organisations such as UNFPA, Amref, Engender Health and World Vision who send money to the ministry to support fistula activities.

Way forward
Often society has misconceptions that fistula is a curse; someone has been bewitched. Based on this, Amone says there is need to send the right message that fistula is a health condition that can be prevented.

Additionally, the Government should allocate a budget for the programme because a lot needs to be done. For instance training medical workers, providing special operating equipment, for example, tables and

consumable such as gloves, gauze and fluids.

After the victims are repaired, they need to get socially integrated, taking them back to their communities. It does not stop at taking them back to their homes, but to equip them with entrepreneurship skills and also give them start-up capital for income activities.

In the same breath, women with fistula are always hidden in the backyard as the condition robs them of their dignity and self-worth to the extent that they cannot work and fend for their families.

Mukasa says there is need to actively look to keep away from and this can be done by sending

information through radio and TV talkshows and newspapers.

"But also we need to use the government structures, for example, using the village health members (VHTs) who can identify the women and refer them to facilities," he asserts.

The other avenue is to use churches by sensitising people about the condition and encouraging people to identify and send the women to health facilities for treatment.

Cost of fistula surgery

Dr Peter Mukasa, a fistula specialist working with United Nations Population Fund (UNFPA), says fistula surgery requires a lot of skills; especially to identify and select a fistula patient.

He explains that fistula can be either a simple or extensive injury depending on how it came about.

Depending on the level of injury the repair takes between one and five hours.

One obstetric fistula repair costs \$300 and \$400 (about \$14m) and this includes surgery nursing care and treatment. This is an amount of money which an average Ugandan woman cannot afford, Mukasa says.