

UGANDA



Creating an Enabling Environment for Fistula Prevention and Treatment in Uganda

WHAT IS FISTULA?

Obstetric fistula is a childbirth injury, usually occurring when a woman is in labor too long or when delivery is obstructed, and she has no access to a cesarean section. She endures internal injuries that leave her incontinent, trickling urine and sometimes feces through her vagina.

Fistula Care works to prevent fistula from occurring, treats and cares for women with fistula, and assists in their rehabilitation and reintegration. For more information about fistula and the Fistula Care project, visit www.fistulacare.org.

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Obstetric Fistula in Uganda

According to the 2011 Demographic and Health Survey (DHS), 438 women die of birth-related causes for every 100,000 live births in Uganda, and for every woman who dies, six survive with chronic and debilitating ill health (UBOS & ICF International, 2012). Obstetric fistula, a devastating and frequent outcome of prolonged or unattended labor, is an example of this chronic ill health and a significant public health problem in Uganda. Although detailed data about obstetric fistula in Uganda are limited, the 2011 DHS estimated that 2% of Ugandan women aged 15–49 had experienced the condition (UBOS & ICF International, 2012).

Obstetric fistula occurs when there has been a gap in maternal health care, preventive services, or community response. Addressing these gaps requires a concentrated and coordinated effort at the national and local levels (WHO, 2006). Surgeons, community leaders, hospital administrators, health care providers, nongovernmental organizations (NGOs), and women needing services are distinct groups with their own needs. Organizing these groups requires leadership, and the Ministry of Health (MOH) is often best placed to provide centralized coordination among the various players to ensure that quality services are available.

Background

The Ugandan MOH plays a critical role in ensuring equitable access to health care and stewardship for health resources. As part of the country's maternal health strategy, the MOH plans for service delivery and integration to address both prevention and treatment. Through the leadership of the MOH, standards, policies, and guidelines are applied within the decentralized health system.

The MOH's Clinical Services Department (MOH-CS) has been working on obstetric fistula for several decades. In the 1990s, fistula surgeons from developed countries provided fistula repair surgery mainly through missionary hospitals, offering committed Ugandan surgeons a chance to work with international surgeons and enhance their skills. (One of those trained Ugandan surgeons is now the Commissioner of Clinical Services.)

Assessment reports have identified financial obstacles, limited access to services, inadequate antenatal and delivery care, and a shortage of trained service providers as barriers to fistula services in Uganda (Karugaba, 2003; Women's Dignity Project & EngenderHealth, 2007). To address these, the MOH has worked to build a supportive environment for fistula prevention, treatment, and reintegration.

A key actor in building that environment has been the Fistula Technical Working Group (FTWG), which was established by the MOH-CS in 2003, under the leadership of Dr. Jacinto Amandua. Its goals are to ensure equitable access to health care for women with fistula, promote prevention strategies, maximize the efficient use of resources, eliminate duplication of effort, and foster a community of providers.

The FTWG's main function is to coordinate stakeholder activities in fistula prevention, treatment, and reintegration. It works to improve data about obstetric fistula in Uganda; plan for service delivery; integrate fistula prevention, treatment, and reintegration services into maternal health care within the Ugandan health system; and provide a forum for stakeholders. Before the group was established, there was no national oversight or coordination for fistula prevention and treatment in Uganda.

Members of the FTWG include:

- Officials from MOH-CS and the MOH's reproductive health unit
- National fistula surgeons

- Development partners, including the Fistula Care project
- Representatives from civil society, such as TERREWODDE and Women's Dignity (both of which implement reintegration activities for women affected by fistula)
- NGOs implementing fistula prevention, treatment, or reintegration activities in Uganda

The Fistula Partnership Forum, a subgroup of the FTWG, was established by the United Nations Population Fund (UNFPA), the African Medical and Research Foundation (AMREF), and Fistula Care in 2009, in consultation with the MOH. The group's goals are to harmonize and strengthen efforts among development partners, leverage resources for fistula services in Uganda, and reduce duplication of effort.

This brief describes three important achievements of the Uganda MOH and the FTWG:

- Building an information base for obstetric fistula, to better plan for and manage prevention, treatment, and reintegration services

- Integrating fistula services into the Ugandan health system
- Establishing standards, guidelines, and protocols to guide services

Building an Information Base

Without sufficient and reliable data, health care managers can neither estimate the scope of obstetric fistula nor effectively and efficiently plan and manage fistula services. In Uganda, detailed information about the prevalence of obstetric fistula and about fistula services has been inadequate (Karugaba, 2003). The MOH and the FTWG have taken steps to build a solid information base for obstetric fistula.

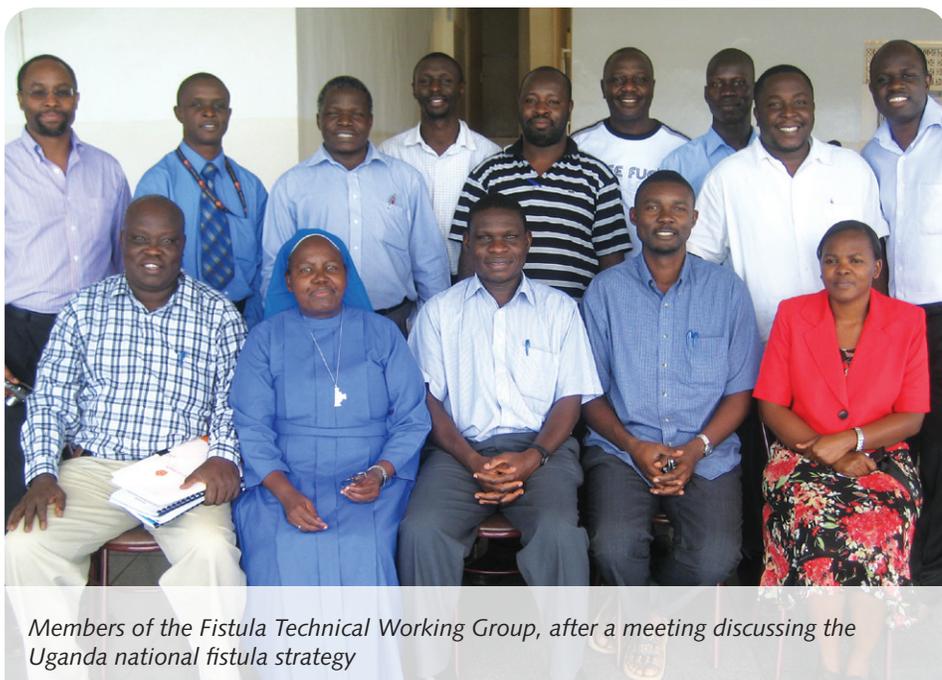
DHS Data on Fistula

The DHS began collecting data on obstetric fistula several years ago; the 2004 and 2005 surveys conducted in Ethiopia, Malawi, and Rwanda included questions on the condition (Johnson & Peterman, 2008). Data collection about fistula in Uganda began in 2006 (Johnson & Peterman, 2008), but the findings were limited and needed to be supplemented with qualitative research. In collaboration with the MOH and the FTWG, the Fistula Partnership Forum worked with the DHS and the Uganda Bureau of Statistics to increase the number of fistula questions in the Uganda DHS from one to the following three:

1. Sometimes a woman can have a problem of constant leakage of urine or stool from her vagina during the day and night. This problem usually occurs after a difficult childbirth, but may also occur after a sexual assault or other pelvic surgery. Have you ever experienced constant leakage of urine or stool from your vagina during the day and night?
2. Have you sought treatment for this condition?
3. Why have you not sought treatment?



A nurse providing preoperative counselling to an elderly fistula client.



Members of the Fistula Technical Working Group, after a meeting discussing the Uganda national fistula strategy

The 2011 Uganda DHS (UBOS & ICF International, 2012) revealed that 2% of women of reproductive age had experienced leakage of urine or stool from the vagina after childbirth. Among women who reported leakage, 62% had sought treatment, 12% felt embarrassed and did not seek treatment, 9% did not know where to go for treatment, 7% did not know that fistula can be repaired, and 3% felt that treatment was too expensive.

The FTWG intends to analyze the DHS data further to identify appropriate interventions in the various regions. Data from the findings will help the FTWG estimate the fistula burden and better understand the behavior of women with fistula by region and district.

Service Delivery Information

Once fistula services have been established, health care managers need information to help them assess demand for and availability and quality of services. To monitor and assess service delivery, the MOH and the FTWG developed three tools:

- A fistula registration form to be used at all facilities providing fistula treatment services
- A fistula client card to give to each client who seeks fistula treatment services (In the future, a woman will present the card when accessing maternal health services, such as antenatal care, to help ensure that she receives appropriate care, including cesarean delivery.)
- A quarterly data collection tool for service delivery sites, adapted from a model developed by Fistula Care (2008a)

These tools can be used to assess how services are being used, to modify services as needed, and to

improve the quality of service delivery. When developing the registration form and the client card, an FTWG subcommittee reviewed various resources currently being used in Uganda and other countries. Members of the FTWG are using the registration form and the quarterly data collection tool; the client card is being printed and will be distributed for use in 2013.

Mapping Fistula Services

During FTWG meetings, it became clear that the MOH and other stakeholders lacked information about key players and where they were working. Therefore, the MOH and Fistula Care worked with a geographic information system (GIS) specialist from the U.S. Agency for International Development (USAID) to develop two maps for Uganda:

- One showed the location of existing fistula treatment facilities and the competencies of surgeons at those locations.
- The other indicated where reintegration activities and other services are provided by development partners.

These maps have been disseminated widely in Uganda, especially among FTWG members. In 2010, a presentation about the maps was given at the conference of the International Society of Obstetric Fistula Surgeons (Meier, 2010).

The maps have enabled the MOH-CS to improve coordination of fistula

“The [FTWG] provides a platform for the participation of community service organizations in the development and running of the national agenda of fistula prevention, treatment, and reintegration.”

—Dr. Anthony Sikyatta, UNFPA

treatment and reintegration services. As a result, the MOH can now:

- Identify areas where no treatment services are offered and where it needs to collaborate with development partners to provide services or referrals
- Establish regional hubs as centers of excellence for fistula training and treatment
- Determine gaps in skills and competency among fistula surgeons and work with development partners to address those gaps

With the help of the maps, the Minister for Primary Health Care Services was able to successfully advocate for fistula prevention and treatment with the MOH's top management. The MOH used the maps to select Hoima Hospital as a regional fistula treatment and care site. After reviewing the maps, the MOH posted a resident fistula care surgeon to Kitovu Hospital; previously, a non-Ugandan surgeon and visiting international surgeons performed repairs there, but in recent years repair services were available only sporadically. The presence of the new resident surgeon has made it possible for Kitovu to once again provide routine fistula care services.

The maps also communicate valuable information to service providers, by identifying the treatment services closest to their catchment areas and enabling them to refer patients to these. Providers can also use the maps to learn about the



Fistula surgeons, anaesthetists, and nurses at Hoima Hospital operating theater.

location of reintegration opportunities for clients and training opportunities for themselves.

Establishing Fistula Indicators in the HMIS

Without regular data collection, the Ugandan MOH has not been able to determine the number of fistula cases repaired in government and private-sector health facilities and the outcomes of those repairs. One of the ways in which to address this gap was to integrate key fistula indicators into the Health Management Information System (HMIS), so that health facilities can regularly report on them. The MOH chose three indicators to include:

- The number of women diagnosed with fistula
- The number of women who have undergone repair surgery (This indicator is broken down by type of fistula, including vesicovaginal and rectovaginal fistula.)
- The outcome of repair surgery (This indicator captures the number of women discharged dry and continent and those discharged but not closed.)

For the first time, health facilities across the country will regularly collect data about obstetric fistula. This new information will be useful in estimating the fistula burden in Uganda; it will also reveal how resources are allocated for prevention, treatment, and training.

Integrating Fistula Services into the Health Care System

A major task of the MOH and the FTWG is to integrate fistula prevention, treatment, and reintegration services into the Ugandan health care system. Fistula

“These maps are a visual representation of how we are doing with regards to fistula treatment care and reintegration. These maps put a face to fistula, a challenge we had ignored for so long.”

—Dr. Amandua Jacinto, Commissioner of Clinical Services, MOH

Care's Levels of Care Framework (Fistula Care, 2009) has proved useful for this task. A key principle underlying the framework is that prevention of obstetric fistula should be integrated into all levels of health care delivery. On the other hand, treatment requires specialized skills usually available at a limited number of facilities; further, treatment facilities must have sufficient bed space and an adequate caseload to maintain and enhance the skills of repair surgeons. The framework describes service delivery for obstetric fistula at three different levels of a health system:

- **Level 1** facilities undertake prevention activities, diagnose obstetric fistula, provide limited treatment, and refer clients to Level 2 or Level 3 facilities. The primary focus at this level is prevention. Facilities providing routine health care services can usually function at Level 1, because surgical skills are not required.
- **Level 2** facilities repair simple fistula cases.
- **Level 3** facilities repair complex fistula cases.

In 2010, the FTWG made three recommendations regarding the framework:

- Uganda's national strategy for obstetric fistula should incorporate the principles of the Levels of Care Framework.
- The national guidelines and service standards for sexual and reproductive health and rights, which were then being reviewed, should incorporate the framework.
- The framework should be aligned with the Ugandan health care system.

The national strategy for obstetric fistula, developed by the FTWG with support from UNFPA and Fistula Care, designates the regional

referral and teaching hospitals in Gulu and Mbarara and the national referral and teaching hospital in Mulago as national fistula referral centers. Each of the three hospitals will have at least one fistula repair team capable of handling simple and complex cases. District and general hospitals will handle simple cases and will arrange for referrals; staff from regional hospitals will provide technical management for fistula care camps. The MOH will strengthen the capacity of lower levels of the health care system to identify cases and make referrals.

Establishing Standards, Guidelines, and Protocols

Health care providers must follow consistent approaches for prevention and treatment that are grounded in current medical knowledge and evidence. The MOH and FTWG have produced a variety of standards, guidelines, and protocols for fistula prevention and treatment, by drawing on a range of existing global resources and adapting them to the Ugandan context.

National Guidelines for Obstetric Fistula

As part of its efforts to integrate fistula services into the Ugandan health system, the MOH has incorporated them into an updated version of the national guidelines for sexual and reproductive health. The chapter on management of obstetric fistula includes a table identifying specific tasks (e.g., community outreach, information and education, counseling, history taking, physical examination, surgical repair) and then indicating which types of health care providers can perform these tasks and the levels of the health care system at which those tasks can be done.

Training of Service Providers

When establishing fistula services, one of the first tasks is to develop a skilled cadre of providers. As is the case in many countries, too few Ugandan service providers have been trained in fistula care (Karugaba, 2003). Fistula Care has developed a training strategy (2008c) that individual countries can adapt to meet their specific fistula training needs. In Uganda, Fistula



A nurse conducts a group counseling session with fistula clients.

Care helped the MOH and the FTWG to review the training strategy, adapt it, and produce the *National Training Guidelines and Standards for Treatment of Female Genital Fistula*. FTWG members are currently using this strategy.

In May 2012, the MOH and FTWG received copies of the *Global Competency-Based Fistula Surgery Training Manual*, which was produced by the International Federation of Gynecology and Obstetrics (FIGO) and its partners (FIGO et al, 2011). The MOH and FTWG recommended that the manual be adopted, and the MOH encouraged FTWG members and other stakeholders to use the manual during training and provide feedback to the MOH. The MOH and Fistula Care have pretested the manual, with the goal of strengthening the capacity of local junior surgeons through mentorship by senior local surgeons. The results of the pretest were promising and were shared with the FTWG.

“We have been able to put a national fistula strategy in place, which had not been there; we have been able to put fistula on the policy level of the Ministry of Health.”

—Dr. Amandua Jacinto, Commissioner of Clinical Services, MOH

Service Standards and Quality of Care

To set standards for fistula service delivery and to establish an ongoing commitment to quality of care, the MOH and the FTWG have adapted three global resources:

- A tool to assess a facility’s readiness to deliver fistula treatment services (Fistula Care, 2011) (Ugandan version: *Site Assessment Tool for Treatment and Prevention of Female Genital Fistula Services in Uganda*)
- Guidelines for medical monitoring and supervision of service delivery

(Fistula Care, 2008c) (Ugandan version: *Supportive Supervision and Monitoring for Female Genital Fistulae in Uganda*)

- A protocol for investigating and reporting mortality (Fistula Care, 2008d)

The MOH and the FTWG have approved the use of these adaptations and are seeking resources to support their wider dissemination.

Contributing to the national strategy, guidelines, and service standards for obstetric fistula has been an important activity for the FTWG; the group has developed a shared vision and unifying goals. Before the FTWG’s formation, health care providers delivering fistula care services worked in isolation, without national direction. Dr. Robert Olupot, a fistula repair surgeon, says, “When we meet as a group, we are able to discuss the challenges we face and the opportunity that may be there. [The FTWG] benefits the client.”

Lessons Learned

Building the capacity of health systems requires leadership. The public and NGO sectors need to coordinate to stay focused and accomplish greater outcomes than each could accomplish separately. Despite limited resources, the Uganda MOH has made significant advances to address the prevention and treatment of obstetric fistula. Thanks to the MOH’s and FTWG’s coordination of several departments, districts, health facilities, and health



One year after having a fistula repaired, Rose was able to have to a child.

care providers, stakeholders now have access to information and resources on fistula treatment and care that were previously lacking. In addition, the MOH's capacity to treat and care for fistula clients has been strengthened.

Because of collaboration between the MOH and development partners, the pool of competent surgeons and facilities is increasing, and they are receiving the equipment, commodities, and supplies needed to provide services. The MOH has accomplished its work by creating a forum for leadership and collaboration, making resources available, and increasing information about fistula.

Leadership

Through regular meetings of the FTWG, participants have exchanged information about high-performing interventions and lessons learned from their work. The FTWG is a forum in which stakeholders can discuss innovations and share information for institutional development—both community groups trying to identify women with fistula and health facilities providing prevention and treatment services. In an example of innovation, one facility developed a pilot program to use mobile phones to send money to women to pay transportation costs for follow-up visits. The FTWG has shared and distributed standardized partographs to partners and MOH facilities. Members of the FTWG discuss programming successes as well as staffing and resource challenges. Supporting the FTWG, the Fistula



Repaired fistula clients at Kitovu Mission Hospital in Masaka District

Partnership Forum has provided coordination and strategic vision for partner organizations.

Information

In efforts to strengthen health care facilities at various levels, planning with accurate data helps to ensure that resources are not wasted. Enhancing DHS data collection about fistula will provide additional insights into the condition, produce critical information for policymakers, and inform decisions about budget and resource allocations. Service delivery information will help providers meet the needs of clients and maintain quality of care. Mapping is a valuable tool that can be used to address gaps in services. Finally, including fistula indicators in the national HMIS will

give planners a countrywide view of obstetric fistula and the services needed to address it.

Resources

Standardization of materials is essential to providing quality fistula services at all facilities. By adapting global resources and by developing its own materials, the MOH has provided standardized tools for health care providers and policymakers. The MOH now has materials on training, fistula treatment, service delivery, supervision, monitoring, and site assessment. It has also pressed for the development of a national strategy that will provide a unified vision for preventing and addressing fistula throughout Uganda.

Ensuring that women have access to skilled care to prevent and treat obstetric fistula is part of a robust health care network. The Uganda MOH, with support from Fistula Care and other partners, has provided leadership, resources, and information for the community working to improve health care access for women.

“The TWG is a voice for advocacy and avenue for training. When we train we encourage those trained to treat vesicovaginal fistula.”

—Dr. Fred Kirya, Soroti Regional Referral Hospital

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Uganda has an estimated population of 34.5 million people; the total fertility rate is 6.4 lifetime births per woman, one of the highest in the world (PRB, 2011). Three out of 10 married women use some type of contraception (UBOS & ICF International, 2012). Almost all pregnant women receive at least one antenatal care visit from a skilled provider (UBOS & ICF International, 2012). Yet only 57% of pregnant women deliver at a health care facility (UBOS & ICF International, 2012).

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