

Good morning. My name is Nawal Nour. I come before you this morning as a Sudanese/American, an obstetrician-gynecologist, a public health practitioner and as the founder and director of the African Women's Health Center at the Brigham and Women's Hospital in Boston. I am delighted to join this distinguished panel of pioneers who are working to stop FGC.

Let me begin by telling you the story of one of my patients.....

Nafisa was a recent arrival in the United States. She was a 22 year old woman from Somalia who went to the Emergency Room in a NYC hospital complaining of persistent nausea and vomiting. The health providers there became distracted by a scar that covered her vagina, and brought in male and female medical students and residents to examine her. Humiliated by the experience, she felt that in time, they might refocus on her nausea. Fighting her tears, she lay there while strangers 'examined' her. She saw their shocked and their horrified faces. "Why were they doing this to her?" she thought, "Shouldn't she feel safe in the United States?"

Nafisa came to me about a year ago. She had undergone the traditional circumcision when she was a child. Somalis perform the most severe form, Type III, also known as the Pharoanic type or infibulation. Her external female genitalia were cut off and the remaining edges were sewn together, obstructing her urethra – where urine passes and her vagina where menstrual blood flows. A small opening was left for these fluids to drip through.

The health providers failed to elicit a critical part of Nafisa's medical history. Back in her home village, during the height of the Somali war, Nafisa hid in her home with her younger sister. Five men stormed her home while her parents were out, and they attempted to rape her. Because of her scar, they were unable to penetrate and in haste, they slit her scar open with a knife. She was subsequently gang raped by all five men. Her sister was not as fortunate - after she was raped, they killed her. In shock, Nafisa dragged herself to the nearest clinic so that they would stop her hemorrhage, only to be dismissed. She was not as emergent as other cases that were coming in. She never found her parents, and a kind neighbor cared for her until she was strong enough to reach Mogadishu, the capital and in time, arrive in NYC.

For Nafisa, having health providers examining her in that manner created more damage than they realized. Nafisa never returned to a doctor until she came to Boston one year later and her abdominal pain resolved on its own. We diagnosed her with post-traumatic stress disorder and depression. When assessing her feelings about being circumcised, she responded much like the rest of my patients: it hurt more the day after she was circumcised, all her female friends and family members underwent infibulation, and no, she was not upset with her mother for cutting her – but rather, she loved and missed her mother very much. It was the rape that traumatized and made her feel like a victim.

Over 130 million women worldwide have undergone FGC and over 168,000 females in the United States have either undergone or are at risk for this procedure. In March 1997, FGC became a federal crime in the United States. Racial and ethnic demographics here are rapidly shifting. Escaping from famine, war and political instability, immigrants and refugees are entering the United States in higher numbers than ever before. At least 80 percent of the African women come from countries where the tradition of FGC is practiced. Because of this influx, health care providers are increasingly seeing women who have undergone FGC and must have better understanding of the health and cultural issues surrounding it.

The African Women's Health Center, which I direct, is located at the Brigham and Women's Hospital in Boston. The overall mission of the Center is to holistically improve the health of refugee women who have undergone female genital cutting. The Center provides culturally and linguistically appropriate obstetric, gynecologic and reproductive health care to meet their needs. Patients are predominantly from Somalia, Sudan and Ethiopia and approximately 90 percent of them have been circumcised. It also performed reconstructive plastic surgery reconstruction of the most painful and debilitating scars.

Women who have undergone female genital cutting worry that practitioners lack the experience to provide quality care. They have expressed dissatisfaction with their care. And in cases, like Nafisa's they are right. Practitioners, on the other hand, request skills necessary to approach and care for these patients. The fears these patients voice and the concerns that providers express are similar nationwide.

With funding from HHS – ORR and OWH, the Center addresses both sets of concerns. We have been conducting two-day reproductive health workshops throughout the United States. These workshops ultimately aim to improve the health of refugee women who have undergone female genital cutting. The two-day workshops are designed to focus on educating two populations. The first day is devoted to teaching refugee women on issues involving access to healthcare, reproductive health, childcare, and female genital cutting. The second day focuses on educating health and services providers on how to give culturally and linguistically competent care to women who have been circumcised. In the end of the two days, the two groups join together to find ways of improving communication, access to health and elevate the overall quality of care to circumcised women.

The question that is constantly being posed to me by health providers is, "Why do these parents do this to their daughters?" The majority of these parents are not doing this *to* their daughters, but rather, *for* their daughters. This tradition transcends all religions, socio-economics status and geography. Girls who are uncircumcised can be shunned by their community. They are labeled as being filthy and undesirable. Parents fear that they may never marry. In some communities, marriage and motherhood are a woman's career. By not circumcising their daughters, they feel they have done them a great disservice. Others perform this practice in order to be 'good Muslims'. They circumcise their girls because they believe it is 'sunna' (sanctioned by the Prophet Mohammed). Although this tradition predates Islam and was never mentioned in the Koran, this

misinformation has been passed down through many generations. Still others circumcise their daughter so that she is cleansed, that the clitoris, which is believed to be toxic, is removed and will not grow or touch and kill a baby during delivery, or so that she remains chaste – a virgin, or to enhance the man’s sexual pleasure. Each family continues this tradition for a multitude of complex beliefs, fears and societal pressures that we may never begin to comprehend.

Several glaring issues have surfaced during these workshops.

- Circumcised women have poor access to health care and little exposure to reproductive health issues
- There is a dearth of culturally competent health and service providers who understand the complexities of FGC
- The African Community and medical community seem unfamiliar with the US law
- There is a growing population that is traveling to Africa to perform the circumcisions on their daughters

Evidence is mounting that parents are taking their daughters back to Africa to be circumcised. Last weekend, I held an African reproductive health workshop in Boston where members in the Sudanese community voiced their concern that two families went back to the Sudan for this very reason. In December, a lawyer in Providence, RI consulted me on a case where an uncle was trying to prevent his niece from returning to the Gambia to be circumcised. Yesterday I spoke with a community leader who mentioned in passing that a few families have returned to Somalia to circumcise their daughters. Europe is further ahead on dealing with FGC issues. Britain passed the FGM Act of 2003 that not only makes it a crime for anyone to advise, assist or perform FGC in the UK, it is also a crime for UK nationals, permanent residents and non-UK nationals to advise, assist or perform FGC outside the UK. Our law 18 USC 116 was enacted in 1996 making it a federal crime to perform FGC in the US but we need to go further. A precedent has been set about crimes committed outside the US. We have a law that makes it a crime to transport US national or permanent resident girls under 18 to other countries with the intent to engage in prostitution or illicit sexual conduct. This issue is growing in an alarming fashion and we must work along with the African community to find a way to stop it.

This leads us to the big question that I am constantly faced with. What can we do to prevent this practice from continuing and to ensure a healthy life for those who have already been circumcised? One of our greatest challenges as physicians and public health practitioners is to try and change detrimental attitudes and behaviors of our patients. How do you help a smoker stop? An obese woman, lose weight and exercise? A pregnant drug addict quit? The purpose of this briefing is to describe the scope and depth of this problem and establish a foundation for further examination by Congress and appropriate regulatory agencies.

FGC is a complex and emotional issue for every one involved. The message I want to leave you with is this:

- African community needs more education and outreach. We evaluated our workshop 6 months later and had a comment section. Unsolicited, 20% in the comment section, requested more workshops. Molly Melching's work in Senegal demonstrates how persistent outreach can change attitude.
- Health Provider's need more cultural and linguistic education. Dr. Toubia produced an excellent manual that is now out of print. The ACOG has a terrific slide-lecture kit that has helped medical students and residents in the US and Canada. More of these manuals are critical.
- Protection of the uncircumcised African here in the US. My plea is that the United States government to take action to protect the young girls.

FGC is a health and human rights issue and must be stopped but I have found that my patients don't want to be pitied. They want to be seen as healthy beautiful individuals contributing to society and be evaluated by health providers with respect and dignity.