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Female Genital Cutting in Immigrant Children—Considerations in Treatment and Prevention in the United States

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Abstract

Purpose of Review Female genital cutting (FGC) is a pediatric practice; however, the vast majority of United States (US) and international review articles and research have focused on women. Given recent immigration to the US of immigrants from countries where FGC is practiced, there are children living in the US who have FGC or are at risk of having FGC performed. Children with FGC are underdiagnosed in the US. It is imperative for medical providers who care for children to learn of FGC including medical findings, treatment, cultural beliefs, as well as the legal and ethical issues that may arise. Required, standardized training needs to be developed for all pediatric providers so that they can appropriately take care of children with FGC.

Recent Findings There are no standardized national training requirements for medical providers who may care for children affected by FGC. FGC is under-identified in children and in general, pediatric providers lack the skills needed to appropriately identify and treat children with FGC as well as training to appropriately discuss prevention of FGC with patients and families. Pediatric legal and ethical guidelines are also lacking.

Summary National training requirements need to be developed for medical providers who take care of children with FGC or who are at risk of being cut. This includes the development of standard of care practice guidelines recommending that all girls have external genital examinations at all well child checks. Without such guidelines and clinical expectations, children with FGC, including those with significant morbidity from the practice, will not be identified or treated. Cultural, legal, and ethical recommendations and guidelines must also be developed to guide medical providers.

Keywords Female genital cutting · Children

Introduction

Background

Female genital cutting (FGC) is known to have no medical benefits and is directly associated with significant morbidity and mortality [1]. It is illegal in much of the world, and yet it is still practiced and has been so for thousands of years, predating Christianity, Islam, and Judaism [2].

It is a mostly pediatric practice, one performed in children ranging in age from newborns to 15 years, depending on geographic region and ethno-cultural beliefs [3]; however, it is unknown how many children are affected in the US and globally. The vast majority of review articles, studies, and guidelines focus on women [4, 5]. Currently, there is no required standard training for pediatric or other medical providers regarding FGC [6••].

FGC is a matriarchal practice, some seeing it as a rite of passage, as a way to ensure virginity, marriageability, purity, and/or cleanliness and is not associated with any particular religion, ethnicity, or race [7, 8].

The practice itself varies in degree and extent of tissue injury and may involve cutting of the external female genital organs, including the clitoral hood, portions of the clitoral glans, labia minora and/or majora, and has no medical indication.

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This review will focus on FGC and children—prevalence, diagnosis, management, and treatment, all the while taking into account ethical issues as well as legal issues that are present in the United States, particularly in the setting of mandatory reporting requirements of medical providers who care for children.

Estimated Pediatric Prevalence International and US-based FGC prevalence studies have looked at numbers of affected women and this data has been used to estimate the number of children who have been cut; however, no studies exist that systematically address prevalence in children, by age. Similarly, age of cutting has been obtained by maternal report of the practice in their children and neither FGC type nor age of cutting has been confirmed by direct examination of children. Data that is available estimates that over 200 million women and girls have FGC, and some believe that approximately 500,000 US women and children have had FGC or are at risk [9, 10].

FGC is still practiced in 37 countries, with high prevalence countries (> 60% of women affected) including Sierra Leone, Guinea, Mauritania, Mali, Sudan, Egypt, Somalia, Djibouti, Eritrea, and Ethiopia [11]. This is notwithstanding laws in place banning the practice in all but 2 of these countries (see Table 1) [13].

FGC in not uniquely practiced in Africa, with reports of cutting occurring in countries including parts of India, Indonesia, Malaysia, Colombia, Yemen, and Iraq [17–19].

Age of cutting varies by geographic and ethno-cultural locale, with children as young as newborns up through age 15 having had FGC performed (see Table 1) [3].

FGC Types and Sub-types There are 4 types of FGC and subtypes to assist in further classification (see Table 2) [20••]. Currently, there are International Classification of Diseases, 10th Revision (ICD-10) codes of the main types of FGC only, with no sub-type classification codes currently available [21].

Approximately 10% of girls and women have undergone type III FGC [3], the most severe form of cutting and otherwise known as infibulation, and is mostly practiced in Djibouti, Eritrea, Sudan, and Somalia [22].

Recent data collected on 79 US pediatricians demonstrated that 73% had received no training in FGC, 89% were unaware of FGM/C-specific ICD-9/10 codes, and 89% were not confident that they could diagnose FGC in their patients (Young J, Johnson-Agbakwu C et al. unpublished data). Several national and international studies have shown similar findings, with lack of training and knowledge of FGC in family medicine, urology, and gynecology providers [6••, 23–25].

Expert experience suggests that general pediatricians do not standardly examine female genitalia at well-child check examinations and recent data support this supposition. Of a cohort of 62 general pediatricians who perform well-child examinations, girls had a progressively decreased likelihood of having their external genitals evaluated (exams in 46% of 13 months–2 years old, 28% of 3–4 years old, 18% of 5–8 years old, 13% of 9–12 years old, 11% in 13–16 years old, and 8% of 17–18 years old (Young J, Johnson-Agbakwu C et al., unpublished data)).

Without expertise in identifying pre-pubertal and pubertal female genitalia norms and variations in these norms, it is assumed that many girls with FGC are missed at well-child care examinations. Similarly, pediatric sub-specialists who may evaluate affected girls also lack training on FGC type and sub-type identification and as such, may miss more subtle types, including pre-pubertal girls with type I or II FGC.

Discussing FGC with Patients and Caregivers Review of signs, symptoms, and morbidity associated with FGC needs to be built into standard discussions with girls and families who are from at-risk countries. Clinical experience suggests that appropriate terminology includes *female genital cutting* to describe the practice and that the term *mutilation* is pejorative and should be avoided.

Expert experience suggests that girls who had FGC performed as young children are unaware that they were cut, as many mothers do not discuss the practice with their daughters and girls have no memory of the cutting. Universally, many girls and women may not be familiar with female genital anatomy and there are existing cultural taboos often associated with such discussions. In such cases, asking an older girl or adolescent if they have had FGC performed may be of low-yield.

It is suggested that the best approach is to show diagrams of female genitalia and to explain that standard of care practice is to discuss all medical issues related to all parts of the body, including female genitalia. Such discussions should be approached in a culturally sensitive manner and it is suggested to offer a female medical provider to do so, if feasible.

It is recommended to include discussion of risks of FGC being performed if travel is planned to country of origin or another region where the practice of FGC is prevalent. So-called *vacation cutting* is a known entity, though data on incidence is lacking. Review of medical complications as well as legal risk to the family should be clearly documented in the girl's chart.

In all cases, it is recommended that these discussions be broached in a non-judgmental and supportive manner, explaining the reasons for a medical provider to do so—to assure the girl or teen is having no medical issues that can be treated, to prevent complications from FGC, as well as to prevent a practice that causes significant morbidity and puts the family at risk of prosecution if performed in the US or on return to a country where it is still practiced (see legal section, below).

Rapport-building and trust are key elements to consider before bringing up FGC with patients and families. Such discussions may need to occur over several visits, after a strong

Table 1 FGC global prevalence, maternal report of age most commonly practiced, and laws in place

Country [12]	Prevalence [12]	Age in years (% prevalence) [3]	Anti-FGC laws adopted post-colonial rule [13]
Benin	< 20%	5–9 (> 50)	2003
Burkina Faso	20–60%	0–4 (> 50)	1996
Cameroon	< 20%	n/a	No law
Central African Republic	< 20%	5–9 (> 50)	1966, 1996*
Chad	20–60%	5–9 (> 50)	2003
Djibouti	> 60%	5–9 (> 60)	1995, 2009*
Egypt	> 60%	10–14 (50)	2008
Eritrea	> 60%	0–4 (> 80)	2007
Ethiopia	> 60%	0–4 (>60)	2004
Gambia	20–60%	n/a	2015 [14]
Ghana	< 20%	0–4 (> 80)	1994, 2007*
Guinea	> 60%	5–9 (> 50)	1965, 2000*
Guinea-Bissau	20–60%	0–9 (> 60)	2011
India	n/a	n/a	No law
Indonesia	20–60%	n/a	No law [15]
Iraq	< 20%	n/a	2011 (Kurdistan region)
Ivory Coast	20–60%	0–4 (> 50)	1998
Kenya	< 20%	5–9 (> 40)	2001, 2011*
Liberia	20–60%	n/a	No law
Mali	> 60%	0–4 (> 80)	No law [14, 16]
Mauritania	> 60%	0–4 (> 80)	2005
Niger	< 20%	0–4 (> 60)	2003
Nigeria	< 20%	0–4 (> 90)	2015[14]
Senegal	20–60%	0–4 (> 70)	1999
Sierra Leone	> 60%	5–14 (> 60)	No law
Somalia	> 60%	0–4 (> 80)	2012
Sudan	> 60%	n/a	2008–2009 (some states)
Tanzania	< 20%	0–4 (> 45)	1998
Togo	< 20%	5–9 (> 50)	1998
Uganda	< 20%	n/a	2010
Yemen	< 20%	n/a	2001

* 2nd dates listed are amendments to original law or new legislation

n/a = not available

therapeutic relationship has been established. Asking about the practice, from the context of wanting to learn more about a patient or family's culture, can go a long way to building trust and allowing the medical provider to learn as much (or more) from their patients as patients and families learn from the medical provider.

Clinical Examination Standards and Charting As discussed above, although data suggest that primary care pediatricians and other medical providers who perform annual physical exams do not standardly examine girls' external genitalia (Young J, Johnson Agbakwu C et al., unpublished data), it is of utmost importance to incorporate an external exam into all well-child care evaluations of all girls, irrespective of risks for FGC. Such an approach will give medical providers the experience needed to identify norms, variations of norms, and other diagnoses of significance in pre-pubertal and pubertal girls (e.g., lichen sclerosis, labial adhesions, peri-clitoral adhesions, sexual abuse). It has been suggested that without such breadth of clinical experience, FGC is often missed in children [26••].

In young children, primary guardian verbal consent to perform external genital examination should be obtained and documented in the child's chart. In older girls and teens, assent of the patient as well as CONSENT of the legal guardian should be documented. In cases where an external genital examination is performed as part of a confidential teen exam (e.g., for evaluation of a sexually

Table 2 FGC types and sub-types [20••]

FGC type	Description
Ia	Clitoral hood (prepuce) removed
Ib	Clitoral hood removed and excision of the glans of the clitoris
IIa	Removal of labia minora only
IIb	Excision of the glans of the clitoris, removal of labia minora (clitoral hood may be affected)
IIc	Excision of the glans of the clitoris, removal of l abia majora and minora
IIIa	Removal and apposition of labia minora with or without excision of the glans of the clitoris and hood
IIIb	Removal and apposition of labia majora with or without excision of the glans of the clitoris and hood
IV	Piercing, scraping, nicking of external female genitalia

transmitted disease), it is recommended that assent of the teen still be documented in the teen's chart. Approach to chaperoning such exams is beyond the scope of this article; however, review of the American Academy of Pediatric standards and documentation approach is advised [27].

Best approach to examination is to position the girl supine, using appropriate draping and in frog-leg position with soles of feet apposed [28]. It is recommended to laterally retract the labia majora, allowing for visualization of all external structures, including the clitoral hood, clitoris, labia minora, and labia majora. In young children, the clitoral hood may need to be partially retracted to visualize the glans of the clitoris. Similarly, the labia minora is underdeveloped in young children, necessitating active visualization of this structure. In young children, labial and peri-clitoral adhesions may mimic signs of FGC.

Chart documentation should include a detailed description of all external structures and it is suggested to include diagrams of affected and unaffected structures [20••]. Use of ICD-10 coding should be included.

If a medical provider is unsure whether a child or teen has had FGC, it is important to identify a regional specialist who has expertise in making such a diagnosis. If FGC is diagnosed in a child or teen, it is recommended that the provider discuss the findings with the care provider and/or child, if the child is at a developmentally appropriate age to comprehend such a discussion. Including diagrams of female genitalia, describing what has been removed as well as what is not affected, reviewing risks of medical complications, return precautions, as well as when the cutting occurred all need to be addressed.

Such discussions are complex and may need to be approached over several visits. If cutting occurred in home country prior to US immigration, there are no legal ramifications for the family (see legal section, below) and the focus is on managing any medical complications, based on type of FGC encountered. If there are no on-going medical issues and the child or teen is comfortable with her history of FGC, there is no need to continue ongoing discussions, unless she has specific questions. Stigma from prior FGC should be avoided and medical provider bias should not play into continuing discussions if the child, teen, and/or parent have no concerns or medical issues.

A culturally sensitive approach is key in all such examinations and discussions.

Immediate and Long-Term Complications of FGC Given that FGC is against the law in most countries and is most often performed in non-medical settings, short-term complications have not been systematically studied. Reports of death from sepsis, tetanus, hemorrhage, and shock have all been reported. Short-term complications also include arm and leg fractures, cellulitis, gangrene, fever, anemia, urethral injury, and urinary retention, though accurate prevalence data is lacking [29–32].

Long-term complications of FGC have been studied and reviewed by many authors, though prevalence of such complications has been fraught with lack of standardization of type and sub-type of FGC. Such complications include urethral strictures, meatal obstruction, pyelonephritis, keloids, hematocolpos, dysmenorrhea, vaginal stenosis, neuromas, and dyspareunia [29]. Psychological complications may include post-traumatic stress disorder, depression, and anxiety [33]. Though there is no data available that links FGC to blood-borne infections, some experts recommend testing for hepatitis B, C, and HIV infection [34].

Given the significant morbidity associated with type III FGC, defibulation is recommended in all cases [20••]. In these cases, Medicaid should cover the procedure due to directly associated medical complications including urinary retention, pyelonephritis, dysmenorrhea, and hematocolpos. In countries where trained professionals are available, it is recommended that defibulation be performed by a gynecologist, urologist, or urogynecologist with experience in managing such cases and pediatric subspecialists should be consulted for young children,

however, the current challenge is that there are few trained specialists in the US to perform such procedures. In countries where there is no access to a trained medical provider, defibulation is a procedure that can be easily learned and open access online training materials are available [20••].

FGC, Minors, and US Law

There are several significant issues that must be taken into consideration when addressing FGC in minors in the US including state and federal laws and mandatory reporting requirements concerning child abuse and neglect. At the time of writing, 28 states have laws that address FGC in minors [35] (see Table 3). In 1996, US federal law first criminalized FGC performed in the US on girls under 18 years of age. In 2013, the Transport for Female Genital Mutilation Act was enacted making it illegal to take minors outside the US to have FGC performed (FGC performed prior to US immigration is not prosecutable in the US).

At the time of writing, the Federal District Court of Michigan (US v. Nagarwala, Criminal No.17-CR-20274) questioned the constitutionality of the 1996 ruling and the federal justice department did not appeal this ruling. Medical providers should consult….and federal laws, as a full legal review is beyond the scope of this paper [37].

Medical providers are considered mandatory reporters when there are signs of child abuse and FGC that occurred in the US or as vacation cutting, where a girl is transported from the US to another country to have FGC performed, are both considered reasons for reporting to local Child Protective Services (CPS). Similarly, if a medical provider is told by the child or parent that they plan to go outside the country to have FGC performed, this needs to be immediately discussed with the family and if risk of FGC is evident, a CPS report should be made, with the goal of preventing FGC from occurring.

Of note, risk of or past history of FGC are both grounds for legal right to asylum in the US for all girls and women [38, 39]. As such, if a minor has FGC or is at risk of return to a country where FGC will be performed and she does not have legal status in the US, it is important to appropriately document current external genital findings and to link her with an immigration lawyer.

Table 3 States in the US with FGM/C laws in place (at time of writing) [12, 36]

Arizona
California
Colorado
Delaware
Florida
Georgia
Illinois
Kansas
Louisiana
Maryland
Michigan
Minnesota
Missouri
Nevada
New Hampshire
New Jersey
New York
North Dakota
Ohio
Oklahoma
Oregon
Rhode Island
South Dakota
Tennessee
Texas
Virginia
West Virginia
Wisconsin

Ethical Issues One difficulty in FGC cases in minors occurs when it is unclear when FGC was performed. Here lies the crux of the problem with current lack of training of medical providers, lack of standard external genital examinations, and lack of appropriate chart documentation and ICD-10 coding. For example, if a US born child ultimately has a history of travel to home country but has had no documented external genital examinations at well-child checks from ages 1–6 years, a medical provider will be unable to determine by examination when FGC occurred (In fact, given that genitalia is highly vascularized, healing occurs within days to weeks and timing of FGC is all but impossible unless evaluated immediately after cutting occurred.) Was she cut in the US as a young child, or did cutting occur on a visit to her home country when she was 3 years old, say, in 2012, before the Transport for Female Genital Mutilation Act was passed in 2013? Is it the medical provider's responsibility to investigate the timing of cutting or do they report FGC to CPS, when it is known that no CPS worker has been systematically trained to address FGC in a culturally appropriate way in the US (at the time of writing). If a CPS report is made, does the provider disrupt trust with the patient and her family and how is such a discussion brought up with them? And, clearly, this type of discussion does not fall under the standard 15–20 min visit time allocated for a primary care medical provider.

Other ethical dilemmas include the difficulty in determining the age when a particular child is developmentally mature enough to learn of her FGC, and how to broach this topic with the child's parents. Parents should be given

an opportunity to explain the cutting to the child and it is possible that they may want to do so alone or with the medical provider present to assist in explaining female anatomy. However, such discussions risk making a pre-adolescent or adolescent girl, who may already be concerned by her appearance, feel abnormal. If she was cut and has no medical issues or concerns regarding appearance, persistent or repeated questioning may do more harm than good, medicalizing an issue that is a non-issue for the girl.

In cases where a girl is concerned about her appearance, is confused about why the cutting was done and/or is suffering from PTSD, depression, or anxiety, mental health supports should be offered. If past injury was extensive, consultation may also be arranged with a surgeon well-versed in FGC repair who can work in concert with a mental health counselor.

FGC diagnosed during a confidential adolescent visit also creates several dilemmas for the medical provider. If the adolescent is unaware of her FGC, how and when does such a conversation take place? Does the medical provider explain to the adolescent that she has FGC and arrange for another visit with the teen's parents? And if the teen has current medical complications from her FGC necessitating treatment (e.g., severe dysmenorrhea, hematocolpos) arrangements to discuss treatment, including defibulation in cases of type III FGC may be quite difficult, given that minors usually need parental consent for such medical treatment.

Extensive review of legal standards and ethical approach to such discussions is beyond the scope of this review. It is recommended that providers consult their local child abuse pediatrician to further explore and review such issues.

Conclusions

FGC in children is underdiagnosed, has significant medical complications, serves no medical purpose, and poses both ethical and legal dilemmas for medical providers who care for affected children. National standards need to be developed for required training of pediatric and other providers and needs to include medical diagnosis, treatment, cultural, legal, and ethical training and support.

Compliance with Ethical Standards

Conflict of Interest Janine Young declares no potential conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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