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FEMALE GENITAL MUTILATION/ CUTTING: HEALTH PROVIDERS SHOULD BE ADVOCATES FOR CHANGE

About
3
MILLION
girls globally undergo
cutting every year.

507,000
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More than 125 million girls and women globally are living with female genital mutilation/cutting (FGM/C) and an estimated 3 million undergo such procedures every year. The World Health Organization defines FGM/C as “all procedures involving partial or total removal of the external female genitalia or other injury to the female genital organs, whether for cultural or other nontherapeutic reasons.” It is a tradition that transcends socioeconomic status and geography; it is performed in some Islamic communities, but has no religious basis. From unknown origins, the practice survives today, often reinforced by customs and beliefs regarding marriageability, rites of passage, maintaining girls’ chastity, hygiene, preserving fertility, and enhancing sexual pleasure for men. Girls usually undergo FGM/C between the ages of four and 12, although it is performed at birth and immediately before marriage in some regions. Minimal or no anesthesia is used and antiseptics are rare.

The immediate and long-term health complications of FGM/C mean a lifetime of suffering for these girls and women. The health risks depend on the severity of the procedure, the practitioner’s skill, the instruments used, and postoperative care. Immediate complications include infection, sepsis, urinary retention, hemorrhage, shock, and even death. Long-term complications, seen predominantly in women who have undergone Type III (removal of all external genitalia and suturing of remnant tissue), include cysts, abscesses, recurrent infections, pain, labor complications, and post-traumatic stress disorders (PTSD). Curative measures include medical treatment as well as surgical excision of infections and reconstructive surgery of the scar. Accurate and effective defibulation, the surgical reconstruction of the infibulated scar, has been proven to relieve and even resolve women’s long-term complications and ensure them safer labor and delivery. However, it requires specialized

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Committed to the eradication of FGM/C, she travels throughout the country conducting workshops to educate African refugees and immigrants on the medical complications and legal issues of this practice. She served on an FGM/C task force for the American College of Obstetrics and Gynecology (ACOG) and was the primary author of *Female Genital Cutting, Clinical Management of Circumcised Women*, published by ACOG.

Dr. Nour was honored as a 2003 MacArthur Foundation Fellow for creating the country’s only center of its kind that focuses on both physical and emotional needs of women who have undergone FGM/C.

Born in the Sudan and raised in Egypt and England, Dr. Nour received her medical degree from Harvard Medical School in 1994 and completed a chief residency in obstetrics and gynecology at the Brigham and Women’s Hospital in 1998. She obtained her M.P.H. at Harvard School of Public Health in 1999.

training. This paper will make a case for the critical role of health care providers in treating girls and women who have undergone FGM/C and in protecting others from this harmful tradition.

The Scope of the Problem

When the African Women's Health Center (AWHC) first commissioned a study based on the 2000 U.S. Census, they found that approximately 228,000 women and girls living in the United States have either undergone or are at risk of FGM/C. The "at-risk" number reflected a staggering increase of approximately 35 percent from the 1990 census estimate. New numbers being released by the Population Reference Bureau on Feb. 6th, 2015, reveal that 507,000 girls and women in the United States today have either undergone or are at risk of FGM/C. These growing numbers demonstrate that U.S. health providers will be examining more patients with FGM/C. Though some hospitals and health centers in the United States have created a culturally and linguistically competent environment for women with FGM/C, these still do not meet the needs of this population. More often, women with FGM/C have received poor-quality care, which understandably creates an environment of distrust towards our health care system. Women with FGM/C are not only likely to experience inappropriate encounters with health providers, but they are also subject to disparities in care, with lower rates of mammograms, pap smears, vaccinations, and family planning services. If medical interpreters are used, evidence-based preventive medicine is more consistently applied.

To highlight these issues, consider the stories of several patients who eventually sought care at the AWHC. These women's names have been changed to protect their privacy.

Najat was a 26-year-old woman who came to the emergency room with abdominal pain. During the physical examination, health providers discovered that she had undergone FGM/C. They were not sure what type or whether this was the cause of her abdominal pain, but because it was a teaching hospital, medical students, residents, and nurses were brought in to "evaluate" her genitalia and learn about FGM/C. Not only was Najat humiliated and left the hospital vowing never to return, she was not treated for her abdominal pain. Had the providers spent time talking with her, they would have learned that she was gang-raped as a teenager in Somalia; her exposure to a group of strangers horribly revived that experience. Her case demonstrates not only a lack of medical knowledge in identifying the type of FGM/C, but a failure to collect a complete history that might have helped them reach an accurate diagnosis: PTSD after sexual violence. The health providers inadvertently succeeded in discouraging her from seeking access to future health care.

Layla visited an obstetrician in her first trimester excited about her first pregnancy. During the examination, providers found infibulation—a scar that covers most of her external genitalia,

with a small hole allowing the passage of menses and urine—evidence that she had undergone Type III FGM/C. At the end of the visit, the obstetrician informed Layla that giving birth would be risky and that she needed an abortion. Though abortion was against Layla's religion, given the grave concerns of the obstetrician, she was convinced to undergo the procedure. Layla regretted this decision, as she discovered later that her scar could have been operated on during her second trimester or at the time of her delivery. Lacking the medical and surgical knowledge to care for Layla, this health care provider's only advice was an unnecessary abortion.

Samia was pregnant and, like Layla, had undergone infibulation. This condition was a great concern to her obstetrician, who told her that delivery would require a caesarean section. It is not uncommon for infibulated women to undergo unnecessary caesarean sections in the United States. Most health providers lack the awareness, knowledge, and understanding of the medical, surgical, and cultural management of women with FGM/C. Studies throughout the Western world have consistently demonstrated that unless providers take the initiative to learn about FGM/C themselves, their knowledge is lacking. Health providers need extensive training on the immediate and long-term complications, and the medical and surgical management of the various types of FGM/C.

United States Law

In 1996, the United States passed 18 U.S. Code § 116 on female genital mutilation, which states in part, "whoever knowingly circumcises, excises, or infibulates the whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years shall be fined under this title or imprisoned not more than 5 years, or both." It also required the Department of Health and Human Services (HHS) to both compile data on FGM/C and to engage in education and outreach to relevant communities. The law directs the Immigration and Naturalization Service to provide information to all nonresidents issued U.S. visas on the health and psychological effects of FGM/C, as well as its legal consequences under criminal and child-protection statutes. At the time the law was enacted, we at AWHC actively participated in outreach and community building, as well as education regarding the law and its consequences. Communities were both surprised and relieved that HHS had made a concerted effort to inform them. To date, there has only been one conviction of FGM/C in the United States.

Numerous attempts have been made to introduce the Girl Protection Act, which would add an extra-territorial component to the law. In January 2013, the federal criminal code was amended "to impose a fine, up to a five-year prison term, or both for knowingly transporting a girl under the age of 18 from the United States and its territories in foreign commerce for purposes of female genital mutilation."

The AWHC conducted outreach in Boston and found that this amendment was seriously misunderstood. Some people mistakenly believed that the original law already incorporated an extra-territorial component, while others were confused about why an amendment was even necessary. But it is thought that some girls are still being taken to their home countries in order to undergo FGM/C and then returned to the United States—a phenomenon known as “vacation cutting.” If this practice is indeed happening, outreach is just as vital as it was two decades ago to educate and engage communities regarding the new amendment and its ramifications. The media and nongovernmental organizations have become more aware of this possibility, but no cases have yet been reported to the authorities.

Significant challenges lie ahead. We must determine whether, how, and to what extent FGM/C and vacation cutting are still happening in the United States. Collection of data will be difficult, given its clandestine nature. In addition, the law is not clear on who should be reporting these cases. Some suggest that reporting should be mandatory among pediatricians, social workers, emergency medical technicians, school nurses, school counselors, police, and immigration officers. As a health provider who has been working hard to maintain access to care for this population, I believe strongly that it would be difficult to make the health system primarily responsible.

In addition, although the data on how many girls and women have undergone and are at risk of FGM/C have been updated, these numbers are still estimates—based on the prevalence of the practice in the country of origin. FGM/C is not done uniformly in a particular country; it depends on the region, ethnicity, and how quickly this practice is being abandoned. The data do not take into account from which region of a country a woman comes. In addition, census data collected every 10 years may not reflect changes in beliefs regarding this practice among immigrant populations. Achieving better data will require improved recordkeeping and coding by health providers, better surveys that capture the countries and regions of birth and the girl’s length of stay in the United States, and sensitive evaluation of changes in attitudes that influence this population. With such detailed data, health providers can tailor clinical treatment to the patient as an individual.

The Role of Medical Societies

In the 1990s, medical associations such as the American Medical Association, the American Academy of Pediatrics (AAP), the American College of Obstetricians and Gynecologists (ACOG), and the Institutes of Medicine published policy statements against FGM/C. ACOG developed and distributed a slide-lecture kit (and subsequently a DVD) on the clinical management of FGM/C to U.S. medical schools and residency programs. Some medical schools, midwifery schools, nursing schools, and residency programs have incorporated FGM/C into their curricula. But these efforts are sporadic and not always consistent from year to year. In an attempt at cultural sensitivity, in 2010 the AAP updated its policy statement

but emphasized that, “It might be more effective if federal and state laws enabled pediatricians to reach out to families by offering a ritual nick as a possible compromise to avoid greater harm.” This policy statement came as quite a shock to the health providers, activists, UN organizations, and policymakers who had been working toward the abandonment of the practice. AAP’s board of directors voted to retire the new policy, stating that it “does not endorse the practice of offering a ‘clitoral nick,’ ” and agreeing that it was “forbidden under federal law and AAP does not recommend it to its members.”

Medical societies must be held responsible for upholding the highest ethical standards through working closely with communities who have undergone FGM/C in order to help improve their medical care. The dictum “First, do no harm” must be applied in the broadest possible humanitarian and cultural sense, as well as clinically and surgically. Thus, health providers need training not just in school but also during their continuing medical education. Providers must understand the fundamental reasons why FGM/C still occurs, where it occurs, why parents choose to cut their daughters, and ultimately how to provide patients with excellent care that is imbued with compassion but free of judgment. Creating educational handbooks, a website, and even laminated pocket cards are some simple solutions; however, training with culturally competent providers allows for in-depth understanding and discussion. Otherwise, our health care delivery will continue to enforce our ethnocentric cultural values, stigmatizing our patients, and relegating them to substandard care.

Conclusion

As a threat to the health and basic human rights of girls and women, FGM/C violates all bioethics principles and must be stopped. However, girls and women in the United States who already suffer the long-term complications of FGM/C deserve both respect and the highest quality of health care possible. Our providers need the skills, knowledge, support, and tools to enable them to provide such care. Better adherence to evidence-based medicine ensures consistency of care for this population, regardless of ethnicity, language, or insurance coverage. Gaps in research remain that need to be remedied to further improve the care we give women with FGM/C.

The AWHC plays two important roles: providing both holistic care and a haven for women who suffer the health consequences of this practice; and offering state-of-the-art academic training for health providers in culturally and linguistically competent care for this vulnerable population. Health providers must play a larger role in advocating to stop FGM/C, informing patients about the health and legal consequences of FGM/C, and finally, understanding the long-term complications and best practices to resolve them. Until our success is reflected in future generations of healthy girls free of FGM/C, we must continue to support and care for those who are still suffering its consequences.

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The African Women's Health Center (AWHC) provides appropriate health and outreach programs to the African community in Boston. Founded in 1999, AWHC, located at Brigham and Women's Hospital, ensures access, understanding, and community to women who have long-term complications from FGM/C. It provides culturally and linguistically appropriate obstetric, gynecologic, and reproductive health care via a collaborative team-based approach that includes obstetricians, gynecologists, nurses, midwives, medical interpreters, nutritionists, social workers, and when needed, psychiatrists. The overall mission is to holistically improve the health of refugee and immigrant women who have undergone FGM/C and inform them of best practices, the importance of well-visits, and clear, accurate information about their anatomy.

Contact the AWHC at: africanwomen@partners.org.

Resources

Charlotte Feldman-Jacobs, *Ending Female Genital Mutilation/Cutting: Lessons From a Decade of Progress* (Washington, DC: Population Reference Bureau, 2014).

Charlotte Feldman-Jacobs and Donna Clifton, *Female Genital Mutilation/Cutting: Data and Trends Update 2014—DataSheet* (Washington, DC: Population Reference Bureau, 2014).

Female Genital Mutilation/Cutting: Data and Trends Update 2014—DataSheet, accessed at www.prb.org/pdf14/fgmc-infographic.pdf.



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