Female Genital Mutilation/Cutting: Challenges, Research Gaps, and Opportunities in a Hidden Population

Crista E. Johnson-Agbakwu, MD, MSc, FACOG
Founding Director, Refugee Women’s Health Clinic, Maricopa Integrated Health System
Assistant Research Professor
Southwest Interdisciplinary Research Center
Arizona State University
Outline

• Historical/Cultural Overview
• Epidemiology
• WHO Classification Scheme
• Health Outcomes
• Challenges and Gaps in Care
• Emerging Evidence
• Research Gaps
• Legal & Ethical Controversies
• Health Policy & Research Directives
Historical/Cultural Overview and Epidemiology
Female Genital Mutilation/Cutting

“Any procedure that involves partial or total removal of external female genitalia or other injury to female genital organs whether for cultural or non-therapeutic reasons.”
Female Genital Mutilation/Cutting

Controversial Terminology:

Cutting vs. Mutilation


Justifications for FGM/C

- Respect for Girl Status
- Family honor
- Rite of passage
- Sense of belonging to a community
- Preserves virginity
- Custom or tradition
- Fulfills religious requirement believed to exist
- Helps cleanliness
- Bad luck / evil spirits
- Safer childbirth
- Aesthetics

Preconceptions

Religious
Predates Abrahamic Religions (Judaism, Christianity, and Islam), however mistakenly linked to religion.
FGC General Information

• Age

• Trending to younger age of girls

• Who Performs: often women (mothers, grandmothers, elders) who child respects and loves


World Prevalence

Countries of Origin

30 African Countries
South-East Asia
Middle East


Prevalence of FGM/C in Africa among women aged 15-49.

- 90 to 100 percent: Guinea, Egypt, Somalia, Djibouti, and Sierra Leone.
- 80 to 90 percent: Mali and Sudan.
- 70 to 80 percent: Mauritania, Burkina Faso, Gambia, and Ethiopia.
- 50 to 60 percent: Liberia.
- 40 to 50 percent: Chad and Guinea-Bissau.
- 30 to 40 percent: Côte d'Ivoire.
- 10 to 20 percent: Benin and Tanzania.
- 0 to 10 percent: Ghana, Togo, Niger, Cameroon, Uganda, and Zambia.

All other countries either did not have data or did not report data.
Variations Within and Across Borders

Looking only at national prevalence rates can hide the regional variations within a country. FGM/C often reflects ethnicity or social interactions of communities across national borders.

- FGM/C rates are above 75 percent in all of Somalia.
- FGM/C rates are 75 percent or higher in western Kenya, 25 to 49.9 percent in eastern Kenya, and less than 25 percent in southern Kenya.
- FGM/C rates are 75 percent or greater in western Ethiopia, 50 to 74.9 percent in most of eastern Ethiopia, and 25 to 49.9 percent in two small regions of Ethiopia (far eastern tip and the far northern tip).
Black immigrant population in the U.S. rose to 4.2 million in 2016

Total foreign-born black population in the U.S. in thousands

513,000 women and girls affected by or at risk of FGM/C in the United States


Jamaica, Haiti, Nigeria are top birthplaces for black immigrants in the U.S.

Total foreign-born black population in the U.S., in thousands, 2016

Note: Foreign-born blacks include single-raced blacks and multiracial blacks, regardless of Hispanic origin. Top 10 largest black immigrant groups shown.
Source: Pew Research Center tabulations of the 2016 American Community Survey (IPUMS).

Source:

USA Prevalence

40% of women and girls at risk of FGM/C live in five metro areas.

<table>
<thead>
<tr>
<th>Top 5 Metro Areas in the United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. New York</td>
</tr>
<tr>
<td>2. Washington, DC</td>
</tr>
<tr>
<td>3. Minneapolis</td>
</tr>
<tr>
<td>4. Los Angeles</td>
</tr>
<tr>
<td>5. Seattle</td>
</tr>
</tbody>
</table>

THE NUMBER OF WOMEN AND GIRLS AT RISK OF FGM/C VARIES WIDELY ACROSS THE UNITED STATES.

Map of the United States showing the number of women and girls at risk of FGM/C by state.

- 25,000 or more: Washington, California, Texas, Minnesota, New York, New Jersey, Maryland, and Virginia.
- 10,000 to 24,999: Michigan, Illinois, Ohio, Pennsylvania, Massachusetts, Georgia, and Florida.
- 5,000 to 9,999: Nevada, Arizona, Colorado, Iowa, Indiana, Tennessee, and North Carolina.
- Less than 5,000: All other states.

Source: Population Reference Bureau, 2013 data.

FGM/C Classification Schema
<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Partial or total removal of the clitoris and/or the prepuce (clitoridectomy)</td>
</tr>
<tr>
<td>Ia</td>
<td>Removal of the clitoral hood or prepuce only</td>
</tr>
<tr>
<td>Ib</td>
<td>Removal of the clitoris with the prepuce</td>
</tr>
<tr>
<td>II</td>
<td>Partial or total removal of the clitoris and labia minora, with or without excision of the labia majora (excision)</td>
</tr>
<tr>
<td>IIa</td>
<td>Removal of the labia minora only</td>
</tr>
<tr>
<td>IIb</td>
<td>Partial or total removal of the clitoris, the labia minora and majora</td>
</tr>
<tr>
<td>IIc</td>
<td>Partial or total removal of the clitoris, the labia minora and majora</td>
</tr>
<tr>
<td>III</td>
<td>Narrowing of the vaginal orifice with the creation of a covering seal by cutting and positioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation)</td>
</tr>
<tr>
<td>IIIa</td>
<td>Removal and apposition of the labia minora</td>
</tr>
<tr>
<td>IIIb</td>
<td>Removal and apposition of the labia majora</td>
</tr>
<tr>
<td>IV</td>
<td>Unclassified. All other harmful procedures to the female genitalia for non-medical purposes, for example, pricking, pulling, piercing, incising, scraping, and cauterization.</td>
</tr>
</tbody>
</table>

*Clitoris – only the glans or the glans with part of the body of the clitoris is removed.*

WHO Classification of FGM/C

**Type I** Partial or total removal of the clitoris (clitoridectomy) and/or the prepuce

FGM Type 1:

Ia: removal of the prepuce/clitoral hood (circumcision)

Ib: removal of the clitoris with the prepuce (clitoridectomy)

WHO Classification of FGM/C

Type II Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision)

FGM Type II:
IIa: removal of the labia minora only
IIb: partial or total removal of the clitoris and the labia minora

WHO Classification of FGM/C

FGM Type II:
IIc: partial or total removal of the clitoris, the labia minora and the labia majora

WHO Classification of FGM/C

Type III Narrowing of the vaginal orifice with the creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation)

FGM Type III:
IIIa: removal and apposing the labia minora with or without excision of the clitoris
IIIb: removal and apposing the labia majora with or without excision of the clitoris

WHO Classification of FGM/C

Type IV All other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, pulling, piercing, incising, scraping and cauterization

FGM Type IV Unclassified.

Health Outcomes
Immediate Complications

- Bleeding/Hemorrhage
- Infection: wound, septicemia
- Shock
- Fever
- Genital Swelling
- Urinary retention
- Tetanus
- Pain
- Death


Obstetric Complications

- Prolonged labor
- Vaginal lacerations
- Instrumental delivery
- Hemorrhage
- Episiotomy
- Cesarean Section
- Increased length of hospital stay
- Infant resuscitation


Urogynecologic Concerns

- Genital tissue damage (scarring/keloids)
- Chronic vulvar or clitoral pain
- Chronic genital tract infections
- Dysmenorrhea
- Irregular menses
- UTI (often recurrent)
- Painful urination
- Cysts

Sexual Dysfunction

- Dyspareunia (pain during sex)
- Decreased sexual satisfaction
- Reduced sexual desire
- Infertility

Mental Health Morbidity

- Post-traumatic stress disorder (PTSD)
- Anxiety Disorders
- Depression

2016 WHO Guidelines on the management of health complications from female genital mutilation
Challenges and Gaps in Care
COMMUNITY
- Distrust
- Fear
- Stigmatization
- Care delay/refusal
- Adverse outcomes

PROVIDERS
- Poor clinical skills
- Limited cultural competence
- Inability to recognize unique needs
## FGM/C diagnosis codes
*(Do not reflect current WHO Typology)*

<table>
<thead>
<tr>
<th>FGM/C Diagnosis</th>
<th>ICD-9</th>
<th>ICD-10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female Genital Mutilation, Unspecified</td>
<td>629.20</td>
<td>N90.810</td>
</tr>
<tr>
<td>Female Genital Mutilation, Type I</td>
<td>629.21</td>
<td>N90.811</td>
</tr>
<tr>
<td>Female Genital Mutilation, Type II</td>
<td>629.22</td>
<td>N90.812</td>
</tr>
<tr>
<td>Female Genital Mutilation, Type III</td>
<td>629.23</td>
<td>N90.813</td>
</tr>
<tr>
<td>Other Female Genital Mutilation</td>
<td>629.29</td>
<td>N90.818</td>
</tr>
</tbody>
</table>
CPT Code Defibulation (Not Specific to FGM/C)

• **13131**  Defibulation (general procedure code)
  Repair, complex procedures on the Integumentary System
  *(forehead, cheeks, chin, mouth, neck, axillae, genitalia, hands and/or feet)*

• **56441**  Lysis of labial adhesions

• **56800**  Plastic repair of introitus

*For complicated procedures, add the -22 modifier and document any additional physician work*
Challenges in the Pediatric Context

- FGM/C constitutes child abuse in female minors
- Every state has mandatory reporting requirements
- Should Pediatricians perform universal GU exams?
  - If not, there’s concern for racial/ethnic profiling
- FGM/C in Pediatric populations difficult to diagnose
- Providers unfamiliar with identifying FGM/C in pediatric populations
- Poor clinical documentation
- Vacation Cutting
  - Lack of clinical documentation of genital exam before/after travel
- Parental consent required
FGM/C-Affected Populations in Arizona

Arizona
7th largest Somalia-born population
7,459 women/girls
Robust community partnerships

Population Reference Bureau, 2013

Somalia
98% FGM/C prevalence
Type 3 FGM/C is most common
Traumatic displacement

Shell-Duncan et al., 2016

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Research Gaps
Future Inquiry

- Impact migration and acculturation
- Optimizing obstetric outcomes
- Psycho-sexual outcomes
- Full spectrum FGC sub-types
- Mental health outcomes
- Validated metrics, cross-cultural equivalency
- Ethno-cultural comparison groups
- CBPR in current political climate
Legal & Ethical Controversies
1996
Congress passes “Federal Prohibition of Female Genital Mutilation Act.”

2012
Resolution passed by UN General Assembly “Intensifying Global Efforts for the Elimination of Female Genital Mutilations” – towards global legislation against FGM.

2013
“Transport for Female Genital Mutilation Act” (Girls Protection Act) protects female minors from being taken out of the country for FGM (‘vacation cutting’).

2015
“Zero Tolerance for Female Genital Mutilation Act” introduced to the House of Representatives urging Federal strategy to prevent and respond to FGM.

2017
HR 3317 – SAFE Act (Stopping Abusive Female Exploitation Act of 2017) unanimously passed the U.S. House of Representatives, increasing federal penalty to 15 years and urges states to employ mandatory reporting policies.
Michigan Doctor Is Accused of Genital Cutting of 2 Girls

By JACEY FORTIN  APRIL 13, 2017

A Michigan doctor has been accused of performing genital cutting on two 7-year-old girls at a medical clinic, in a case that federal officials believe to be the first prosecution under a law banning the brutal practice.

The doctor, Jumana Nagarwala, 44, was arrested on Wednesday on charges that she performed the genital cutting at an unnamed medical clinic in Livonia, Mich.; transported minors with intent to engage in criminal sexual activity; and lied to federal agents.

According to a criminal complaint filed in federal court on Wednesday, Dr. Nagarwala performed the procedure on two girls from Minnesota who traveled to the clinic with their parents in February. The complaint also said that “multiple” other girls, including some from Michigan, may have been victimized between 2005 and 2007.

One of the girls told investigators that she thought she and the other girl had gone to the doctor because “our tummies hurt.” The other said the cutting procedure was so painful that she screamed and could barely walk afterward. She drew a picture of the room where the procedures were allegedly carried out, marking an “X” on
Dawoodi Bohra Federal Prosecution

- ~ 1 million worldwide
- India, Pakistan, Sri Lanka, Europe, N. America, SE Asia, Australia
- Ismaili Shia Islamic sect
- Girls circumcised age 7 (Khatna/Khafd)
- ~100+ girls cut over 10 year period in Livonia, Michigan
- First federal prosecuted case in U.S. history since federal law passed in 1996

**FGM law deemed Unconstitutional (11/20/18)**

- Most federal charges dismissed
- Interstate Commerce Clause
- Congress has no authority to enact FGM law
- Jurisdiction of States
- Gender Discrimination (violates Equal Protection Clause of 14th Amendment)
- Federal appeal likely
Legal Status

• FGM/C is a form of Child Abuse

• Child abuse/Sexual assault is prosecutable in every state

• Vacation Cutting

• Grounds for Asylum

US Federal Statues

• 18 U.S. Code § 116(d) states:
  “Whoever knowingly transports from the United States and its territories a person in foreign commerce for the purpose of [female genital mutilation] with regard to that person that would be a violation of subsection (a) if the conduct occurred within the United States, or attempts to do so, shall be fined under this title or imprisoned not more than 5 years, or both.”

• First passed in 1996, amended in 2013 to include transport out of country

• 8 USCS § 1374

• US Immigration officials provide immigrants with info about severe physical and mental harm caused by FGM and legal consequences in US

Source: TheAHAFoundation.org

Current FGM/C Legislation by State

• 28 states have passed legislation
• Individual state laws vary in terms of:
  • Ban on Vacation Cutting
  • Inclusion of female minors and adults
  • Parents/Guardians penalized even if they did not perform actual FGM/C
Ethical Controversies

• Iatrogenic Pathologization
• Genital Self-Image
• Ongoing Controversies

☐ Female Genital Cosmetic Surgery (*Re-infibulation/Clitoral Reconstruction/Hymenoplasty*)

☐ Human Right to Bodily Integrity/Genital Autonomy regardless of sex/gender (*female, male, and intersex children*)

☐ Adult woman’s right to choose

Current Climate in USA

• Anti-immigrant/anti-refugee/anti-Muslim policies and initiatives can trigger hostility toward migrants (refugees, immigrants and asylum-seekers)

• Targeted vulnerable populations may experience perceptions of vulnerability, threat and psychological distress

• Negative health effects such as lower birth weight babies have been documented in Hispanic populations after large immigration raids, and in Arab-American women post-Sept 11th

• Women may not feel safe seeking public assistance or preventive and prenatal care

Health Policy and Research Directives
End Violence Against Girls: Summit on FGM/C

*Healthcare Sector Working Group’s Recommendations for Strategies to Respond to FGM/C in the U.S.*

A. Provide high quality care to **affected women and girls**

B. Provide high quality care to **those at risk** for FGM/C

C. Work with collaborators, including affected teens and women, to **prevent FGM/C** in the U.S. and elsewhere

D. **Expand research** on FGM/C, including, but not limited to:
   1) its prevalence in the U.S. and how the practice changes in the context of resettlement;
   2) its medical and psychological sequelae; and
   3) appropriate, evidence-based interventions.

Washington, D.C. November 30, 2016
Multi-pronged strategy

- Clinical Care
- Research
- Community Engagement
Community Engagement

• Community outreach/education
• Trust-building is paramount
• Bi-directional learning
• Engage multiple stakeholders
  ✓ Men
  ✓ Women
  ✓ Youth
  ✓ Elders
  ✓ Religious leaders

• Ethnic Community-based Organizations
• Social Service Agencies (e.g., Refugee resettlement agencies)
• Schools, law enforcement, social work
• Economic empowerment, gender equity, intimate partner violence, stigma-reduction
Optimizing FGM/C-related Clinical care

Women/Girls

- Address Social Determinants of Health
  - Health Literacy
  - Distrust
  - Western vs Traditional health beliefs
  - Patient autonomy in decision-making
  - Stigma reduction

- Address structural barriers to care
  - Insurance coverage
  - Language barriers/Interpretation
  - Transportation
  - Gender concordance of staff

- Engage the Male partner/spouse/ father (as appropriate)

Healthcare providers

- Sustained Provider Education
  - Appropriate clinical documentation/coding
  - Culturally sensitive counseling
  - Surgical skills competency (within scope of practice)
  - Culturally appropriate treatment paradigms
  - Ethical dilemmas

- Patient-Centered Multidisciplinary Care
  - Peds, OB/GYN, FM, Emerg Med, PA, CNM, NP, RNs
  - Psychiatrist/Psychologist
  - Sex therapist/Counselor/SW
  - Pelvic Floor Physical Therapist
  - Peer Mentor/Support/Community Advocate/Navigator
Promote public-private partnerships (Federal/State/Local)
Ethno-cultural specificity in data collection/tracking
Validated instruments with cross-cultural equivalency
ICD-10/ICD-11, CPT Procedural codes specific to WHO FGM/C Typology
Library of educational photos/videos of FGC among pre-pubertal girls/adolescents
Joint/Consensus Clinical Practice Guidelines across professional societies (ACOG, AAP, AAFP, ACNM, NASPAG)
Design quality improvement metrics, track longitudinal outcomes
Partnership across multi-center research sites within and across countries
Ongoing Controversies
Female Genital Cosmetic Surgery (Re-infibulation/Clitoral Reconstruction/Hymenoplasty)
Human Right to Bodily Integrity/Genital Autonomy regardless of sex/gender (female, male, and intersex children)
Address current U.S. political landscape/rhetoric: (Anti-refugee/Anti-immigrant/Anti-Muslim)
Pocket Guides & Posters

FREE Online

https://sirc.asu.edu/content/resources

For Hard Copy Print Orders:

John Keeney
Phone: 480.965.3094
E-mail: john.keeney@asu.edu
Thank You!