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ARTS & HUMANITIES

Experiences with Obstetric Fistula in Rural Uganda

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She lost her baby 20 years ago. It was a long labor, lasting four merciless days, followed by a seemingly longer trip to the hospital on the back seat of an antique motorcycle, culminating in a desperate cesarean section, with only one life left to save. Two decades later, it is not the brooding absence of a long lost child that lingers on her features, but rather the accumulated sorrow of a life sullied by an unrelenting shame, wasted by pain and disability, and suffered in a complete and despairing isolation. Sitting obliquely on the hard-packed, red African soil in the shadow of a banana tree, she wore a faded green dress and gave off an odor of ash, charcoal, and urine. She described her experiences living with obstetric fistula and how she was certain she would bear that curse until her death.

The local name for it is "okudabadaa" or "kaisemainhe" — words in the Ugandan language of Lusoga for "flowing" and "bladder," respectively, appropriate descriptors of a condition that results in chronic incontinence. Obstetric fistula is characterized by an abnormal passageway between the vagina or uterus and internal organs such as the bladder or rectum, leading to persistent leakage of urine and/or feces through the vagina. Obstetric fistula is predominantly caused by neglected obstructed labor. If the labor is unrelieved by a prompt cesarean section, the baby typically dies, and the prolonged pressure of the baby's head compresses the mother's soft internal tissues against her pelvic bones, resulting in a lack of local blood flow, death of the surrounding tissue, and the development of a fistula. In places where fistula is common, women either are unable to obtain a cesarean section or receive one too late, after the fistula and fetal death have already occurred. The persistent incontinence and the rank odor that result, together with myriad other possible outcomes, such as secondary infertility, chronic infection, excoriation of the skin, and neurologic injury, are debilitating and humiliating enough in and of themselves, but a far more devastating outcome awaits most of those with obstetric fistula. Such women frequently find themselves abandoned by their husband and family, shunned by society, and barred from employment. That the condition is essentially an affliction of the very poorest of society

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seals the fate of its victims, who often spend the rest of their lives alone and destitute. Although surgical repair can cure most cases of obstetric fistula, poverty, social stigmatization, widespread misconceptions about the condition, and a paucity of surgical capacity effectively make treatment unattainable for most of these women. Virtually eradicated in industrialized countries after cesarean section became routinely available, obstetric fistula remains a scourge in large swathes of the developing world. Over 2 million women live with untreated fistulas, with most concentrated in sub-Saharan Africa and South Asian countries. It has been estimated that there are 140,000 women living with the condition in Uganda alone.

In the summer of 2008, I, along with six other volunteers, worked on a program run by Uganda Village Project to promote the prevention and treatment of obstetric fistula. Uganda Village Project is a small, nonprofit public health and development organization that operates in the Iganga district of Uganda, a densely populated, agrarian patch of rolling green in the central-eastern part of the country. In 2006, a team from Uganda Village Project determined that there was a marked deficiency in awareness of the problem in the district, as well as a complete lack of treatment capacity. Most hospitals in Uganda are unable to repair fistulas because of a lack of surgeons trained in the specialized procedures required to properly close them, as well as an inability to pay for the requisite sutures, antibiotics, and anesthetics. As a result, most victims tend to go from one hospital or medical clinic to another without finding adequate care or resort to using local traditional medicines until they lose hope and become resigned to their fate. In a country of nearly 30 million, the number of hospitals that can treat a fistula can be counted on one hand, and most fistula victims either do not know they exist or cannot afford to travel to them.

Since 2007, Uganda Village Project has been setting up referral networks centered around rural government health centers where women with the condition can be screened for fistula and be transported to one of these hospitals for free surgical treatment. In 2008, we set up a referral system between Namungalwe Health Centre, 10 kilometers north of Igangatown, and Kamuli Mission Hospital, a private hospital approximately one hour's drive to the north west. Kamuli Mission Hospital offers fistula surgical camps two to three times a year, with surgical services donated by Dr. Brian Hancock and Dr. Glyn Constantine, both of the United Kingdom, with Dr. Alfonso, a Ugandan physician assisting with the surgeries. Surgical and follow-up care expenses, as well as a small amount of money to provide for patient living costs and transportation fees, are subsidized by the Uganda Childbirth Injuries Fund, a registered charity in the United Kingdom operated by Dr. Hancock. On average, 25 patients are seen at a typical 10 day-long fistula camp session, and there are always more patients than can be seen in a single session.

Even though surgical treatment may be available, significant efforts need to be made to merely locate the patients. Although Uganda has one of the highest rates of fistula in the world, it is very difficult to actually find its cases. Because of the severe social stigmatization, victims are usually hidden away, living by themselves in a remote hut or hidden in the back of a family compound. We were told by clinical officers at Namungalwe Health Centre that a single case of fistula had not been seen at the clinic for the prior 15 years; by the end of the summer, we identified nearly two dozen victims from the immediate vicinity and neighboring villages by going door-to-door, speaking to community leaders, and running radio programs asking victims to come in to the health center for screening.

Nalwoga, clinical officer and head of the maternity ward at Namungalwe Health Centre, looks and acts as if she were the headmaster of a high school. Officious, compassionate, and despairing by turns, she runs the ward with a slightly imperious air. About 60 women lined up at the ward's steps on the clinic's first screening day for obstetric fistula. They'd heard about the screening by word of mouth or through the

radio, and Nalwoga ran through the screening questionnaire in Lusoga with a sharp, ordered, yet empathetic manner: "Do you have leakage of urine or feces from your vagina?" "How did the leakage start?" The questions are frank, personal; "okudabadaa" and "kaisemainhe" echo in the conversation. A woman who presents with chronic urinary or fecal incontinence that was precipitated by a prolonged, difficult labor is considered to have fistula, and she is asked to come back to the clinic several weeks later for transport to Kamuli Mission Hospital. By mid-afternoon, the screening wraps up, and the clinic's cracked leather log book notes that 12 women were found to have fistula over the course of the day. A look at the entries for the 50-odd women turned away offers a revealing look at the state of women's health care in the district: menorrhagia, uterine and vaginal prolapse, fibroids — all untreated. Cervical cancer can be confused for fistula, as there is no cervical cancer screening in Uganda and most cases are very advanced; if the cancer spreads to the bladder, it can have symptoms similar to fistula. Unfortunately, the free service offered at Kamuli Mission Hospital is restricted to victims of fistula, and these women were told to go to Iganga hospital nearby, although it was quite likely that they had already tried that option.

Over the next several weeks, Nalwoga and her nursing staff were able to screen and confirm seven more women with fistula. With ages ranging from 18 to 78, some had been living with fistula for just a few years, while others had been living with the condition as far back as the 1970s. All had attempted to seek treatment and failed, and most believed that their condition could not be cured; many still were deeply skeptical that the surgery would be of any benefit. After transport to the hospital in a packed bus over crumbling roads, the 15 patients who returned to the clinic were checked in and screened to clinically confirm they have fistula and to evaluate the extent of the damage. In Dr. Constantine's experience, Uganda seems to suffer a different kind of fistula than countries such as Chad or Nigeria. In those latter countries, fistulas have slightly less extensive damage, as the mother either survives the obstruction without having skilled medical care present or she dies in the prolonged labor. In Uganda, a woman with obstructed labor is usually able to eventually get to a hospital, but arrives too late. The attending doctors are focused on saving the mother's life, and in the process of removing the dead fetus, the tissue damage associated with the fistula is often made more severe. As a result, it requires a surgeon with extensive experience to cure these cases of fistula, and often the damage has been so extensive that surgery is not possible, and only palliative care and patient counseling is feasible.

Three weeks after their surgery, 12 of the 15 women treated by Dr. Constantine, Dr. Alfonso, and the staff of Kamuli Mission Hospital were confirmed to have successfully had their fistula closed. The lengthy follow-up time is necessary due to the need for bladder catheterization while the sutured tissue heals. The remaining three patients, with more extensive scarring and tissue damage, will be seen at a subsequent camp when more time will be available to give them attention. Although those who return home dry will still need time to re-adjust and re-integrate their lives into the local community, in time they will be able to live far different lives from the ones that preceded their surgery.

Although facilitating access to surgery has the capacity to drastically improve the lives of women living with obstetric fistula, it only treats the symptoms of a far larger public health problem. Fistula is an entirely preventable condition, reflected in the fact that it effectively does not exist in the developed world. Nevertheless, new cases of fistula occur on a daily basis in places such as Uganda, and it is unlikely that a surgical solution will ever be able to keep up with the growing number of cases. That fistula keeps occurring is the result of myriad contributing factors, including poverty; a low status of women; childhood malnutrition and disease, which restricts pelvic growth; an early age of first pregnancy, when pelvic growth is in-

complete; poor education regarding maternal health; lack of access to facilities that offer cesarean section; and lack of transportation to a hospital in case of an obstetrical emergency. There are also cultural barriers to receiving proper obstetrical care, as there can be significant social stigma attached to receiving a cesarean section, as well as a preference for delivering with traditional birth attendants and avoiding the unpleasant and abusive labor practices often regarded to be prevalent in medical centers. Even though a traditional birth attendant may refer an expectant mother to a hospital if she anticipates complications, the preference for avoiding health centers or hospitals may be so strong that the mother will merely seek out another birth attendant with whom to deliver. All of these issues must be addressed in order to prevent obstetric fistula and reduce maternal mortality. Much of the focus of tackling the obstetric fistula problem has centered on its surgical treatment, but the scourge of fistula will only disappear once significant, systematic efforts are made in promoting its prevention.

Of the woman we found hunched over under a banana tree, I last saw her recovering in the bed of the post-surgical ward at Kamuli Mission Hospital. She had a haggard look in her eyes, and her hand was warm and moist. The pain from the operation and the catheter was evident, but her voice danced with vitality. Small breezes whisked the curtains of the ward, bringing in lush and earthy scents. Twelve women from Iganga now had the opportunity for a new life, but it seemed a mere drop taken from an impalpable and gluttonous ocean. My thoughts wandered through the villages, over the dusty streets, and across the mighty landscape, where remain the vast hosts of the victims of obstetric fistula.

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