Summer 7-2-2018

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Journal of Immigrant and Minority Health
https://doi.org/10.1007/s10903-018-0782-x

ORIGINAL PAPER

Depression, Anxiety, Post-traumatic Stress Disorder and a History of Pervasive Gender-Based Violence Among Women Asylum Seekers Who Have Undergone Female Genital Mutilation/Cutting: A Retrospective Case Review

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Abstract
We sought to evaluate the frequency of anxiety, depression, PTSD, and any experiences of violence in women who had undergone Female Genital Mutilation/Cutting (FGM/C) and were seeking asylum in the United States. We undertook a retrospective qualitative descriptive study of FGM/C cases seen in an asylum clinic over a 2-year period. Standardized questionnaires provided quantitative scores for anxiety, depression and PTSD. Clients' personal and physician medical affidavits were analyzed for experiences of violence. Of the 13 cases, anxiety and depression were exhibited by 92 and 100% of women, while all seven women screened for PTSD had symptoms. Qualitative analysis revealed extensive violence perpetrated against these women, demonstrating that FGM/C is only part of the trauma experienced. The high level of mental health disorders and endured violence has implications for providers working with FGM/C survivors and indicates the need for accessible mental health services and trauma-informed care.

Keywords Mental health · Depression · Anxiety · PTSD · Female genital mutilation/cutting · Gender-based violence · Asylum seekers

Introduction

Approximately 200 million women worldwide in 30 countries that routinely practice female genital mutilation/cutting (FGM/C) have undergone the procedure [1]. While 24 of these nations have outlawed the practice, enforcement is negligible, and FGM/C remains widespread [2]. The World Health Organization (WHO) defines FGM/C as: "all procedures that involve the partial or total removal of external genitalia or other injury to the female genital organs for non-medical reasons" [3]. Numerous studies have linked the practice to myriad negative medical outcomes, including post-partum hemorrhage, obstructed labor, recurrent urinary tract infections, infertility, painful intercourse, and sexual dysfunction [4, 5]. The psychological impact of FGM/C is less well described, although studies to date report that depression, anxiety, and post-traumatic stress disorder (PTSD) are prevalent among women with FGM/C [4, 6, 7]. A recent World Health Organization (WHO) publication on guidelines on the management of health complications from FGM/C calls for additional research into the practice's

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Published online: 02 July 2018

psychological effects and for the development of effective treatment modalities that are culturally appropriate for the target communities [8].

Previous studies have shown an increased prevalence of anxiety, depression, and PTSD among women with FGM/C in their home countries compared with women without FGM/C in their home countries [4, 9, 10]. A 2005 study found that 23 Senegalese women with FGM/C showed a significantly higher prevalence of PTSD (30.4%) and other psychiatric syndromes (47.9%) than 24 unexcised Senegalese women [9]. A 2010 study of 1842 pregnant women with FGM/C seen in antenatal clinics in Kuwait found that 80% continued to have flashbacks to the FGM/C event, 58% had an affective disorder, 38% had anxiety disorders, and 30% had PTSD [4]. A 2011 study of 79 excised Kurdish girls in Northern Iraq between 8 and 14 years of age compared with 30 unexcised girls from the same area and 31 unexcised girls from other areas of Iraq revealed that girls with FGM/C showed a significantly higher prevalence of somatic disturbance (36.7%), anxiety disorder (45.6%), depression disorder (33.6%), and PTSD (44.3%) than the unexcised girls [10].

Far fewer investigations have been undertaken in the context of resettlement. In a 2015 study of a mixed population of 66 women with FGM/C from five African countries (Somalia, Sudan, Eritrea, Ethiopia or Sierra Leone) who had previously immigrated to or were in the process of seeking asylum in The Netherlands, Knipscheer and colleagues found that 30%, 33%, and 20% met the criteria for anxiety, depression, and PTSD respectively, and 18% of them met the criteria for all three disorders [11]. There currently remains a large gap in in the literature regarding the mental health of FGM/C women in resettlement situations.

Since the 1990s, the United States has seen a marked increase in the immigration of individuals from FGM/C practicing countries [12]. Experts currently estimate that about 513,000 women and girls now living in the US have emigrated from FGM/C-practicing countries or have been born in the US to mothers from countries where FGM/C is prevalent, and, thus, have either already undergone FGM/C or are perhaps at risk of being cut [13]. With the influx of immigrants, there has been a corresponding increase in the number of women applying for asylum based on their history of FGM/C [12]. The Mount Sinai Human Rights Program (MSHRP) in New York City is a network of clinical evaluators—physicians, psychologists, nurse practitioners, and licensed clinical social workers—who conduct pro-bono forensic medical evaluations for asylum seekers (clients) who have suffered human rights abuses, including FGM/C. Trained to conduct culturally-sensitive forensic exams, the clinical evaluator documents physical and/or psychological sequelae of persecution and submits an affidavit as part of the client's asylum application. It is important to note that MSHRP clinical evaluators do not provide medical or psychological treatment for asylum clients, although clients are often connected to appropriate medical, psychological, and social services, on a case-by-case basis.

To date, few studies have investigated the mental health profile of women with FGM/C in the US. The purpose of our study is to describe the mental health status of our FGM/C-affected clients who are seeking asylum in the US primarily due to their FGM/C status, as well as other gender-based persecutions. Our findings may aid in the development of follow-up care protocols and provision of improved services for survivors of FGM/C and other gender-based persecutions who are seeking asylum.

Methods

We undertook a retrospective qualitative descriptive study [14] of all FGM/C women who were seeking asylum and seen in the MSHRP from November 2014 to November 2016. This study was reviewed and approved by the Mount Sinai Institutional Review Board. All records were de-identified, and personal health information was protected in accordance with the IRB-approved protocol. Inclusion criteria were: (1) adult women > 18 years of age who were applying for asylum in the US primarily on the basis of FGM/C; (2) completed medical/gynecological examination; and (3) completed Hopkins Symptoms Checklist-25 (HSCL-25). In addition, results from the Harvard Trauma Questionnaire Revised-Part IV (HTQR-IV) were included in the review in those cases in which it had been administered. Women applying for asylum on account of FGM/C who present to the MSHRP are routinely administered the HSCL-25, which is used to screen for anxiety and depression, and are sometimes administered the HTQR-IV, which is used to screen for traumatic life events and PTSD. Both questionnaires have been shown to be reliable and valid tools for the evaluation of trauma-related mental health disorders in refugees [15–17]. In addition, they have been used specifically to evaluate immigrant women who have suffered FGM/C [11]. The MSHRP first began using the HSCL-25 for psychological evaluations of FGM/C women and, once the disease burden in this population was revealed, added the HTQR-IV to capture PTSD. Thus, fewer clients included in this study had completed the HTQR-IV than had completed the HSCL-25. All clients were fluent in either English or French and all were evaluated by one physician (author DO), who is fluent in both languages. French versions of both the HSCL-25 and HTQR-IV have been previously validated [18, 19].

We conducted an analysis of the results of the clients' psychological questionnaires. Anxiety and depression scores were calculated from results of the HSCL-25, which had

been administered to 13 (100%) of the women, and PTSD scores from results of the HTQR-IV, which had been administered to 7 (54%) of the women. In addition, answers to individual questions on each instrument were examined across clients for recurring or common patterns of symptomatology. Answers on both instruments are reported on a four-point scale from 1 (not at all) to 4 (extremely), with higher values indicating the increased likelihood that the respondent has symptoms associated with trauma. For the HSCL-25, an average value of ≥ 1.75 is consistent with a diagnosis of anxiety or depression, while for the HTQR-IV, a value of ≥ 2.0 is consistent with PTSD [16].

In addition, for each case, we conducted a qualitative content analysis of the client's personal affidavit and physician's medical affidavit by first utilizing a standardized form, recording data regarding demographic information, type of asylum claim, reasons and basis for seeking asylum, physical and psychological sequelae post FGM/C, any previous diagnosis of a mental health condition and/or treatment for a condition, and broadly, whether there was any history of violence suffered in addition to FGM/C. Second, we sought to describe what experiences of violence each woman had reported either in her personal narrative or to the physician evaluator as recorded in the physician's affidavit. We explored FGM/C as a marker among our clients for having suffered additional kinds of violence against women, defined as "any act of gender-based violence that results in, or is likely to result in, physical, sexual, or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life" [20]. All team members individually read both affidavits for all 13 clients and logged each specific instance of violence exactly as noted in the contents of the client records. The team then utilized the constant comparative method [14] to code for categories of violence and combine specific instances of violence into "kinds" of violence. Frequencies of kinds were then tallied. Kinds of violence were then grouped into three major types: physical, psychological, and sexual. Physical violence was defined as physical abuse perpetrated by another member of the household, extended family, or community; psychological violence was defined as verbal humiliation or degradation, or having been threatened or made fearful of harm/danger by one or more individuals; and sexual violence was defined as coerced or forced sexual contact of any kind.

Results

Thirteen cases met the inclusion criteria (Table 1). The mean age of the clients at the time of evaluation was 34 years (SD = 9.0). The vast majority of women came from West Africa (n = 12, 92%), particularly The Gambia (5, 38%), Burkina Faso (2, 15%) and Guinea (2, 15%). Over three-quarters of the women (11, 85%) applied for asylum through the affirmative application process.[1] All women in the study were seeking asylum based on persecution due to "membership in a particular social group" (i.e., women forced to undergo FGM/C), one of the five protected grounds for asylum in the US [21]. Additional reasons for seeking asylum included severe domestic violence (3, 23%), sexual violence (3, 23%) and human trafficking (1, 8%). The mean age at the

Table 1 Characteristics of study sample (n = 13)

Mean age (SD)	34 (9.0)
Mean age at FGM/C (SD)	9 (6.1)
	n (%)
Country of origin	
Burkina Faso	2 (15)
Djibouti	1 (8)
The Gambia	5 (38)
Guinea	2 (15)
Liberia	1 (8)
Nigeria	1 (8)
Sierra Leone	1 (8)
Type of asylum case	
Affirmative	11 (85)
Defensive	2 (15)
Basis for asylum application	
Race	0 (0)
Religion	2 (15)
Nationality	0 (0)
Membership in a social group	13 (100)
Political opinion	7 (54)
Reasons for seeking asylum	
FGM/C	13 (100)
Severe domestic violence	3 (23)
Sexual violence	3 (23)
Human trafficking	1 (8)
Type of FGM/C	
Type I	0 (0)
Type II	11 (85)
Type III	2 (15)

[1] "To affirmatively apply for asylum, a foreign national must submit Form I-589 to the United States Custom and Immigration Services (USCIS). When applying for affirmative asylum, a foreign national must be present in the United States. This application needs to be filed within a year of the foreign national's last arrival in America, unless the individual can show changed circumstances that affect his or her eligibility for asylum. After filing, the foreign national then meets with an asylum officer who determines whether or not the case is approved. If it's not approved, the case is referred to an immigration judge." From http://immigration.findlaw.com/asylum-refugee/affirmative-asylum-applications-vs-defensive-asylum-applications.html.

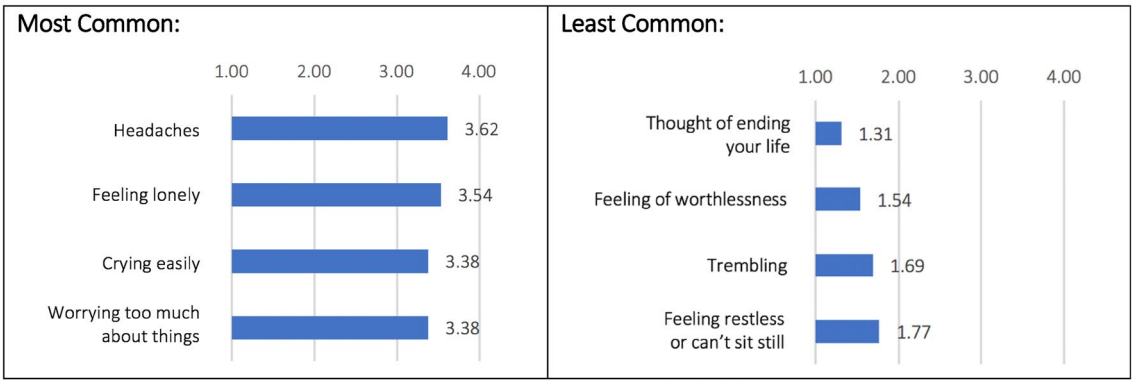

Fig. 1 Most and least common symptoms reported on the HSCL-25. HSCL-25 scored on a four-point scale: 1 = "not at all"; 2 = "a little"; 3 = "quite a bit"; 4 = "extremely"

time of undergoing FGM/C was 9 years (SD = 6.1). As determined by gynecologic examination, the majority of women (11, 85%) exhibited Type II FGM/C, while the remaining women (2, 15%) exhibited Type III.[2] It should be noted that all but the last evaluation was completed prior to the release of the revised WHO 2016 typology of FGM/C [22]. For the sake of consistency, we used the older typology classification for the final client seen in July 2016.

Of the 13 women, checklist positive scores from the HSCL-25 (≥ 1.75) indicated anxiety in 12 of 13 (92%) and depression in 13 of 13 (100%) respondents, respectively. Anxiety scores ranged from 1.50 to 3.40, with a mean of 2.47 (SD = .49). Depression scores ranged from 2.00 to 3.20, with a mean of 2.56 (SD = .38). All seven women screened with the HTQR-IV had checklist positive scores, indicating they met the criteria for PTSD (≥ 2.0). PTSD scores ranged from 2.31 to 3.31, with a mean of 2.77 (SD = .35).

As indicated by responses to the HSCL-25, the most commonly reported symptoms ranked by mean score were: headaches (3.62), feeling lonely (3.54), crying (3.38), and worrying too much about things (3.38). The least common symptoms reported were: thoughts of ending life (1.31), feeling of worthlessness (1.54), trembling (1.69) and feeling restless or can't sit still (1.77) (Fig. 1).

The most commonly reported symptoms ranked by mean score in the HTQR-IV were: recurrent thoughts or memories of the most hurtful or terrifying events (3.86), trouble sleeping (3.71), difficulty concentrating (3.43), sudden emotional or physical reaction when reminded of traumatic or hurtful experiences (3.43), and feeling that someone betrayed you (3.43). The least common symptoms reported were: feeling that you are the only one that suffered these events (1.29), feeling a need for revenge (1.29), blaming yourself for things that have happened (1.43), feeling guilty for having survived (1.43), hopelessness (1.43), and feeling as if you don't have a future (1.42) (Fig. 2).

During their forensic evaluations, two of the 13 women spontaneously reported that they had received treatment for their psychological symptoms; however, this data is not routinely gathered in the setting of a forensic examination and thus may underestimate treatment-seeking behavior by our clients.

The major physical sequelae self-reported by the women included sexual dysfunction (10, 77%), complications with childbirth (6, 46%), pain with menstruation (5, 38%), heavy menstruation (4, 31%), and chronic abdominal/pelvic pain (4, 31%) (Table 2).

The analysis of the clients' personal affidavits and the physician's medical affidavits revealed the frequency of the major types of violence experienced by the women, in addition to FGM/C. Of the 13 women, 10 (77%) had experienced physical violence; 11 (85%) had experienced psychological violence; and 6 (46%) had experienced sexual violence. All women experienced at least one type of violence in addition to undergoing FGM/C. Many women (10, 77%) had experienced more than one type of violence, with some (4, 31%) experiencing all three—physical, psychological or sexual. Within these three major types, the most common kinds of violence were fear of physical violence (6, 46%), domestic violence (5, 38%), forced marriage (4, 31%), the threat of forced marriage (4, 31%), and polygamy (4, 31%) (Table 3).

Discussion

We have presented a retrospective qualitative descriptive study of the results of validated psychological questionnaires and of the personal and medical affidavits of 13 women who

[2] The World Health Organization defines FGM/C Type II as "excision of the labia minora in addition to the clitoris," while Type III is defined as "the narrowing of the vaginal opening by the approximation of either the labia minora or the labia majora, with or without clitoridectomy."

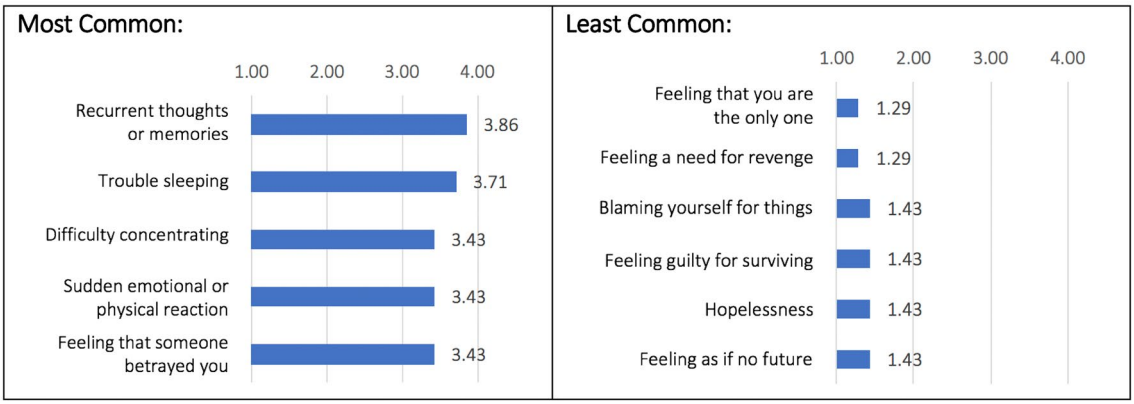

Fig. 2 Most and least common symptoms reported on the HTQR-IV. HTQR-IV scored on a four-point scale: 1 = "not at all"; 2 = "a little"; 3 = "quite a bit"; 4 = "extremely"

Table 2 Physical sequelae of FGM/C (n = 13)

Physical sequela	n (%)
Sexual dysfunction (pain and/or lack of interest)	10 (77)
Complications with childbirth	6 (46)
Pain with menstruation	5 (38)
Heavy menstruation	4 (31)
Chronic abdominal/pelvic pain	4 (31)
Vulvar itching	3 (23)
Frequent infections	3 (23)
Pain with urination	2 (15)
Difficulty becoming pregnant	1 (8)
Facial disfigurement/paralysis	1 (8)
Frequent menstruation	1 (8)

Table 3 Self-reported history of additional violence (n = 13)

	n (%)
Type of violence	
Physical	10 (77)
Psychological	11 (85)
Sexual	6 (46)
Kind of violence	
Fear of physical violence	6 (46)
Domestic violence (DV)	5 (38)
Forced marriage	4 (31)
Threat of forced marriage	4 (31)
Polygamy	4 (31)
Rape/sexual assault outside of DV	2 (15)

were seeking asylum in New York primarily due to FGM/C. We found increased rates of anxiety (92%), depression (100%), and PTSD (100%) among our sample population of asylum seekers compared with rates previously reported in the literature. The findings also reveal that our FGM/C asylees have experienced a lifelong arc of violence that extends beyond their genital cutting. FGM/C has not been an isolated experience for these women, rather it is one of many kinds of gender-based violence (GBV) that have permeated their lives. We postulate that the substantially increased psychological burden found among our clients compared to those in other studies is multifactorial.

One primary source of increased psychological distress among our clients is the high prevalence of other kinds of violence the women reported having suffered. All of our clients were seeking asylum due to "membership in a particular social group" as defined by their gender and the harm they had experienced or they feared would continue to experience on the basis of being female. It is therefore not surprising that our clients reported a high frequency of other kinds of GBV, in addition to their FGM/C. This hypothesis is supported by findings by Akinsulure-Smith and Chu who evaluated 514 African-born women at intake at the Bellevue/NYU Program for Survivors of Torture (PSOT) [7]. They found that a significantly larger proportion of women who reported having undergone FGM/C had also experienced psychological and sexual torture (e.g., violence) as compared to women without FGM/C. Their data revealed that the higher prevalence of psychological and sexual violence in FGM/C women, unlike the control non-FGM/C group, correlated with higher HTQR-IV scores, indicating more psychological distress. Compared to other studies, the Akinsulure-Smith and Chu population is most similar to our own, as both include African-born women living in the US, although the women in their study had a wide range of immigration statuses ranging from being undocumented to having citizenship. Nonetheless, their findings corroborate our own in that FGM/C-affected women tend to have higher rates of additional GBV, which presumably contribute to increased rates of anxiety, depression and PTSD.

In addition, the increased frequency of psychological sequelae among our clients may be due to the psychological stressors stemming from the very process of seeking asylum. The asylee population is a distinct one, not to be elided with the larger population of immigrants. The asylum-seeking process has its own dynamic, including inherent uncertainties, and has been shown to cause stress and affect health [23, 24]. Asylees have statistically significant higher scores than immigrants on measures of past trauma, symptoms of anxiety, depression, PTSD and on all dimensions of post-migratory difficulties [25]. This differentiation of asylees from other immigrants may explain the difference in frequencies of mental health sequelae we found compared to that of Knipscheer and colleagues (whose population included non-asylees as well as asylees), the only study identified occurring within a resettlement context [17]. It is therefore reasonable to hypothesize that the increased psychological distress found among our clients may partially derive from the arduous legal process of seeking asylum in the United States. Furthermore, asylees attempting to rebuild their lives in the US may experience additional stressors that are related to the acculturation process, including facing myriad socioeconomic hardships as well as an increasingly hostile political climate due to a growing anti-immigration sentiment among the US population. In sum, our findings of higher rates of psychological distress among our study population, as compared with prior studies, is likely due to three primary factors: the high prevalence of having experienced multiple kinds of GBV, the stressors integral to the asylum process, and the additional stressors inherent in acculturating into American society.

One major limitation of our study is the small sample size of 13 women. A second limitation is that the majority of the women in our review (11) had undergone Type II FGM/C. Thus, our findings cannot be generalized to women who have undergone Type III, although given that Type III is more severe with infibulation the hallmark, we postulate that both the physical and psychological complications are more injurious. A third limitation is that the sample is drawn from a highly specific population: FGM/C survivors seeking asylum in New York City, with the majority also, incidentally, coming from West African nations. FGM/C women who are seeking asylum in the US likely form a distinct group of traumatized women, with distinct emotional and social needs arising from both extensive histories of GBV and the unique stressors inherent in both the asylum and acculturation processes in America. These specific characteristics of our study sample limit the generalizability of the results not only in terms of FGM/C survivors, but also in terms of broader resettlement and refugee settings. Additional studies are required to corroborate our findings and, if confirmed, would call for further exploration of the type of FGM/C experienced (e.g., Type II vs. Type III), the interplay between a history of FGM/C with other kinds of GBV, and the subsequent effects on the mental and physical health of survivors. More refined research should investigate the specific experiences of women seeking asylum, particularly asylum claims based on various forms of gender persecution, to understand the nuances of subpopulations of women.

Nonetheless, the elucidation of the most common psychological symptoms exhibited by our FGM/C clients may be helpful in the clinical evaluation of similarly affected women. The high frequency of mental health disorders among them has major implications for health providers working with FGM/C survivors who are also asylum seekers. The need for and provision of mental health services among FGM/C survivors is rarely given emphasis in articles that discuss the care of women with FGM/C, even though many studies suggest that mental health issues are more common than physical sequelae, such as infibulation, which receive the most attention. Our findings indicate the need for greater attention to be paid to mental health issues among this population and the further development of culturally-sensitive and linguistically-accessible mental health services that recognize the complex psychological trauma often suffered by these women. Additionally, knowledge of the often-concomitant history of other kinds of gender-based violence among FGM/C women should prompt all providers, not just mental health specialists, to screen for such experiences and provide care or referral accordingly. Finally, we need to better understand the health-seeking behavior of FGM/C survivors themselves, particularly for mental health issues. What are the immigrant community's perceptions around mental health, and how does cultural stigma or personal shame interfere with health seeking behavior? What steps need to be taken to enhance help-seeking behavior on the part of these traumatized women? Clearly, major gaps remain in the identification, care and treatment of FGM/C women regarding their mental health needs.

New Contribution to the Literature

This retrospective qualitative descriptive study describes the mental health profile and specific psychological symptomatology in the context of documenting histories of extensive gender-based violence among women with FGM/C who are seeking asylum in the United States.

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