General Clinical Practice

The Fistula Crisis in Sub-Saharan Africa: An Ongoing Struggle in Education and Awareness

Linda Narcisi, Andrew Tieniber, Leslie Andriani, Timothy McKinney

Urinary incontinence (UI) afflicts about 30% of women over the age of 45 in first world countries (Minassian, Drutz, & Al-Badr, 2003). A correlation between age and UI shows this condition is more likely to appear in elderly individuals or in those with exposure to a certain number of risk factors. However, there are surprisingly higher rates of young women in Africa suffering from UI (see Figure 1). While these exact rates are not known, more than two million women in third world countries suffer from UI, and most of these women are under the age of 30. The primary cause of UI among this population is obstetric fistula.

Obstetric fistula is a medical condition of the past in first world countries. Prior to the emergence of gynecology as an independent specialty in the early 20th century, women living in first world countries often suffered from complications during childbirth. Unlike today, where it is rare to give birth at home, it was commonplace in the U.S. during the 19th century to give birth at home without much more medical supervision than a midwife. As a result, obstructed labor was a frequent occurrence, and obstetric fistula rates were high in the U.S. During this time, surgeons such as Dr. J. Marion Sims, who is considered the Father of Gynecology, began formulating surgical operations to reverse the damage of obstructed labor (Ojanuga, 1993).

At the turn of the 20th century in the U.S., women began giving birth in local hospitals rather than at home; consequently, rates of obstructed labor and obstetric fistula rapidly decreased. Today, in the U.S. and other modern countries, obstetric fistula is a condition of the past; however, this is not the case in many sub-Saharan countries, including Niger (Wall, 2006).

While numerous countries have ghastly high rates of obstetric fistula, Niger has the highest fertil-
Early Marriage Breeds Early Health Problems

In the sub-Saharan region, young girls shortly after their first menstrual period are married to older men, who are typically strangers. These girls are arranged to be married between the ages of 9 and 15, the average age in Niger being 15. This time frame is believed to be ideal because it almost guarantees that a girl is a virgin on her wedding day, a very desirable quality to men in this region (UNFPA & EngenderHealth, 2003). While it may seem as if this cultural practice is the sole reasoning for the young ages of married girls, poverty and mass starvation in the sub-Saharan region of Africa have necessitated these marital practices.

A girl is regarded as a financial burden to her family; therefore, it is advantageous for families to agree to have their daughter married in exchange for a dowry. This marriage, which is more of a financial transaction, gives families one less mouth to feed and helps with finances, while the young girl is hoped to have a better life under the protection of her new husband.

As a result, more than half the girls in Niger have their first, and in many cases, their only pregnancy before the age of 16 (Lendon, 2001). The unfortunate combination of youth and malnutrition often results in an under-developed pelvis. This leads to complications during labor, such as cephalopelvic disproportion (CPD). CPD is a condition caused by the physical constraints of a narrow pelvis; thus, the fetus may fail to progress and becomes stuck after the head has descended into the birth canal. The most common way to manage this condition is by performing a cesarean section; however, 85% of Nigerien women give birth in thatched huts, unassisted by trained medical personnel and miles away from any medical facility that could perform this operation. The pressure from the prolonged positioning of fetus’ head inhibits circulation to vaginal tissue, causing necrosis. This creates a fistula into the bladder, bowel, or both, depending on the location of the prolonged pressure.

The fistula is classified as either a vesicle vaginal fistula (an abnormal opening of the vagina into the bladder) or a rectal vaginal fistula (an abnormal opening of the vagina into the bowel), depending on its location. The size of a fistula is determined by the amount of necrosis created during labor. Fistulas are characterized by size and location; however, there is no standard classification, thus comparisons of observed fistulas and the success rates of fistula repairs from one hospital/region to another are not

### Table 1. Understanding the Context

<table>
<thead>
<tr>
<th>Country</th>
<th>Total Fertility Rate (2000-2005)</th>
<th>Mates and Mortality (Deaths per 100,000 Live Births)</th>
<th>Infant Mortality (Per 1000 Live Births)</th>
<th>Percentage of Births with Skilled Attendants</th>
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<td>128</td>
<td>44</td>
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<td>Niger</td>
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<td>126</td>
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<td>42</td>
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<td>Uganda</td>
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<td>Zambia</td>
<td>5.66</td>
<td>870</td>
<td>80</td>
<td>47</td>
</tr>
</tbody>
</table>

Source: Adapted from UNFPA & EngenderHealth, 2003. Used with permission.

The physical constraints of the young, narrow pelvis and lack of proper medical attention during labor mean these young mothers endure labor that lasts on average between three to four days (Nathan, Rochat, Grigorescu, & Banks, 2009). One patient explained that her birthing experience was in a thatched hut assisted by older family members. “Since it was my first, they said it is normal for this to take a long time. When they realized it wasn’t going as planned, they tried to find a car, but couldn’t, so I went on a donkey cart. The trip took a whole night” (McKinney, 2006).

In the U.S., the average duration of labor for a first-time mother is 12 to 18 hours, one-fifth of the time for a mother in Niger. Such a perilously prolonged labor is caused by the physical constraints of a narrow pelvis; thus, the fetus may fail to progress and becomes stuck after the head has descended into the birth canal. As a result, more than half the girls in Niger have their first, and in many cases, their only pregnancy before the age of 16 (Lendon, 2001). The unfortunate combination of youth and malnutrition often results in an under-developed pelvis. This leads to complications during labor, such as cephalopelvic disproportion (CPD). CPD is a condition caused by the physical constraints of a narrow pelvis; thus, the fetus may fail to progress and becomes stuck after the head has descended into the birth canal. The most common way to manage this condition is by performing a cesarean section; however, 85% of Nigerien women give birth in thatched huts, unassisted by trained medical personnel and miles away from any medical facility that could perform this operation. The pressure from the prolonged positioning of fetus’ head inhibits circulation to vaginal tissue, causing necrosis. This creates a fistula into the bladder, bowel, or both, depending on the location of the prolonged pressure.

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always possible (Creanga & Genadry, 2007). The pressure not only creates an abnormal pathway between organs, but the prolonged inability to expel the fetus also causes fetal death 85% to 100% of the time (Ahmed & Holtz, 2007; Wall, 2006; Zheng & Anderson, 2009). Only when the fetus dies and becomes emaciated will the mother be successful at delivering her dead baby vaginally.

Consequences of a Fistula

In Niger, 1100 in 100,000 births result in a maternal death. For those who survive and develop a fistula, their futures are not much brighter (UNFPA & EngenderHealth, 2003).

Social Factors

In lieu of carrying their newborn after giving birth, women carry the burden of being an embarrassment to their husband and community. Sub-Saharan cultures view children as a measure of a family’s wealth and as economic assets. Therefore, a woman’s self-worth and value are directly correlated to her ability to produce healthy children. If a woman fails to successfully produce multiple children, she and her family are viewed as socially and financially inferior (Roush, 2009). In addition to failing to serve as a mother, women suffering from obstetric fistulas are often prohibited from performing daily chores, such as cooking and cleaning, and participating in social activities and religious rituals due to their smell and trail of urine and feces. Unable to fulfill the role of a mother or perform the characteristic duties of women, sufferers are often isolated from their families and communities.

Due to the extremely limited knowledge about obstetric fistulas, stigmas regarding this condition add to the emotional pain. Fistulas are commonly believed to be caused by witchcraft or evil spirits, venereal disease, and even punishment from God for sexual misconduct (Roush, 2009).

Additionally, many sub-Saharan countries are primarily Islamic, a faith that emphasizes the importance of cleanliness. The rural areas in which these women live are usually far from water, and frequent washing is not possible. Unable to maintain their hygiene, these women are often prohibited from attending religious services.

Engulfed by the stench of waste, these wives are no longer desirable to their husbands because they cannot perform womanly duties or satisfy their husbands sexually. While some women remain married to their husbands, most become separated and are no longer welcomed in their homes. Additionally, Roush (2009) states that divorce rates post-labor increase since the condition becomes long-term (two years or longer); Roush cites one study with a divorce rate as high as 89%. While some families and husbands remain supportive, women are more likely to be ousted from their homes and communities over time because of their stench and growing stigmas.

Psychological/Emotional Factors

Along with the great physical damage of fistulas comes severe psychological and emotional consequences. While there are very few studies that analyze the mental status of women suffering from fistulas, all show common trends. Depending on the sample population, infant mortality ranges from 85% to 100% (Ahmed & Holtz, 2007). Countless women are often devastated and tormented by the loss of their child. Additionally, they reportedly feel humiliated, depressed, and anxious, and have low self-esteem because of their stench and inability to perform the role of a woman or wife (Ahmed & Holtz, 2007).

Barriers to Care

Outcasts from society, these women are left hopeless and penniless in search for help. They tend to form small communities with other women plagued with urinary and fecal incontinence. Alone and without protection, most women begin their journeys to medical centers on foot through the sub-Saharan environment where their odor serves as a target for hungry wildlife. For the lucky few who are able to find transportation to a medical facility and are given permission from their husbands to use funds, it costs on average of $14.07 (U.S. dollars), which is 5.2% of their average annual income. This means the average income for these women is a mere $280 (U.S.). This trip takes a lengthy 11 hours and 52 minutes on average (McKinney, 2006).

Combating the Fistula Crisis

Numerous hospitals have been established throughout the sub-Saharan to battle the ongoing fistula crisis. Institutions, such as the Zone Hospital of Tinguiéta, the National Hospital and University Centre, and the Evangelical Hospital of Bemberéke, have been established in Benin. While fighting the fistula crisis, most of these hospitals are very limited in the realm of prenatal care. For example, in the Evangelical Hospital of Bemberéke, prenatal care staff includes one expatriate obstetrics and gynecology (OB/GYN) physician who volunteers three or four months a year, one person with a nursing certificate, and seven informally trained hospital workers (UNFPA & EngenderHealth, 2003). In some countries, such as Ethiopia, activists have really taken charge in fistula repair and prevention. In 1974, Drs. Reginald and Catherine Hamlin founded the Addis Ababa Fistula Hospital, now the largest fistula repair center in the world (Zheng & Anderson, 2009). Overall, the progress in most other sub-Saharan countries, such as Niger, has not been as profound. As one of the worst fistula-stricken countries in the world, its case demands a closer look.

Currently, there are only two medical centers in Niger willing and able to perform corrective surgeries for fistulas. Doctors and nurses from around the world volunteer at these hospitals and provide hope for those who suffer the
horrific repercussions of young pregnancy. Traveling annually to Niger, as well as other sub-Saharan countries listed in Table 1, these individuals operate on many of these unfortunate young women.

At first, many physicians experience culture shock when observing the discrepancy between health care in developed and developing countries. For instance, Dr. McKinney describes one of his first fistula repair surgeries: “An example of what we needed to understand was with anesthesia...we used epidural/spinal anesthesia on most of these patients. When the spinal wore off, they wouldn’t let us know, didn’t move, didn’t scream or complain. Fortunately, I looked at the patient every few minutes, and now, we assign an interpreter to them during the surgery. But that first patient, I just saw a little tear on her face and that was all to let me know she was in pain” (McKinney, 2006). These types of obstacles are easily overcome by gaining a full understanding of local cultures and their social cues.

Physicians who travel to fistula repair centers take pride not only in their ability to cure women of this horrific condition, but also the opportunity to share their surgical and pre/post-operative care knowledge. Typically, a mission trip will begin with giving lectures and performing surgeries for local surgeons to observe. Over time, the local doctors begin to assist and perform surgeries until they are deemed self-reliant. “When first arriving we found out that there were only six surgeons qualified to learn to perform fistula repairs in all of Niger. Three actually participated in my first mission. One of the doctors, Abdoulaye, after several years working with the government, was permanently assigned to the women’s center at the National Hospital. This represented the turning point in the mission work. Niger could function independently from International Organization for Women and Development (IOWD). We also worked with the nursing staff and anesthesiologists to create a complete team” (McKinney, 2006). One mission trip is never long enough to help make a local hospital fully capable to perform repair surgeries without aid from foreign doctors; thus, physicians and nurses often participate in many mission trips.

In addition to limited equipment available for each surgery, fistula repair is considered extremely difficult because each patient is plagued by a unique fistula and is very prone to post-operative infection. Due to lack of trained surgeons and scarce medical facilities, many young women are treated by insufficiently trained doctors and midwives, many still using ancient home remedies. On one of Dr. McKinney’s trips to Niger, a woman presented with a third-degree burn of the perineum. She was told to put two steel rods into the fire, and when they became hot, she was told to remove them and sit on them (see Figure 2). This is just one example of the desperate measures taken by some of these young women to find a cure from incontinence and regain acceptance into their families and communities.

Physicians and other individuals donate their time and skills to those in need by working with organizations (for-profit and nonprofit) that make frequent trips to these hospitals. Timothy McKinney, as well as about 100 other individuals, travel to Niger and Rwanda with IOWD, a nonprofit/volunteer organization. This organization runs four to five missions per year to provide relief to those suffering from fistulas in Western Africa. Over 1000 women have received corrective surgeries performed by IOWD group members, and thousands have been evaluated at no cost. The average cost of these corrective surgeries ranges from $100 to $400 (U.S.), and many organizations offer these services free of charge (Nathan et al., 2009). Surgeons and nursing/medical volunteers have joined forces to produce an amazing 91% success rate on primary fistula repair. Patient conditions are evaluated and classified from Stage 1 to 4; a Stage 1 fistula indicates a hole of about 1 cm in diameter, and a Stage 4 fistula indicates a 6 cm hole involving the urethra or trigone area of the bladder. As the stage of severity and number of previous surgeries (performed by

![Figure 2. Third-Degree Burns from a Woman Who Used Two Metal Rods in Attempt to Cure Her Incontinence as Recommended by “Tribal Medicine Man”](image_url)
insufficiently trained doctors and midwives) increases, success rates of initial operations drop, thus multiple surgeries must be performed to restore full continence. Some programs only offer one fistula repair per patient; however, others open their doors to patients for a second, third, and even fourth time to perform more difficult repairs (McKinney, 2006).

Many organizations take a holistic approach to rehabilitation by providing psychological counseling for those suffering from depression and loss of self-esteem. Through education on how and why fistulas form, patients are relieved of their fear that their condition was a punishment from Allah. Roush (2009) suggests supplying women with occupational training. Various organizations have already been doing this and have provided instruction for sewing, jewelry making, drip irrigation gardening, and needlepoint. These workshops ensure an easier reintegration process because not only can these women perform daily tasks again, but they also have special skills allowing them to contribute to society.

While corrective surgeries are helping those affected today, there is still much to do to prevent this from being a problem of tomorrow. Many organizations provide training for native nurses so they can perform emergency Cesarean sections, a much safer alternative to vaginal delivery if the pelvis is under-developed. These nurses, or midwives, are specially trained in programs such as Problem Solving for Better Health Nursing, which develops a problem-solving ability useful in home birth situations outside the realm of first world technology. The presence of trained nurses decreases the rates of obstructed labor and fistula development, as well as the rates of maternal and fetal death (McKinney, 2006).

**A Preventable Tragedy**

It is estimated that nearly two million women suffer from obstetric fistulas worldwide. While corrective surgeries are helping some of those affected today, there is still much to do to prevent thousands more from facing the same fate. Since the cultural marriage practices of afflicted countries are so deeply rooted, only education and better accessibility to proper medical help will ameliorate the negative effects of young pregnancies.

Despite promising initiatives, the Nigerien government has not been able to establish the budget required for women’s health care and education. Conversely, the Rwandan government has made prenatal care a priority and is a prime example of how cooperation between government, education, and communities can ameliorate this condition. In the spring of 2005, the Rwandan government founded the Inshuti Mu Buzima, or the Partners in Health Organization. The Partners in Health Organization formed a partnership between many existing public and private organizations, such as the Rwandan Ministry of Health and the Global Fund to Fight AIDS. This organization provides and strengthens the country’s awareness and treatment of HIV, as well as tuberculosis treatment, primary care, prenatal care, family planning, malnutrition programs, and emergency obstetrical care. The program also has social services, which provide important information for the remaining healthy post-operative patients. This combination of prenatal, obstetrical, and post-operative care is a progressive model other countries can implement to accommodate the growing health crisis (Partners in Health Organization, 2010).

In countries where women’s health is not a governmental priority, it is imperative that volunteer organizations promote the benefits of delaying pregnancy and family planning. Culturally sensitive campaigns explaining the health risks of young pregnancies, and thus, lower rates of obstetric fistulas. Additionally, it is necessary to stress the importance of modern medical care during pregnancy to avoid complications. While cultural practices regarding pregnancy and child birth must be respected, the importance of modern medical care must be emphasized. Educating midwives and others in the community about signs and symptoms of complications during pregnancy will ensure that women have safer pregnancies and labor in the future. Furthermore, increasing awareness of fistula risk factors and causes will help improve fistula stigmas. While trained attendants during home birth are important, it is just as important for women to have the option to deliver in a professional medical center. Though this is not always possible today due to individuals’ financial constraints and the scarcity of ambulances and other vehicles, transportation of women in labor needs to become a priority of local medical centers.

By stressing these educational concepts to young mothers and local governments, the fistula crisis in the sub-Saharan region of Africa could become an issue of the past, as it will be in the foreseeable future of Rwanda. Though there is still much to do to ensure that all future mothers in Niger and any third world nation can safely deliver their children, many windows of opportunity have been opened by various organizations that are fervently working towards the empowerment of African women and making their health a priority.

**Getting Involved**

Nurses, anesthesiologists, and those in the field of OB/GYN and uro-gynecology who are interested in participating in mission trips are encouraged to contact any of the organizations in Table 2. For those who cannot leave the country for mission trips or do not have medical degrees, the best way to get involved is to bring awareness to this crisis. Organizations, such as The Fistula Foundation and One By One, encourage individuals to host...
informational gatherings, called Giving Circle and Circle of Friends events, to spread knowledge of the fistula crisis. Aside from participating in mission trips, bringing awareness to this crisis is the best way to help ameliorate this crisis in the future.

References


Additional Reading

### Table 2. Volunteer Organizations

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<td>Fistula Care at EngenderHealth</td>
<td><a href="http://www.fistulacare.org/pages/index.php">http://www.fistulacare.org/pages/index.php</a></td>
<td><a href="mailto:fistulacare@engenderhealth.org">fistulacare@engenderhealth.org</a></td>
<td>Phone: 212-561-8000</td>
<td>Fistula Care at EngenderHealth 440 Ninth Avenue 13th Floor New York, NY 10001</td>
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<td>Physicians for Peace</td>
<td><a href="http://www.physiciansforpeace.org">http://www.physiciansforpeace.org</a></td>
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<tr>
<td>One By One</td>
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<td><a href="mailto:info@lightfistula.org">info@lightfistula.org</a></td>
<td>Phone: (206) 297-1418 Fax: (206) 374-3010</td>
<td>One By One 4041 Roosevelt Way NE Suite C Seattle, WA 98105</td>
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<td>The Worldwide Fistula Fund</td>
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<td>Online contact form available on web site under “contacts”</td>
<td>Phone: (314) 991-6955 Toll-Free: (866) 991-6955</td>
<td>Worldwide Fistula Fund PO Box 27879 St. Louis, MO 63146-1379</td>
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