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Public Health Research Priorities to Address Female Genital Mutilation or Cutting in the United States

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Female genital mutilation or cutting (FGM/C), an age-old tradition that is still widely practiced around the world, is gaining recognition as an important public health issue in the United States. Increasingly, because of migration, women and girls affected by FGM/C have become members of host communities where the practice is not culturally acceptable.

According to recent conservative estimates, more than 513 000 immigrant women and girls living in the United States 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 United States.

We have identified numerous gaps in our understanding of the magnitude of the problem in the United States and in the availability of scientific data informing a variety of interventions (preventive, clinical, educational, legal). We catalog these major gaps and propose a research agenda that can help public health experts, researchers, clinicians, and other stakeholders to establish priorities as we confront FGM/C as an important health issue affecting hundreds of thousands of women and girls in the United States. (*Am J Public Health*. 2019;109:1523–1527. doi:10.2105/AJPH.2019.305259)

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The World Health Organization (WHO) has defined female genital mutilation or cutting (FGM/C) as "all procedures that involve partial or total removal of the external female genitalia, or other injury to the female genital organs, for non-medical reasons," and has classified FGM/C into four fundamental types (with several subclassifications added in 2016.)[1] FGM/C is practiced around the world, primarily in Africa (e.g., Somalia, Guinea), the Middle East (e.g., Iraq, Yemen) and Southeast Asia (e.g., Indonesia).[2] Increasingly, because of migration, women and girls affected by FGM/C have become members of societies where the practice is not normative, including the United States.

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.[3] 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 United States who have undertaken the cutting of their daughters' genitalia.[4] There have also been reports of traditional cutters performing FGM/C on girls living in America.[5] In part because of the media coverage of these cases, as well as 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 health care 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.

In collaboration with colleagues, we have identified numerous gaps in our understanding of the magnitude of the problem in the United States and in the availability of data informing a variety of interventions (clinical, educational, legal, etc.). In this commentary, we catalog these major gaps and propose a research agenda that can help establish priorities as we confront FGM/C as a public health issue in the United States. Our research agenda (see the box on page 1524) 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.

RESEARCH PRIORITIES

We have identified seven research priorities.

Prevalence and Incidence

Although the exact number of girls and women globally who have experienced FGM/C remains unknown, more than 200 million girls and women in 30 countries are estimated to have undergone FGM/C, on the basis of data from countrywide surveys.[2,6] In some practicing countries FGM/C is widespread, affecting the vast majority of the female population, whereas in other countries FGM/C is practiced only among subpopulations, affecting a far smaller percentage of women and girls.[2]

A challenge to addressing FGM/C in the United States is the absence of an accurate count

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PROPOSED RESEARCH PRIORITIES FOR FEMALE GENITAL MUTILATION OR CUTTING

1. Prevalence and incidence: determine the prevalence and incidence of FGM/C in the United States with greater precision and determine the demographics of affected girls and women and at-risk girls.
2. Identification and screening: determine best practices to educate health care providers on accurate identification and documentation of FGM/C types and validate screening tools to identify at-risk 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 and complications, including obstetrical issues, gynecological 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.

Note. FGM/C = female genital mutilation or cutting.

of women and girls already affected or at risk. The latest estimate, from 2012, is that approximately 513 000 women and girls in the United States had either already undergone FGM/C or were at risk for being cut, a substantial upward readjustment of the 2000 estimate of 228 000.[7] This half-million estimate is imprecise for several reasons: it uses country-specific, national prevalence statistics and applies them to a unique segment of a country's population: migrants living in the United States. It also conflates women and girls who may have already been cut with girls who were born to women from FGM/C-practicing countries and may be at risk of being cut.

Further, the estimate only includes immigrants from practicing African nations and Yemen, as only those countries' data were then available. It does not include the high prevalence of FGM/C in other countries that have been subsequently documented (e.g., Indonesia).[2] There is a pressing need to collect accurate data on the prevalence of women and girls living in the United States who have already been cut, as well as the incidence of the cutting of girls from FGM/C-practicing groups living in the United States, in order to promulgate policies and evaluate practices. We also need to understand the age at which FGM/C is performed on girls living in the United States, as well as how often it is performed here in America versus in the family's country of origin during visits abroad ("vacation cutting"), who is doing the cutting, how it is being carried out, and the types of FGM/C being performed and the resulting complications.

Identification and Screening

Education of medical providers about accurate identification of FGM/C type and appropriate *International Classification of Diseases, 10th Revision* coding is critical for the documentation of prevalence and incidence in the United States. The accurate identification of FGM/C would be greatly facilitated by the development of a visual "atlas,"—that is, a clinical visual guide. Several basic atlases exist, the most recent of which was published in 2016[8]; however, a more comprehensive atlas would be beneficial. The appearance of scarring due to FGM/C varies dramatically with age and parity, making visual guidance invaluable in the assessment of affected patients. In addition, there are currently no visual aids for the assessment of FGM/C in the pediatric patient. Recognition of FGM/C is difficult but crucial in this population, both to provide medical guidance to girls who have been cut and to identify at-risk siblings.

Currently, there are no validated screening tools available to American clinicians. Although screening tools are available in other countries,[9] including the widely used British Safeguarding and Risk Assessment tool[10] (which assesses the risk of girls undergoing cutting and the medical consequences of FGM/C in girls and women), they may not be directly applicable to the United States given the differences in the health, social service, and legal systems. Research is needed to determine the most appropriate, culturally sensitive means of screening, as well as the overall costs and benefits of screening women and girls from high-prevalence countries currently residing in the United States. In addition, development of a validated screening tool with which to identify at-risk girls in pediatric settings is vital to preventing FGM/C from occurring in the United States or through vacation cutting.

Clinical Management

There are few evidence-based, comprehensive clinical management guidelines for the care of women and girls who have been subjected to FGM/C. The American College of Obstetricians and Gynecologists published an educational resource on FGM/C in 2008; however, it has not been revised since then.[11] Extensive professional guidance has been

developed in the United Kingdom[9]; however, the applicability of these recommendations in the United States has yet to be determined. Most of the international expert recommendations address obstetrical care, specifically regarding the timing and technique for deinfibulation. However, consensus is lacking with respect to the optimal timing and best surgical technique. Researchers need to conduct US-specific obstetric outcomes studies investigating deinfibulation timing and technique, delivery techniques and complications, and morbidity and mortality among mothers and newborns.

There has been little attention paid to developing management recommendations or systematic guidelines for addressing gynecological and urological pathology and pelvic pain among affected women, although these are widely recognized complications of FGM/C.[1] Additional areas suffering from a lack of systematic, comprehensive evaluation of outcomes include sexual health and function, clitoral reconstruction, and self-image related to genital alterations. Further, the importance of developing nonsurgical techniques, including physical therapy, for treating sexual dysfunction among women with FGM/C cannot be overemphasized.

Finally, evidence-based best practices for addressing the mental health needs of women and girls living with FGM/C have yet to be elucidated. There is evidence that many FGM/C-affected women suffer high burdens of anxiety, depression, or posttraumatic stress disorder.[12] This is in addition to the psychological consequences among those who suffer from FGM/C-associated sexual dysfunction.[13] WHO currently recommends cognitive behavioral therapy as the preferred therapeutic modality[1]; however, a systematic evaluation of a variety of psychological interventions for affected women and girls is needed.

Workforce Education

Women and girls affected by FGM/C invariably engage with a variety of practitioners in the health care sector, whether during routine well-woman–well-child visits, primary care encounters, and pre-, peri-, and postpartum appointments, or as part of the management of chronic and acute health issues related to FGM/C. Yet our literature review reveals that American medical practitioners are not sufficiently prepared to care for affected women and girls.[14] There is a need for the development of FGM/C-related educational competencies, improved training, better assessments of clinicians' knowledge and proficiencies, evaluations of attitudes and practices, appraisals of communication skills, and the creation and validation of standardized questionnaires and assessment tools.

Workforce training has been studied sporadically in other host countries, in different specialties, and at various levels of education. Multiple published reports address the readiness (or lack thereof) of host countries' health sectors, and their ability to successfully and appropriately manage those affected by FGM/C. Small studies have assessed the knowledge, attitudes, and practice of practitioners of various disciplines, including nurses, midwives, and physicians, and from multiple specialties.[15] Studies also have assessed the knowledge, attitudes, and practice of learners at all levels of health professional education and show a substantial need and desire for improved training at all levels of practice and among different specialties, including obstetrics and gynecology.[16,17]

Ultimately, research into educational interventions regarding FGM/C should aim to produce robust curricula for US health professionals at all levels of education, identify educational best practices, and disseminate high-quality training programs for multiple specialties. Women and girls with FGM/C seek care from a number of different specialists, including not only obstetrician–gynecologists and midwives but also pediatricians, family physicians, nurse practitioners, physician's assistants, emergency medicine physicians, dermatologists, plastic surgeons, and urologists, all of whom need baseline knowledge regarding FGM/C and its management.

Legal Issues

FGM/C is considered a universal human rights violation.[1] In 1996, Congress passed the Federal Prohibition of Female Genital Mutilation Act, which made it illegal to perform FGM/C in the United States on anyone younger than 18 years.[18] In 2013, the federal law was amended to include a provision banning vacation cutting, which prohibits knowingly transporting or attempting to send a girl younger than 18 years outside the United States to undergo FGM/C. The federal law was recently declared unconstitutional by a Michigan federal judge; as of this writing, several attempts at both state and congressional levels are under way to address this decision.[19] This resultant period of uncertainty will no doubt serve to further confuse many who work with FGM/C-affected populations. Anecdotal evidence from expert meetings and a study of obstetrician–gynecologists by Moaddab et al. suggest that many US health care providers were unaware of existing legislation prohibiting FGM/C—before the Michigan ruling.[17]

With the challenge to the federal law, individual state laws are bound to become critical in efforts to outlaw and curb this practice. To date, 35 states have specific laws prohibiting FGM/C,[20] including seven states that explicitly ban vacation cutting. State laws, however, differ with regard to the age at which the FGM/C prohibition applies, the individuals who are subject to prosecution, the penalties for performing FGM/C, and whether religion or culture can be used as a defense of the practice. Some states, moreover, establish explicit mandatory reporting duties for health care providers and other professionals. In all 50 states, child abuse statutes define either "physical abuse" or "sexual abuse" in such a manner that they arguably encompass FGM/C. As a result, health care providers—as mandated reporters of child abuse—have a duty to report cases of FGM/C among patients younger than 18 years to the authorities.

The existence of FGM/C laws does not necessarily mean that they are implemented or enforced. There is little to no information about the effectiveness of enforcement of state FGM/C laws on immigrant populations, or about how criminalization affects trends regarding FGM/C acceptance and practice. Many experts believe that law enforcement should go hand in hand with culturally sensitive approaches to educating practicing migrant communities, as well as educating those in law enforcement who may come in contact with them.

Cross-sectoral medical and legal collaboration is required to assess some critical interdisciplinary issues, including the following: What will be the consequences of overturning the federal law? What are the effects or unintended consequences of mandatory reporting laws? What are the effects of the criminalization of FGM/C on parents' behaviors and patients' disclosures and on immigrant communities' attitudes and behaviors? What are the effects on children if they are removed from their parents because they were cut?

Ethical Issues

Health care providers' behavior and decision-making in the clinical setting are shaped by a variety of issues, including professional guidelines, legal obligations, personal morals, cultural biases, and medical ethics. Clinicians can face a number of conflicts regarding medical, moral, ethical, and legal obligations surrounding professional duty, obligations to the patient, respect for autonomy and culture, human rights, and regard for laws, regulations, and policies.

Clinical recommendations about FGM/C rarely address the interplay of these complex issues. For example, there is ambiguity surrounding reinfibulation in a consenting adult woman.[21] Mandatory reporting requirements can present physicians with ethically fraught situations related to dual loyalties—for example, supporting well-meaning parents and preserving an intact family versus upholding the demands of the state and potentially causing the removal of a child from a loving family. Suspicions regarding the risk of vacation cutting in particular raise ethical dilemmas.[22] Other dilemmas include consideration of "ritual nicks" as a compromise type of FGM/C[23] and the ethical difference between FGM/C and cosmetic labiaplasty,[24] as well as the medicalization of FGM/C as a means of harm reduction.[25,26] Clinical guidelines should incorporate the interplay of moral, ethical, legal, and patient-oriented perspectives.

Eradication and Prevention Strategies

FGM/C is a complex phenomenon and has different significance and meaning among the various cultural and ethnic groups who practice it. Years of international efforts to eliminate FGM/C have resulted in a significant decline in overall prevalence in some countries; however, it remains a pervasive practice in others, and evidence-based prevention and intervention strategies that are culturally and religiously sensitive remain a public health priority.[27] Prevention and eradication in the United States is complicated by the mixing of multiple practicing ethnic groups who differ in language, culture, and traditions. To formulate effective strategies, it is essential to systematically evaluate outcomes data of FGM/C eradication programs, both in the United States and abroad. Eradication and prevention of FGM/C will ultimately occur at the intersection of public education, professional advocacy, policy enactment, judicial action, and community engagement.

CONCLUSIONS

FGM/C is gaining recognition as an important public health issue in the United States. With rapid growth in the numbers of immigrants from FGM/C-practicing countries living in America, health care providers will invariably encounter women and girls who have undergone or are at risk for 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 of affected women and girls residing in the United States. AJPH

CONTRIBUTORS

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CONFLICTS OF INTEREST

The authors report no conflicts of interest.

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