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Awareness, Clinical Experience and Knowledge of Female Genital Mutilation/Cutting Among Female Pelvic Medicine and Reconstructive Surgeons in the United States



Hannah S. Thomas, Nnenaya A. Mmonu, Gregory Amend, Alexandra Dubinskaya, Crista Johnson-Agbakwu, Tami S. Rowen, Jennifer T. Anger, and Benjamin N. Breyer

OBJECTIVE To promote the recognition and care of patients with female genital mutilation/cutting (FGM/C),

we aimed to evaluate the awareness, clinical experience and knowledge of FGM/C among female pelvic medicine and reconstructive surgery (FPMRS) specialists. FGM/C is a cultural practice whereby there is removal of external female genitalia for non-therapeutic reasons. Despite the high prevalence of urogynecologic complications, there is a paucity of literature discussing FGM/

C from the lens of urologists and urogynecologists.

METHODS By cross-sectional design, we distributed a 27-item survey via email to members of the Society of

Urodynamics, Female Pelvic Medicine and Reconstructive Surgery. We collected variables pertaining to previous FGM/C education, clinical confidence, cultural and medical knowledge, and desire for

future education.

RESULTS A total of 54 US-based, mostly urologists and FPMRS specialists, completed the survey. All pro-

viders had heard of FGM/C; however only 13% received formal education during medical training. Over 50% had encountered a patient with FGM/C in clinical practice. Only 19% and 13% felt completely confident recognizing and discussing FGM/C, respectively. Seventy percent believed religious doctrine informed FGM/C practice and 24% correctly identified FGM/C type on clinical representation. Finally, only 17% of respondents were aware of FGM/C guidelines, and

providers expressed a desire for increased availability of multimodal resources.

CONCLUSION Education regarding FGM/C remains sparse and variable for US FPMRS specialists. Cultural and

clinical knowledge is also lacking, which is a detriment to patient care. In order to strengthen awareness and knowledge, we must develop high-quality FGM/C educational resources for urolo-

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n estimated 200 million women and girls have undergone female genital mutilation or cutting (FGM/C).¹ Defined as "the partial or total removal of external female genitalia or injury to the female genital organs for non-medical reasons," FGM/C is widely practiced in 31 different countries, centered in

Africa, Asia and the Middle East. In the United States (US), where it is illegal to perform FGM/C on any girl under the age of 18, the Center for Disease Control reports that approximately 513,000 women and girls have been affected.² Largely attributed to increased migration from countries where FGM/C is regularly practiced, this represents a three-fold increase in prevalence since 1990.² The World Health Organization (WHO) classifies FGM/ C into four main types: Type 1 (partial or total removal of the clitoris), Type 2 (removal of the clitoris and labia minora), Type 3 (narrowing of the vaginal opening) and Type 4 (all other harmful procedures ie, scraping, incising, cauterizing). FGM/C is performed for cultural reasons. including the belief that the practice is essential for womanhood and future marriage prospects. Women affected by FGM/C are at risk for harmful short-term complications such as haemorrhage, urinary retention and genital

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tissue swelling.³ In the long-term, women report significant urogynecologic and obstetrical complications as well as psychosexual morbidity.³

Surveys of US-based nurse-midwives and obstetricians have revealed significant gaps in providers' knowledge and awareness of FGM/C, 4,5 prompting organizations such as the American Academy of Pediatrics to construct policies/guidelines surrounding the issue. Women who have undergone FGM/C may present to multidisciplinary specialties for related or unrelated care. Research has found that up to 20% of FGM/C survivors report urological complications such as recurrent UTIs (10%-30%), lower urinary tract symptoms (LUTS) (10%-20%), and urogenital fistula (10%-15%), with increasing severity by WHO type. ^{7,8} In a cohort from Egypt, nocturia (39% of FGM/C patients), frequency (37%), urgency (32%), intermittency (24%) and incomplete emptying (23%) were the most commonly cited LUTS, with greater prevalence among patients with Type 2 and 3 FGM/C.9 Moreover, sexual dysfunction has been reported in up to 85% of cases of Types 1 and 2 FGM/C, 10 along with reports of decreased arousal, lubrication, orgasm and satisfaction. 11 Even without a urologic complaint patients may seek out female pelvic medicine and reconstructive surgery (FPMRS) specialists to provide information on options for surgical reconstruction, including clitoral reconstruction. 12 Despite the urogynecologic complications associated with FGM/C, the extent of awareness among urogynecologists, remains unknown.

In 2019, Atkinson et al outlined a series of important, emerging research priorities pertaining to FGM/C in the US. 13 As part of this call-to-action, authors emphasized the need to evaluate healthcare professionals' (HCPs) knowledge and awareness of the issue in order to standardize high-quality educational content and tools on FGM/C across a variety of relevant subspecialties, including urology. 13 To our knowledge, despite its ever-growing presence in the US, there have been minimal efforts to better understand how urologists and/or FPMRS specialists can best serve and care for patients with FGM/C. However, lessons from case studies dictate that we must work to strengthen US-based FPMRS providers' knowledge and awareness of FGM/C and associated referral/management recommendations.¹⁴ We aimed to evaluate the awareness, clinical experience and knowledge of FPMRS specialists practicing in the US regarding FGM/C. We sought to identify gaps in knowledge and future priorities for urology and FPMRS-focused FGM/C educational materials.

MATERIALS AND METHODS

Questionnaire Development

This cross-sectional study was conducted via a structured, online questionnaire. We formulated the questionnaire based on common questions derived from previously published work surrounding HCPs awareness and knowledge of FGM/C. 4,15,16,17,18 During this process, feedback was solicited from academics and clinicians with expertise in FGM/C research and practice,

regarding survey design. To mitigate selection bias towards a particular speciality/training background, comprehensive language was used throughout the questionnaire (eg, urologist/FPMRS/gynecologist). There is significant precedent for the use of questionnaires to assess HCPs knowledge and attitudes towards FGM/C. ^{19,20}

Study Sample

The survey was distributed to members of the Society of Urodynamics, Female Pelvic Medicine and Urogenital Reconstruction (SUFU) in December 2020. Originally a subspecialty society of urologists, SUFU is presently a specialty society of mostly FPMRS surgeons (both urologists and gynecologists), but includes any physician or researcher with interest in the field. Two requests for survey participation were advertised through society email communications. Eligible participants included SUFU members who were physicians practicing in the US. Survey data was collected and stored using the Research Electronic Data Capture platform.

Study Variables

A complete list of the 27 survey questions is provided in Supplementary Material 1. Provider demographics queried were age, gender, race/ethnicity, training and qualifications and type of practice. We also evaluated providers' clinical contact with refugee/immigrant patients from the most prevalent FGM/C-practicing areas of the world (Africa, Asia and the Middle East according to the WHO¹). At baseline, variables pertaining to general awareness of FGM/C were collected, including previous types of formal (training curricula) and informal (non-training curricula) learning. We subsequently inquired about providers clinical experience with FGM/C and, using Likert scales, quantified their confidence in both recognizing and discussing FGM/C with a patient.

To assess cultural knowledge, we evaluated respondents' knowledge of where FGM/C is largely performed and beliefs surrounding the practice. Further, guided by the WHO's standard classifications, providers were asked to identify types of FGM/C along with known, urogynecologic complications. We also inquired about their knowledge regarding FGM/C laws in the US.

Finally, in order to gauge providers' interest in future FGM/C learning, specific to FPMRS practice, we collected variables regarding the relevance of FGM/C to clinical practice, existing awareness of clinical practice guidelines and desire for future, multimodal resources.

Statistical Analysis

Descriptive analyses were carried out inside the Research Electronic Data Capture data storage and analysis platform. Due to the homogenous nature of the sample (ie, mostly urologists or FPMRS with urology residency, as compared to gynecologists), no differential comparisons were made between providers of different training backgrounds. Data is presented according to the STROBE guidelines (Supplementary Table 1).

Ethics

This project received ethical approval from the Institutional Review Board at the University of California, San Francisco [#20-31190].

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RESULTS

Demographics

A total of 54 SUFU members completed the survey (Table 1). Based on the number of members who "clicked" the survey link in both the first and second disseminated emails, the completion rate was 63% (54/86). Based on the number of SUFU members the email was sent to, the response rate was 8% (54/679). Over half of participants identified with the female gender (59.2%, 32/54), while twenty identified with the male gender (37%, 20/ 54). The majority of participants were 36-55 years (59.2%, 32/ 54; range: <25-66+ y/o) old and were White/Caucasian (61.1%, 33/54). Attending level providers represented 91% of respondents (49/54), with associated board certifications in urology (68.5%, 37/54) and gynecology (5.6%, 3/54). Fifty-six percent of respondents were board-certified in FPMRS (30/54). Two out of the three board-certified gynecologists were also FPMRS specialists. Approximately 48% of providers had been in practice for 16 years or more (26/54), with most working in a universityassociated healthcare setting (53.7%, 29/54). Survey participants' location of practice varied widely across the US. Finally, 96.2% of participants reported that refugee/immigrant patients from Africa, Asia and/or the Middle East comprised <20% of their clinical practice (52/54).

Awareness of FGM/C Among FPMRS Specialists

All participants reported they had previously heard of FGM/C prior to this survey (100%, 54/54) (Table 2). Approximately 85% of providers (46/54) reported they had never received education regarding FGM/C during formal medical training and curricula (medical school, residency, fellowship or otherwise). Conversely, 44% of providers (24/54) had experienced previous forms of FGM/C education from informal, non-medical curricular forums. Overall, most participants had learned about FGM/C from educational lectures/seminars (42.6%, 23/54), cultural humility/competency courses (14.8%, 8/54) and online postgraduate modules (13%, 7/54).

FPMRS Specialists' Clinical Experience with FGM/C

The majority of respondents had previously encountered a patient with FGM/C in clinical practice (57.4%, 31/54). Of those who reported clinical exposure, most had seen one to ten patients with FGM/C throughout their career (44.4%, 24/54). On a Likert scale, most participants felt 'somewhat' or 'fairly' confident in diagnosing FGM/C in clinical practice, while most felt only 'slightly' or 'somewhat' confident discussing FGM/C with a patient (Fig. 1). Few participants felt completely confident both recognizing (18.6%, 10/54) and discussing (13%, 7/54) FGM/C with a patient in clinical practice.

Knowledge of FGM/C Among FPMRS Specialists

The majority of participants cited Africa (92.6%, 50/54) and the Middle East (64.8%, 35/54) as regions where FGM/C is frequently performed; however only 37% noted Asia (20/54) (Table 3). When asked about practice motivations, 24% of participants believed FGM/C is performed on the basis of religion (13/54), and 44% believed the practice was multi-factorial- due to tradition, beliefs around women's beauty, marriageability, sexual pleasure and religion (24/54). Only 37% of participants identified the correct number of WHO's FGM/C broad classification types (20/54), and 24% correctly identified the WHO type of FGM/C in a clinical representation (13/54). Respondents were most commonly aware of sexual dysfunction as a long-term

Table 1. Demographics of survey participants

Table 1. Demographics of survey participant	IS
Demographic	Participants n (%)
Gender	
Male	20 (37)
Female	32 (59.2)
Gender non-conforming	1 (1.9)
Prefer not to answer	1 (1.9)
Age	1 (1.5)
<25	1 (1.9)
25-35	7 (13)
36-45	14 (25.9)
46-55	18 (33.3)
56-65	11 (20.4)
66+	3 (5.6)
Race/ethnicity (all that apply)	0 (0.0)
American Indian or Alaskan Native	0 (0)
Asian/Pacific Islander	8 (14.8)
Black/African American	4 (7.4)
Hispanic/Latino	1 (1.9)
White/Caucasian	33 (61.1)
Multiple ethnicity	0 (0)
Prefer not to answer	5 (9.3)
Other	2 (3.7)
Training Level	_ (-:- /
Resident	1 (1.9)
Fellow	3 (5.6)
Attending	49 (90.7)
Qualifications (all that apply)	,
Board-cert urologist	37 (68.5)
Board-cert gynecologist	3 (5.6)
Board-cert FPMRS	30 (55.6)
Other	4 (7.4)
Years practicing as FPMRS/	
urologist/gynecologist	
1-5	8 (14.8)
6-10	10 (18.5)
11-15	9 (16.7)
16+	26 (48.1)
Practice type	
University hospital or clinic	29 (53.7)
Private hospital or clinic	19 (35.2)
Locum	1 (1.9)
In training	1 (1.9)
Retired	0 (0)
Other	1 (1.9)
Practice location (all that apply)	10 (00 0)
Northeast	12 (22.2)
Midwest	13 (24.1)
Southeast	6 (11.1)
Southwest	10 (18.5)
West	14 (25.9)
Proportion of refugee/immigrant patients	50 (OS 0)
0%-20% 21%-40%	52 (96.2) 1 (1.9)
41%-60%	0 (0)
61%-80%	0 (0)
>80%	0 (0)
/ UU / U	U (U)

Note: Not all totals add to n=54 due to incomplete responses. FPMRS, female pelvic medicine and reconstructive surgeon.

complication of certain forms of FGM/C (100%, 54/54) and less commonly aware of infertility as a long-term complication (66.7%, 36/54). Finally, 80% of participants were aware that FGM/C is illegal in the US (43/54); however, 17% were unsure (9/54).

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Table 2. Awareness of FGM/C among US FPMRS specialists

Variable	Participants n (%)
	(- /
Have you heard of FGM/C before?	
Yes	54 (100)
No	0 (0)
Unsure	0 (0)
	0 (0)
Prior FGM/C in medical training?	7 (40)
Yes	7 (13)
No	46 (85.1)
Unsure	1 (1.9)
Prior FGM/C outside medical training?	,
Yes	24 (44.4)
No	30 (55.6)
110	,
Unsure	0 (0)
Prior modes of FGM/C education	
Educational lectures/seminars	23 (42.6)
Cultural humility/competency courses	8 (14.8)
Online postgraduate modules	7 (13)
International electives	4 (7.4)
Published literature	4 (7.4)
	` ,
Child protection courses	1 (1.9)
Other	11 (20.4)

FGM/C, female genital mutilation/cutting; FPMRS, female pelvic medicine and reconstructive surgeon.

Future FGM/C Resources for FPMRS Specialists

Overall, 89% of participants believed that FGM/C and its' associated health consequences were relevant to their practice (48/54). However, only 17% were aware of guidelines related to the presentation and management of FGM/C. FPMRS specialists were interested in further FGM/C education in the form of online training modules (57.4%, 31/54), clinical practice guidelines (51.8%, 28/54) and peer-reviewed publications (48.1%, 26/54) (Supplementary Fig. 1).

COMMENT

Our study provides a novel depiction of the awareness, clinical experience and knowledge of US-based FPMRS specialists towards FGM/C. At baseline, all respondents were aware of FGM/C; very few received education on the topic during medical and/or postgraduate training. This lack of formal FGM/C education is not unique to the US, and is a problem with international medical curricula as well.^{21,15} In our cohort, it appears that when FPMRS specialists' do receive FGM/C education, this is delivered via informal curricula, thereby introducing uncertainty regarding the quality of teaching and reliability of sources. In 2001, the WHO published a comprehensive guideline for integrating FGM/C teaching within nursing and midwifery curricula; however, formal strategies for integration into medical and/or postgraduate curricula remain to be seen.²² With known, long-term genitourinary complications such as recurrent UTIs, LUTS, urogenital fistula and sexual dysfunction, there remain existing gaps and opportunities for integration of FGM/C education into urology and gynecology training alike.8

Over half of our respondents, which largely included FPMRS specialists from both urology and gynecology, had encountered a patient with FGM/C in clinical practice. Comparatively, this rate of clinical exposure is similar to that of a Swedish cohort of gynecologists, paediatricians and allied healthcare providers. ¹⁸ Among pediatricians in Australia, approximately 10% of providers had encountered a child with FGM/C. ¹⁶ In the US, there are known regional concentrations of patients with FGM/C, which may increase local prioritization and clinical implications of the condition. ² However, as women's health providers, we believe FPMRS specialists play an essential role in both the care and advocacy for patients with FGM/C, regardless of practice location. In addition, evolving data

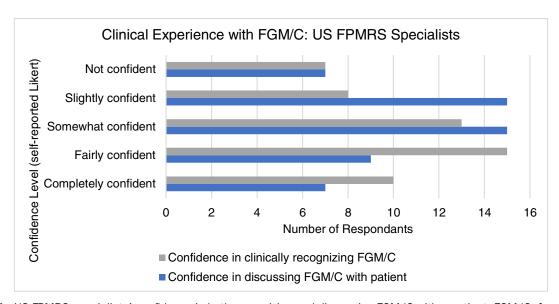
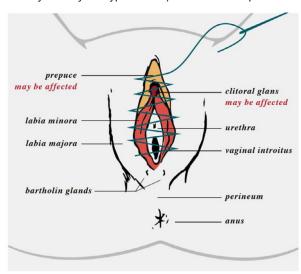


Figure 1. US FPMRS specialists' confidence in both recognizing and discussing FGM/C with a patient. FGM/C, female genital mutilation/cutting; FPMRS, female pelvic medicine and reconstructive surgery. (Color version available online.)

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Variable	Participants n (%)
What regions of the world FGM/C is frequently performed?	
Africa*	50 (92.6)
Middle East*	35 (64.8)
Asia*	20 (37)
North America	6 (11.1)
South America	0 (0)
Unsure	0 (0)
FGM/C is largely performed due to the belief that	
It keeps an important tradition alive*	22 (40.7)
It makes a woman more beautiful*	9 (16.7)
It makes a woman more marriageable*	20 (37)
It keeps a woman from having pleasure during sexual relations*	23 (42.6)
It is required by their religion	13 (24.1)
All of the above	24 (44.4)
Do not know	3 (5.6)
As classified by the WHO, how many types of FGM/C are there?	
Three	4 (7.4)
Four*	20 (37)
Six	0 (0)
Seven	0 (0)
Unsure	29 (53.7)

Correctly identify the type of FGM/C in the below photo



Type 1 Type 2 Type 3* Type 4	1 (1.9) 5 (9.3) 13 (24.1) 8 (14.8)
Unsure	27 (50)
Are genital piercings, cosmetic labiaplasty considered a form of FGM/C? Yes No Unsure*	9 (16.7) 30 (55.6) 15 (27.8)
Urologic complications	,
Recurrent UTIs* LUTS* Infertility* Urogenital fistula* Sexual dysfunction* Other	49 (90.7) 49 (90.7) 36 (66.7) 49 (90.7) 54 (100) 1 (1.9)
Is it legal to perform FGM/C on women under 18 in US?	
Yes	2 (3.7)
No*	43 (79.6)
Unsure	9 (16.7)

Note: Not all totals add to n=54 due to incomplete responses.

FGM/C, female genital mutilation/cutting; LUTS, lower urinary tract symptoms; UTIs, urinary tract infections; WHO, world health organization.

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^{*} Correct response.

regarding the safety and efficacy of reconstructive surgery for FGM/C is relevant to FPMRS surgical expertise. 12

On the whole, FPMRS providers in this cohort appeared to feel less confident discussing FGM/C with a patient (compared to recognizing or diagnosing the condition). Clinical directives and guidelines may help to overcome these expressed concerns. Women with FGM/C report disempowerment and disrespect in regular interactions with HCPs, therefore there is an essential need for early patient engagement and input when crafting clinical tools such as guidelines or policy statements. ^{23,24}

Misperceptions and lack of knowledge further underscore the need for increased FGM/C-related education, particularly when it comes to cultural beliefs and clinical knowledge. Our results demonstrate a widespread assumption that FGM/C is a practice associated with religious doctrine- this belief is consistent with literature surrounding nurse-midwives. The reasons behind FGM/C are rooted in deep cultural and societal customs and beliefs surrounding young women's sexual repression and transition from girlhood. The WHO informs that there are no religious scripts that advise the practice, therefore it is important to not ascribe FGM/C to a singular religious body. The word in the practice of the p

Approximately half of respondents in this study were unsure about the classification system for FGM/C and how to appropriately recognize and distinguish between types. This type of clinical knowledge remains poor among primary healthcare professionals and obstetric providers as well. ^{17,15} Efforts to expand FPMRS specialists' knowledge surrounding the medical logistics of FGM/C is crucial in order to strengthen both recognition and explanation of the condition, as well as management strategies for long-term morbidity.

Finally, despite believing the topic was relevant to their practice, there was a widespread lack of awareness of existing guidelines for FGM/C and ultimately a desire for future, multimodal educational resources. Resources like the International Continence Society's white paper on FGM/C represent an important start; however further work needs to be done in order to elevate comprehensive FGM/C teaching relevant to urology and FPMRS providers and the patients they treat.²⁵ In our cohort, it appears that FPMRS specialists desire to acquire greater education on the subject in the form of online training modules, clinical practice guidelines and peer-reviewed publications. Work such as that done by Abdulcadir et al enforces high-quality FGM/C resources for HCPs. 26 Support from national and international urogynecologic organizations will aid further integration of FPMRS specialists into this topic, such as through the development of professional society guidelines. At the end of our survey, high-quality, validated FGM/C resources were provided to participants for further review. This step, while small, served to encourage further learning and discussion of FGM/C among our community of participating surgeons.

FGM/C is an infrequently investigated topic in existing urology literature and journals, and we believe this study represents an important step towards future investment

and research surrounding the topic. However, our study has limitations worth of mention. In 2015, there were 1,133 FPMRS specialists reported in the US.²⁷ Therefore, our sample captured a relatively small proportion of the total US-based FPMRS population. While this limits the external validity of the results, our findings attempt to provide novel insight into the topic among this community of women's health practitioners. There may have also been a selection bias among survey participants in which those with a pre-existing interest in FGM/C were more likely to participate. In this way, awareness and knowledge surrounding FGM/C among urogynecologists may be even less than what we captured in this sample. However, reported clinical experience with FGM/C patients was low and participants were from various US regions, possibly indicating there was no overt regional bias towards clinicians practicing in areas with a high FGM/C prevalence. Finally, in future work it would be valuable to further investigate the FGM/C patients' perspectives regarding clinical encounters with FPMRS professionals. This would serve to strengthen our awareness of the practice and better understand how to translate future knowledge into meaningful, patient-centered clinical care.

CONCLUSIONS

Overall, our study provided novel insight into FPMRS specialists' awareness and knowledge surrounding FGM/C. In the US, where FGM/C is becoming increasingly prevalent due to globalization, it is vital that providers with urogynecologic training both understand and advocate for this patient population. The continued development of high-quality educational resources, targeted at relevant FPMRS practice, may prove essential to strengthen the care and advocacy towards patients with FGM/C. Continued investment in research that expands understanding of the nuances of FGM/C, including patients' perceptions of clinical care, is also warranted.

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SUPPLEMENTARY MATERIALS

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