

Research Priorities to Address FGM/C in the United States

The City College
of New York

CUNY School of Medicine

Holly G. Atkinson MD¹; Deborah Ottenheimer, MD²; Ranit Mishori, MD, MHS³

Department of Medical Education, CUNY School of Medicine, NYC¹; Clinic for Human Rights, Weill Cornell School of Medicine, NYC²;
Department of Family Medicine, Georgetown University School of Medicine, DC³



Abstract

Female genital mutilation/cutting (FGM/C), a millennial-old tradition that is still widely practiced around the world, is gaining recognition as an important public health issue in the United States. Increasingly, due to migration, women and girls affected by FGM/C have become members of host communities where the practice is not culturally acceptable. Recent conservative estimates reveal that over 513,000 immigrant women and girls living in the US have undergone or are at risk for FGM/C, a significant increase from the 1990 estimate of 168,000. The arrests of physicians in Michigan in 2017 for performing FGM/C on minors underscores the fact that cutting is happening in the US as well.

We have identified numerous gaps in our understanding of the magnitude of the problem in the US and in the availability of scientific data informing a variety of interventions (preventive, clinical, educational, legal). We catalogue these major gaps and propose a research agenda that can assist public health experts, researchers, clinicians, and other stakeholders establish priorities as we confront FGM/C as an important health issue affecting hundreds of thousands of women and girls in the US.

Introduction

In October 2018, a federal judge in Michigan ruled that the 1996 US federal law banning FGM/C is unconstitutional, and dismissed key charges against two physicians accused of performing FGM/C on upwards of 100 girls from several states. The ruling has rattled survivors and anti-FGM/C advocates, putting the legal battle to ban FGM/C, even in the US context, front and center. Past media reports have publicized the arrests of parents in the US who have undertaken the cutting of their daughters' genitalia. There have also been reports of traditional cutters performing FGM/C on girls living in America. In part due to the media coverage of these cases, as well as to outreach efforts by the US Department of Justice following the Michigan case, the medical community has become increasingly aware of the knowledge gaps and complex issues facing healthcare providers with respect to FGM/C. This has led to an enhanced interest in exploring the evidence regarding prevention of the practice, management of its consequences, and culturally-appropriate support of affected women and girls.

Proposed Research Agenda

1. Incidence and Prevalence: Determine the incidence and prevalence of FGM/C in the US with greater precision and determine the demographics of affected girls and women and at-risk girls.

2. Identification, Screening, and Documentation: Determine best practices to educate healthcare providers on accurate identification and documentation of FGM/C types and validate screening tools to identify at-risk women and girls.

3. Clinical Management: Identify best practices, assess their outcomes in this population and develop best practice guidelines for clinical management of a range of FGM/C issues/complications including obstetrical issues, gynecologic and urological problems, sexual functioning, chronic pain and mental health issues; validate clinical assessment tools; evaluate outcomes of surgical interventions.

4. Workforce Education: Identify gaps in health providers' knowledge, attitudes and practices; develop and validate educational tools and best practices to train the workforce across all specialties and training levels.

5. Legal Issues: Determine the effectiveness of enforcement of federal and state laws on the practice of FGM/C, with particular attention to the consequences of mandatory reporting laws on physicians, immigrant communities, parents and at-risk or cut girls.

6. Ethical Issues: Determine the pressing ethical, moral, legal and cultural conflicts facing physicians, families and patients and incorporate into nuanced practice recommendations.

7. Eradication and Prevention Strategies: Systematically evaluate eradication programs' outcomes data and determine best practices for the eradication and prevention of FGM/C in the US context.

Methods

We have, in collaboration with colleagues, identified numerous gaps in our understanding of the magnitude of the problem in the US and in the availability of data informing a variety of interventions (clinical, educational, legal, etc.). Our research agenda (Table) is informed by a narrative review of the literature, a consideration of WHO priorities, and a synthesis of the conclusions of the US Network to End FGM/C: Health Care Working Group at the *End Violence Against Girls: Summit on FGM/C* in December 2016.

Conclusions

FGM/C is gaining recognition as an important public health issue in the US. With the rapid growth in the numbers of immigrants from FGM/C-practicing countries living in America, healthcare providers will invariably encounter women and girls who have undergone or are at risk of cutting. There is an urgent need to undertake a comprehensive research agenda to address the major gaps in knowledge and establish more rigorous evidence-based interventions to address FGM/C's manifestations and complications, as well as to deliver compassionate, culturally-sensitive care to the hundreds of thousands affected women and girls residing in the US.

Selected References

1. World Health Organization. Care of women and girls living with female genital mutilation: a clinical handbook. Geneva: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO. Available at <http://www.who.int/reproductivehealth/publications/health-care-girls-women-living-with-FGM/en/>.
2. Belluck P. Federal Ban on Female Genital Mutilation Ruled Unconstitutional by Judge. The New York Times. Nov. 21, 2018. Available at <https://www.nytimes.com/2018/11/21/health/fgm-female-genital-mutilation-law.html>.
3. Goldberg H, Stupp P, Okoroh E, Besera G, Goodman D, Danel I. Female Genital Mutilation/Cutting in the United States: updated estimates of women and girls at risk, 2012. *Public Health Rep.* 2016;131(2):340-347.
4. 18 U.S. Code § 116 (a) - Female genital mutilation. (n.d.). Available at <https://www.law.cornell.edu/uscode/text/18/116>. Accessed November 27, 2017.

Acknowledgements

We would like to acknowledge the contributions of the members of the *Health Care Working Group* at the *End Violence Against Girls: Summit on FGM/C* and the members of the *US Clinician Network on FGM/C*