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Understanding Female Genital Mutilation Experiences to Inform Future Healthcare Practices

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Abstract

This study explored the pattern of Female Genital Mutilation and how it affects both those who have undergone the procedure and the healthcare professionals tending to them particularly in San Diego County. The participants were divided into two groups; the first one was six women who have undergone Female Genital Mutilation. The second group consisted of six healthcare professionals in San Diego County who tend to patients who have undergone the procedure. The researchers held interviews for both groups although the survey questions differ between the two groups. Each group was also required to sign consent before beginning the interview. The first aim of this research was to assess knowledge of FGM among health service providers in San Diego County. This was achieved by going to different hospitals and clinics and conducting surveys for some of the faculty and staff. This was detrimental to gauging the healthcare professional's knowledge of Female Genital Mutilation. The second aim was to develop materials that are culturally competent, which can be used for clinical management training for healthcare professionals. In order to achieve this objective, the researchers created an informative booklet that provides: background information for Female Genital Mutilation, explains what the procedure is and the different forms of cutting, what areas are known to perform the procedures and lastly it has recommendations for training and advocacy. Results are discussed and separated in terms of information gathered, analyzed and interpreted from the interview questions of both the Female Genital Mutilation participants and the healthcare professionals.

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Introduction

The World Health Organization (WHO) estimates that approximately 140 million women and girls have undergone Female Genital Mutilation (FGM) worldwide (Reisel and Creighton 2015). Considering that the FGM procedure is shrouded in secrecy, experts believe that the reported number is a gross underestimation of the actual number of females that are affected. FGM, also known as female genital cutting or female circumcision, is a procedure that intentionally alters or removes parts of the female genitalia for non-medical reasons (Terry and Harris 2013). The intended purpose of FGM is to limit and/or control the sexuality of the female with an understanding that it will be preventing masturbation and libido and ultimately preserving women's sexuality within these communities.

The FGM procedure is considered harmful as it often leads to both immediate and long-term complications. FGM is a very prevalent and is socially and culturally accepted practice that has been reported in about 28 countries, including regions of Africa, Middle East, and Asia (Feldman-Jacobs 2010). Although FGM has not been specifically advocated by religious beliefs and does not appear anywhere in the Quran or Bible, it has been adopted and is acceptable in both Muslim and Christian communities throughout the world. Elderly women of affected communities are often the torchbearers for FGM because they play key roles in performing the procedures and perpetuating the tradition while the men in the communities often remain as bystanders with no definitive roles in

the procedure (Perron et al., 2013). Their pacification stems from the preferred status that is given to women who have undergone female genital mutilation because they are looked upon as desirable during marriage. The aim of this paper is to better understand female genital mutilation, to inform future healthcare professionals.

Types of FGM

Female genital mutilation is classified into four major types based on their consequences. The World Health Organization identifies four major types of FGM classifications, including Types I, II, III and IV (WHO, 2008). Type I FGM is clitoridectomy and consists of partial or total removal of the clitoris. Clitoridectomy is considered the most common type of FGM procedure undergone by young girls and women who often experience no sexual desire (Rashid and Rashid 2007).

Type II FGM involves excision (partial or total removal) of the clitoris and the labia or the outer lips of the vagina (WHO 2008). A number of researchers have reported that approximately 55% of women with Type II FGM suffered from both long-term and short-term complications (Kaplan et al., 2011). The most common risk complications reported for females who have undergone Type II FGM include hemorrhages, scarification, and genital infections.

Type III FGM is infibulation and it involves tightening the vaginal opening by sewing the labia together so that there is a tiny opening that would be available for the passage of urine and menstrual flow (WHO 2008). Women, who undergo Type III FGM will have their labia be cut open for sexual intercourse and childbirth. Type IV FGM generally includes any type of harm to the genital area, including piercing, cutting,

scraping, and burning (Terry and Harris 2013). Available data shows that the prevalence of Type I FGM is 66% and Type II FGM is 26% (Kaplan et al., 2011). Although female genital mutilation has been classified into four major types, most affected women were usually unaware of the type of circumcision or mutilation that was conducted on them (Shell-Duncan et al., 2006). In Somali, distorted interpretations of the Quran indicated that women mistakenly equated “no sex until marriage” as a form of Type II FGM (LeJeune and Mackie 2009). It must be noted that although FGM is a form of ritual it has been linked to religious groups and belief, this information is not published anywhere in the Quran or Bible (LeJeune and Mackie 2009).

Risk Factors

FGM is an ancient cultural practice that has been affecting women and girls in the regions of Africa, Middle East, and Asia, but has been most prevalent in Africa (Zurynski et al., 2015). In some parts of Africa, the prevalence rate has been reported to be as high as 70 percent. Elderly women have routinely performed FGM, using unsterilized and barbaric instruments (e.g., knives, glass, scissors, and fire) and often without anesthetics or antibiotics. The procedure requires holding down the children and women against their will while the procedure was completed (Odukogbe et al., 2017).

Young girls between infancy and adolescence are at greatest risks of FGM (WHO 2010). According to the United Nations International Children’s Emergency Fund (UNICEF), about 44 million girls below the age of 15 years have undergone FGM. However, the age range has varied from newborn until a woman was married. Cultural norms have been the persuasive and major contributing factor in decision making to

implement FGM in a household. According to Shell-Duncan (2011), 97% of the women in Senegal reported that FGM has occurred in their family. The FGM tradition has been so deeply instilled in the community, culture and cultural beliefs and significantly affects an individual's overall quality of health.

In a previously published study, researchers in East Africa reported that social norms and health beliefs play a key role in perpetuating the practice of FGM (Feldman-Jacobs 2010). To gain acceptance and eventually get married, a female must undergo FGM. A study of 500 women in Nigeria found that 90% of the women interviewed believed that FGM was performed for cultural reasons (Utz-Billing and Kentenich 2008). Although this study was not a representation of an entire population, the majority of girls continued this ritual in compliance with the tradition and for cultural reasons. Young girls that do not practice FGM are often looked down upon by members of the society (Utz-Billing and Kentenich 2008). According to Utz-Billing and Kentenich (2008), migration has contributed to a situation whereby healthcare professionals in developed countries are now dealing with patients affected with FGM. For an example, studies in Canada and Switzerland have revealed that FGM patients were unsatisfied with the level of knowledge doctors had regarding FGM and often believed that they did not receive appropriate and adequate medical treatment for their conditions (Utz-Billing and Kentenich 2008). In order to better understand FGM and its short and long-term complications, health professionals need to care for patients in a culturally sensitive manner and to create needed trust to encourage patients to seek medical attention.

Short-term Complications

There are no reported health benefits of FGM and available reports showed that it causes both physically and psychologically harm in affected women and has the potential for lifelong health consequences (Kaplan et al., 2011). A number of studies have reported that patients who were recently circumcised observed obvious symptoms and signs of complications of FGM within the first few hours and days of completing the procedure (Rashid and Rashid 2007). Reported short-term complications included severe pain, infections, bleeding, shock, urine retention, and even death (Reisel and Creighton 2015). FGM women often experienced very painful menstrual periods for a lifetime due to small vaginal opening. Studies have reported that 90% of FGM women expressed feelings of "intense fear, helplessness, horror, and severe pain" during the cutting stage (Behrendt and Moritz 2005). Immediately after the cutting stage, several women had difficulties passing urine and this resulted in extreme pain and infection. In addition, the removal of the clitoris caused irreversible effects to the female body, including obstruction of the vagina due to the formation of inclusion cysts over the clitoral area " (Reisel and Creighton 2015). Excessive bleeding, tissue swelling, and urine retention are the most commonly reported short-term complications due to FGM. Although statistical data on mortality rate is lacking on FGM, excessive bleeding due to improper wound closure has been reported as a major cause of death (Kaplan et al., 2011).

Long-term Complications

A number of long-term complications have been reported for women with FGM and include increased risk of childbirth complications and newborn deaths (Odukogbe et al., 2017). Women who have undergone infibulation usually suffered from perineal tear

due to the small opening of their vagina. Deinfibulation is a procedure that involves reopening the infibulation in Type II FGM with a view to improving birth and sexual intercourse outcomes (Rashid and Rashid 2007). In some cases where deinfibulation was not performed, stillbirths have been reported. Both deinfibulation and reinfibulation have been shown to cause death and excessive blood loss that resulted in chronic anemia (Whitehorn et al., 2002).

A study conducted among African women attending Singleton delivery examined the effect of different types of FGM on obstetrics outcomes (WHO 2008). The results of the study concluded that women who had undergone Types II and III FGM procedures were more likely to have delivered their babies by cesarean section and to have lost at least 500 ml of blood. A recent study by Reisel and Creighton (2015) showed that 63% of women with FGM in rural area Gambia experienced long-term complications, including urinary tract infections. Due to lack of antibiotics and continued use of unsterile equipment, FGM women have increased the likelihood of being infected with either the human immunodeficiency virus (HIV) or Hepatitis B and C (WHO 2008). Additionally, HIV and hepatitis are two of the most common long-term complications related to FGM that were often transmitted through infected blood or vaginal fluids.

Other detrimental health impacts of FGM include mental health, increases in depression, anxiety, and post-traumatic stress disorder (WHO 2008). It is estimated that 90% of women that have undergone FGM often develop a feeling of helplessness, horror, and severe pain (Mulongo, Mcandrew, and Martin 2014). Psychological disorders and mental illness are underreported among girls and women in Africa who are often in

denial and because such disorders are considered taboos in these societies (Knipscheer et al., 2015). A good understanding of community and cultural involvement, as well as the social norms of the health implications of FGM, will help individuals realize why FGM has been perpetuated for many years. The emotional closeness of the relationship between health practitioners and the victims of FGM can lead to a deep sense of betrayal that can lead to lasting harm from the victim's perspective (Whitehorn et al., 2002).

Laws

The practice of FGM has been widely recognized as a violation of a series of human rights and principles such as the Universal Declaration of Human Rights, the Convention on the Elimination of all Forms of Discrimination Against Women, the Convention on the Rights of the Child (WHO, 2008). FGM has been illegal in the United States since 1996, however, the law for what has been defined as "vacation cutting" was not passed until 2012 (Goldberg et al., 2011). Vacation cutting occurs when girls living in the United States, Europe, and Australia travel back to their home countries to undergo FGM (Zurynski et al., 2015).

Future interventions

In order to accomplish successful interventions and training for healthcare professionals, barriers are important. Providing patients who have undergone FGM and healthcare professionals' recommendations for successful interventions are ways to safeguard young women at risk. There is a lack of field proven methods, the prevalence of FGM in these communities is still rampant which shows the importance of FGM

health practices. Advocacy on the part of healthcare professionals is first and foremost in making progress. Providing availability to support systems and culturally competent counseling services would help those seeking care by presenting options (Perron et al., 2013). Educating the practitioners in depth would bring awareness to their last effects on the young women. With knowledge, young women could realize that female cutting isn't healthy and embolden them to seek medical attention. Lastly, intervention strategies should be communal. From the healthcare professionals to the practitioners of FGM, to the victims; all should be included in reforming efforts to make the interventions successful.

Study Objectives

There is need to develop a culturally-tailored competent guide to assist healthcare providers who often encounter women of childbearing age who have undergone FGM during their practice. California remains the number one place for refugees to resettle and San Diego specifically is a big hub. There is a growing population of FGM women who are primarily African and Asian immigrants or refugees from diverse cultures and traditions. From the public health perspective, it is important that healthcare providers are knowledgeable of not only the health complications of FGM but also the cultural implications with a view to meeting the healthcare needs of this special population.

This capstone project is designed with a view to developing a guide that will be useful in bridging the gap between women who have experienced FGM and healthcare professionals in San Diego County. A good understanding of the risk factors, health complications, and forces that underlie FGM is necessary for all healthcare providers

who routinely attend to FGM patients. This is with a view to prevent or control the continuation of this practice and ensuring improved healthcare to all those affected by FGM.

The purpose of this study is to better understand female genital mutilation, by developing a culturally competent guide for health care providers working with patients affected by FGM.

Chapter 2: Methods

Overview

The purpose of this capstone project is to create comfortability and ease for both the women who have experienced FGM and the healthcare service providers. The topic of reproductive health is a sensitive topic for all parties involved. This capstone project was aimed at understanding the cultural practices and health complications of FGM among a pilot group of women and the knowledge of healthcare professionals who attend to them with a goal to developing a culturally tailored guide. As a first step, the researchers applied for and were granted approval by the Institutional Review of Board (IRB) at California State University San Marcos on March 26, 2018. The following information was provided in the IRB application: informed consent forms for FGM participants and healthcare professionals, interview questions for FGM participants and healthcare professionals, and recruitment flyers (see Appendix A for details).

Recruitment and Interviews for Healthcare Professionals: The second recruitment effort involved healthcare providers. Flyers were distributed at community

clinics that served a wide range of diverse ethnicities in San Diego. Interview questions targeted providers' overall knowledge and awareness of FGM. Healthcare providers were then contacted for their willingness and availability to participate in the study and a total of six providers were recruited to participate. An audio- tape recorder was used to document the discussions. Informed consent forms signed by the participants were locked in a secured cabinet. To find common themes, qualitative methods were used to identify health barriers for FGM participants and healthcare professional's knowledge of FGM complications and experiences.

Recruitment and Interviews for FGM Participant : The initial step in the recruitment of FGM participants involved handing out flyers in community clinics, community centers, and local mosques to recruit participants. Six FGM participants were chosen to conduct in person interviews. During the interviews, an audio-voice recorder was used to document the experiences of all the 6 recruited women who were over 18 years old and have undergone FGM. The participants consisted of women with past experiences meeting with healthcare professionals on issues relating to FGM. The interviews were necessary for soliciting their input and in determining what changes would be recommended and implemented to improve their overall healthcare experiences. The interviews were conducted with each participant in private rooms at a specific community center. Each interview section lasted approximately 20-30 minutes during the afternoon period. Each participant was asked to answer twelve interview questions (see Appendix A for details).

Healthcare Providers Recruitment: Six healthcare providers that were comprised of medical doctors and nurse practitioners were selected for the healthcare provider interviews to determine their knowledge of FGM. By interviewing the healthcare professionals, an insight on their self-reported experiences working with FGM patients was evaluated. In-person interviews involving nine questions were conducted at the healthcare providers clinical offices during the evenings for approximately 20-30 minutes. (see Appendix A for details).

Data Analysis

The capstone project was a qualitative study that consisted of conducting interviews with healthcare professionals in a variety of clinics through San Diego. All interviews were audiotaped with written and verbal consent of the participant. After the interviews, the audiotapes were transcribed manually using Microsoft Word and Google Docs. Once the transcription was completed, Atlas Ti was used to help reveal the insight and relationships among the interviews, that allowed the researchers to create themes to gain a better perspective of the interviews and the insight gained from them.

Using Atlas Ti and manual coding, themes were created that researchers felt would allow for a better understanding of the interviews as well as appropriately gather the thoughts of the participants and health professionals and organize them to add to the results. Some of the themes that the researchers originally thought would be useful towards the research actually did not have much information, however, it was still

included to cover all aspects of the interviews and ensure that thoughts, knowledge, and beliefs were included. One specific sub-theme was created within the theme of education. This was created due to the amount of information within the education theme. Researchers decided to break it down for participants as what they know regarding FGM from their perspective and personal experience, and what FGM participants want health professionals to know. The sub-themes for education for health professionals was the following: What training or education they received in school, and what training or education they want to receive to better assist women that have undergone FGM. As previously mentioned, some themes were able to overlap with each other. However, because each theme was thoroughly explained, the overlap was not as evident once the results were interpreted except where noted in the results section.

After the data was analyzed, a culturally competent guide was designed to help health professionals better address patients that have undergone FGM. This will allow health professionals to grasp a better understanding of what FGM is and how it affects women first hand while providing suggestions and tips from women that have undergone the procedure. Additionally, the guide will assist in gaining confidence to speak culturally respectful to their patients and also allows them more options and avenues to give their patients who have experienced FGM moving forward in their practice.

Chapter 3: Results for FGM Participants

Cultural Beliefs on FGM

A major theme that populated from the interviews was cultural beliefs about FGM. While none of the women were given a specific reason why FGM was performed on them, there were a few similar presumptions the participants explained during the interviews. These explanations allowed the researchers to have a better understanding of the cultural mindset behind FGM. All of the women believed that the reason they had undergone FGM was because as a culture, they believed that having girls and women undergo FGM would lead them to be pure and virginal until they were married, as well as help deter women from becoming promiscuous. Additionally, all participants explained that the practice of FGM was not questioned in their native country, as it was a norm and most girls and women had undergone FGM, to question the decision, was to question their culture. Participant 2 elaborated and embodied similar sentiments that other participants had made regarding the cultural beliefs behind FGM that they are not vocal about in the country of birth.

"Actually they didn't have (an) explanation, it's (a) cultural issue and they feel like if they circumcise their daughters, they will stay out of reach of men and they will be pure women and they will be applied and not needing a man was uh until she get(s) married." - FGM Participant #2

Physical Health Consequences Due to FGM

Participants were asked if they believed that undergoing FGM caused health problems and were encouraged to elaborate any health problems that they felt were due to FGM and 4 out of 6 believed that their abnormally severe menstrual cycles were in fact

due to FGM. They explained that their periods caused more severe cramps, back pain, and headaches. In addition to possible infections due to the blood not having a large enough passageway, some women interviewed also experienced increased difficulties during labor due to the size of their vaginal opening compared to the size of the baby. Another physical consequence that 3 out of the 6 women talked about was the pain or numbness felt during sexual intercourse with their partners. One participant compared sexual intercourse with her husband to rape (FGMP 5), while another stated that she felt no pleasure during sex (FGMP4). While no physical exams were conducted on participants, their sentiments and beliefs on physical consequences that they attributed to having undergone FGM were included, since all participants expressed some kind of physical ailment associated with FGM.

"Yes, yes. More cramping, more blood flowing and kidney problems and um I feel pain in my kidney like I cannot walk that much uh so it affects my walking ability and them also um you get a lot of headaches." - FGM Participant #3

Psychological Consequences due to FGM

Psychological consequences included any type of mental or emotional trauma that participants felt was due to FGM. 4 out of the 6 participants mentioned some kind of PTSD that they felt from the memory of actually having FGM performed on them at a young age. Some participants said they could remember the face, room, and people that were there when the FGM took place. Other participants noted that they felt shame and embarrassment when going to see the doctor because of their mutilated vaginal area and

they didn't know what to say to the doctor. Additionally, another participant stated she did not want to go to the doctor because she didn't want to relive the entire experience and embarrassment associated with FGM. FGMP 6 compared it to PTSD in the sense that she had flashbacks and remembers vividly each second of the procedure that she underwent. Her feelings towards the procedure and description about the trauma coincided with other participants who felt the same way.

"There's no anesthesia so you feel every single little thing that's happening to you. So, it's a very, very traumatic, it's a very visual memory that you have in your memory that you feel and experience everything." FGMP6

Religious Beliefs

Religious beliefs were a minimal theme that was included as a means to analyze whether or not participants felt that their religion was a reason why the FGM was so widely accepted in their country. Coincidentally, the 3 participants that brought up religious beliefs all said that FGM had nothing to do with religion, it was simply a cultural thing.

"Educate the people, this is not any religion or anything, this is the culture and that's not (a) good thing to do for women." -FGM Participant #1

Attitudes & Beliefs on FGM

Attitudes & Beliefs on FGM was used to analyze the current viewpoints of the participants about FGM and their concerns or sentiments towards having FGM performed on their daughters. 6 out of 6 participants responded "No" when asked if they would

have this procedure done to their daughters. Participant #3 brought up struggling to forgive her parents for having her get FGM and she explains that it causes anger in her towards her parents that makes it very difficult to forgive them, but she has to, since they are her parents. That same participant also noted that mental stability and a healthy lifestyle was important to her for her daughter, implying that FGM would cause opposite emotions. Participant #6 advocated for women by stating that the procedure was "rooted in misogyny and its rooted in pleasing (a) man as opposed to pleasing women. It doesn't benefit women (in) any way." She continued by voicing her belief that the practice needs to be eliminated completely from her culture. The concerns of FGM participant #2 shown below, implicate the opposition to the procedure and the current attitude and belief towards the procedure, which was expressed by all 6 participants.

"Because I don't want them to have what I had. The problems I came with and there in not benefit as I say." -FGM Participant #2

Barriers to Accessing Healthcare

Barriers to Accessing Healthcare were another theme found while coding with Atlas. One specific barrier that all of the participants identified with was being uncomfortable with the medical professionals in the clinical setting. This barrier presented itself multiple times throughout the interviews when participants looked back on the struggles they had with health professionals when visiting with them for the first time or prenatal care. The importance of having a health professional offer solutions and address the issue to help educate the participants on their options was stated specifically

by participant 2, but expressed in other ways by most of the other participants. Additionally, participants felt another barrier to accessing healthcare was fear of judgment and shame. Some participants shared stories that involved health professionals being completely insensitive and either asking them directly what had happened to their genitals and others that just stared in disbelief without regard for the patients. In one instance a participant shared that after seeing the doctor's reaction to her vaginal circumcision, she wanted to run away because she was so ashamed and embarrassed (FGMP4). Language was yet another barrier to accessing healthcare that multiple participants brought up. For example, FGM Participant #2 stated that it would be best to have an interpreter for patients to help them understand the medical treatment they would be receiving, as opposed to a simple check-up and no explanation

"I cannot exactly say they never seen, but the was not comfortable o explain what they can do for you and I would like to know ahead of time, what's going to happen to me and how they going to deal with my situation" -FGM Participant #2

Education: What FGM Participants Know

Participants were asked what they knew about FGM based off of their own experience, not necessarily education obtained at a school. The topic that stood out the most was that this procedure was due to a cultural belief, not a religious thing and that was very important for participants because some felt that people tried to promote this as a religious thing, which is not true. FGM participants all felt that the procedure was unnecessary and did not benefit women in any way, so they were adamant about

increasing awareness about the subject to aid in the reduction of the number of girls that undergo this. Participants know the health consequences that they are faced with due to having undergone FGM which include but are not limited too: Excessive cramps, headaches, infections, problems with labor and delivery, reduced sensitivity, emotional trauma. Additionally, they say they or someone they are close too are faced with difficulties in their marriages due to not having sexual pleasure due to FGM. While the participant's medical history or current conditions were not evaluated, it's important to use their first-hand experiences and knowledge regarding this subject matter to create something that will positively help address their concerns for themselves and women in their community.

Education: What FGM Participants Would Like Health Professionals to Know

Participants were asked to discuss what they would like for health professionals to know about when seeing patients who have undergone FGM. 6 out of the 6 participants that were interviewed coincided with each other in believing that health professionals need to help educate the younger generation in order to prevent FGM from continuing as a cultural practice. Most women expressed concerns that Health Professionals did not know enough about the topic, therefore causing patients that have undergone the procedure to feel uncomfortable in the doctor's office. Being able to talk to patients about the procedure they had done and explain to them whether it is reversible or not and what they can offer to them, is another key point that participants wanted Health Professionals to learn more about. Additionally, some women wanted health

professionals to better explain what exactly would happen to them and their bodies during labor and what the possibilities would be of a natural birth vs. cesarean-section.

The difference between the participant's culture and American culture is shown to cause a rift in the quality of healthcare that these individuals are receiving, not on purpose, just due to lack of experience on the health professional with FGM patients. There is also a connection between the physical consequences due to FGM and what participants feel that health professionals need to know more about. Lastly, all participants wanted health professionals to educate the community about the practice, in hopes of preventing future generations from having to undergo the procedure through education obtained here.

“ Because they don’t understand like they don’t know what’s going on. Like, in America, they don’t practice that, so I don’t think they have anything to offer me.” - FGM Participant #3

Results for Health Professionals

Laws of FGM

All health professionals were asked if they knew laws specific to FGM in the United States. 6 out of 6 responded that yes, they knew it was illegal to perform FGM here in the United States. HP 6 elaborated more on the increased awareness around the world surrounding FGM and how it’s being addressed more so now than before. Additionally, all of the Health professionals were aware of the vacation cutting law,

which went into effect in 2012, which makes it illegal for parents to take their children out of the country to perform the circumcision.

"Yeah so I know that that's been a Hot Topic, so um even worldwide not just here in the United States just in general, people and different countries and communities are starting to put more and more laws in place again I don't know specifics, but in general starting to protect our women and young girls against this."- HP6

Barriers to Providing Healthcare

Coinciding with participants, the interviewed health professionals felt that a major barrier to providing proper care was their own comfort level with FGM and that of the patient as well. HP4 explained that they felt that one reason for patients discomfort with them was because they understood that FGM was part of their culture, but not our society, so it made them more uncomfortable when going to the doctor. Moreover, HP1 explained that the patient's overall hesitation with exams and just seeing a doctor or gynecologist, in general, creates a barrier to providing appropriate care because of the lack of trust. An additional barrier that HP3 brought up was simply addressing FGM, which they said was something they normally did not do unless their FGM is going to affect their labor and delivery.

"**I felt uncomfortable,** so I can only imagine from the patient perspective going and finding a physician who feels comfortable, what's going on to be able to go and sit and have that conversation, um, so I think that that's also a barrier and another one of the challenging things."-HP6

Psychological Consequences Observed

Researchers believed that Atlas would help uncover psychological consequences observed in patients that had undergone FGM. However, not all professionals commented on possible psychological implications during the interviews, making psychological consequences more relevant for the FGM participants, since they shared their personal experiences with FGM.

Health Consequences

Health consequences observed by health professionals were gathered throughout the interviews with stories and examples provided by health professionals. While no health professionals stated that they had research-based evidence that female genital mutilation had health consequences, their stories and examples provided a clear visual to issues that women faced after undergoing this procedure. An example provided by HP1 explained that some women with type 3 or 4 FGM would likely have to undergo a cesarean section because their body simply cannot expand more than 5mm in some instances (HP1). All participants stated that one of the more common health issues they had come across, were scarring due to infections that had not been treated appropriately and scarring had covered the labia. HP5 went into detail involving a little girl that they had to take care of in the ER that had undergone vacation cutting and had acquired an infection, which is why her parents rushed her to the hospital.

"We have a family be consulted in the ER because the girl was only 3 and she had an infection following the procedure in another county…"- HP5

Education: Education or Training Received in School

Four out of 6 HP's stated that they had received education or training while they were in school, while the others said they learned once they started their rotations and/or moved to San Diego and started working with refugee/immigrant populations. HP5 explained that they had more training on the subject after they treated the little girl in the ER for an infection. Additionally, HP6 said she received very brief training during school, but states that she asked experienced residents to help her learn more about patients with FGM once she started working in San Diego. She is very adamant that more training is needed in order to better serve this population. HP1 was in school in Nebraska over 30 years ago, so she stated that FGM was not even a topic back then. She stated that her training was all hands-on experiences. HP4 completed her schooling in West Africa and stated that she was never encountered FGM, likely because her region did not practice FGM, so she did not have any experience until she met with her first patient.

"I went to an OB-GYN residency and we had like uh I don't know, maybe (a) 30-minute presentation on like circumcision happen and this is kind of what they are and that's kind of all we learned about."- HP #?

Education: What Health Professionals would like training/education regarding FGM

When asked if they wanted more training, all 6 of the interviewed healthcare professionals agreed that training and education would be well received in their areas. It

was noted by most professionals, that culturally competent guides would only be useful for health professionals in areas with a higher refugee/immigrant population. It wasn't possible to narrow down what specifically they wanted to learn more about, but some of the comments included cultural beliefs, approaching the patient, using correct terminology when asking questions, creating better rapport to make the patient comfortable with asking questions, and training regarding the types of circumcision that women can possibly have in order to better explain to them what parts were removed from their body.

"I think as much information as we can get on these things the better. I think it would better help serve our patients um and help us again be better Physicians…"- HP6

Attitudes & Beliefs Observed in Patients

Attitudes & Beliefs observed in patients highlighted the patient's attitudes towards FGM through the health professionals experiences. The attitudes were consistent throughout in terms of the patients not favoring or promoting FGM to doctors. However, it was observed that the ages of patients seemed to favor between providers. For instance, HP1 shared that women seemed to be more scared and reactive to exams if it was their first pregnancy, but after that, they seemed okay with asking questions and sharing with the medical professional. HP1 also mentioned that during exams they do ask if they have any questions, but HP1 feels that patients just accept what has happened to them and maybe don't even realize that they are different. Additionally, HP3 brought up the point that the patients they see now have already had children and are sexually active,

so the hesitation regarding their private area has minimized, since they already had to endure seeing medical professionals during their prenatal care and for pap smears, so their attitudes are more passive about the procedure and medical visits. In contrast, HP6 has had the experience of actually having younger women that have undergone FGM before they are of childbearing age come to them and talk about what happened. HP6 stated that this has become a group of young women that express themselves, share their story, and seek recommendations for seeking healthcare and for possible reversal of the procedure they underwent. What all health professionals agreed on is that no woman has ever been asked to be sewn back up completely after giving childbirth. While they wouldn't be able to sew them back up due to laws, the sentiment that women are eager to not be sewn shows resilience against this procedure and not viewing it as a positive or beneficial part of their life that they want to keep.

"Most patients don't express their feelings about this, they just accept it."- HP1

Cultural Beliefs Associated with FGM

Health professionals all agreed that cultural beliefs were a major underlying factor that caused women to have had to undergo FGM in their native countries. HP4 noted that patients understood it was part of their culture, but not that of our (American) society, in turn causing hesitation when speaking with doctors. However, HP4 continued by explaining that since they understood that it was apart of the patient's culture, they accepted it and were comfortable treating the patient with both sensitivity and understanding. It seemed that a possible reason for patients not asking questions about their medical condition had to do with their cultural acceptance of it, meaning that since it

had already been done to them in their native land, they did not question it, they just lived with it. Cultural beliefs and the patient's attitudes and beliefs can overlap in this instance because of patients willingness to not be sewn up after giving vaginal birth and their more progressive mindset of seeking options or methods to possibly reverse or lessen the severity of the procedure they had done on them as young girls.

"It is a cultural thing. I think they don't understand why it was done and they are not going to have their daughters have it done."-HP1

Religious Beliefs Observed in Patients with FGM

No Healthcare Professionals commented on associations between religious beliefs and FGM, either because they had never had a patient that felt it was religious, or they themselves felt there was a religious tie to FGM.

Chapter 4: Discussion

Findings

The research indicated that the participants struggle to be understood and overcome barriers in the healthcare setting. This is vital when FGM participants have to go to the medical doctor's office for routine checkups such as pap smears or when they are in labor. A common thread among the anonymous participants was that they believe American health professionals have little to no information about FGM, therefore, there is nothing they can do to help. Conversely, some of the health professionals have been trained or have had experience with women who have undergone FGM and some can be of assistance although all health professionals included in the research agreed to

supplemental training. Trainings will be more specifically related to communicating effectively and demonstrate how to be more culturally competent when discussing FGM with their patients who have undergone the procedure. In regards to healthcare professionals, another barrier was that some of these professionals in the health setting lack tools and training pertaining to FGM. In the interview portion of the research, only one health professional mentioned using separate tools for their FGM patient. By using a significantly smaller tool during pap smears it makes it easy for their patients to be as comfortable as they can be while also minimizing the pain of the patient. Some health professionals are aware of these barriers and find ways to assist their patients. However because FGM is not widely known throughout all of the United States the trainings, techniques, and education varies depending on their location of study and educational background.

All of these findings led to the culmination that there is a disconnect between the FGM participants and the healthcare professionals that are tending to them. From the research and data collected it was clear that non-effective communication between the two was detrimental to both parties in furthering the knowledge and experiences of FGM.

Implications

Some implications or consequences of expanding the knowledge and discussing FGM amongst those who have undergone the procedure and to healthcare professionals is the expansion of awareness of FGM and the importance of cultural competence. By holding interviews and creating a culturally competent guide it amplifies the knowledge

of the reader and expectantly starts the conversation with others, again increasing the awareness of FGM. Although the cultural guide was initially intended for healthcare professionals all can use it. The guide is written using plain, uncomplicated verbiage so that the cultural competence portion of the guide can also be beneficial to all parties reading the guide. The guide illustrates how sensitive of a topic FGM is and what women who have undergone FGM have gone through. Lastly, by a FGM patient seeing the guide they may be prone to be more comfortable and open to discussing more on their procedure. All implications further the results and the met objectives.

Recommendations

After accumulating the research and gaining both the opinions and suggestions from the FGM participants and the healthcare professionals the consensus for future recommendations included: effective communication between FGM participants and healthcare professionals. Increase trust and sensitivity for patients who have undergone FGM. Furthermore research can be done to add an increase to the quality of care for FGM patients. To conclude there can be trainings, open discussion panels and more culturally competent guides distributed to healthcare professionals and health settings.

From the gathered research it is concluded that there is a disconnect between the FGM participants and the health professionals in terms of communication. Those who have undergone the procedure are less likely to talk openly about their cutting. The topic of sex, especially before marriage is taboo for most of the cultures that perform FGM. Thus making it harder to open up to a healthcare professional who may not know about

the procedure. Conversely, health professionals may not know how to open the discussion regarding FGM.

The importance of increasing trust and sensitivity for patients who have undergone FGM is a vital key to avoiding health consequences of FGM such as infections and birth complications. It is recommended that more health professionals especially those who work in areas of high refugee and immigrant communities understand the severity of FGM and the cultural differences that can be looked on as a more conservative view. By doing so it allows the healthcare professional to increase their knowledge of FGM thus allowing them to better aide patients who have undergone FGM and increase the quality of care.

Concluding the recommendations, there can be forums held for trainings, open discussions panels, and more distribution of the culturally competent guide. The trainings could involve: the best ways to talk to patients with FGM based on the actual patient's feedback. What resources to provide to the FGM patients. Also, a background or history lesson of FGM and how it came to be can also be pertinent to the healthcare professionals and could also aide to their quality of care for this specific group of patients. Another recommendation would be to hold open discussion panels between women who have undergone FGM and healthcare professionals. By holding such events it allows a safe space for both the patients and health professionals to ask questions and gain a better understanding of both spectrums, therefore, increasing the level of comfortability and trust between both parties. Another useful aid would be more distribution of tailored culturally competent guides to those in the healthcare settings. This will be especially

helpful for new health professionals who haven't gotten any training on FGM or for those how have never come across FGM during their education or career.

Limitations

The researchers gathered much information without regards to some limitations such as: the women being self-reported, having a small sample size, and limiting the study to those who are English proficient. As a result of the women being self-reported, the researchers were going off of trust rather than actual facts. The research conducted did not include medical confirmation that the women interviewed have truly undergone FGM. Along those lines, the researchers also never clarified with the women which of the four types of FGM they had done to them. By not including this in the research it could skew the results. Another constraint to the research was the size of the sample participants. The researchers only interviewed the first six women and six health professionals who were qualified to participate in the interview process. With a bigger sample size, it will allow for more representations of both parties. Which will then increase the suggestions and recommendations for future healthcare professionals dealing with patients who have undergone FGM. Lastly, because the researchers conducted the interviews in English and required all participants to be proficient in English it limited the point of view especially, with the women who have undergone FGM. Assuming majority of the FGM participants first language was not English the researchers could have gotten a better understanding or an expansion to their answers during the interview had they not had this limitation. In the future, it would be prudent to have an interviewer who spoke their primary language or have an interpreter present during the interview.

Future Direction

In order to increase the research, the researchers would like to further the study by holding more interviews with those involved with FGM, expand what interview questions are asked, and lastly relate how the type of cutting affects the women differently. To continue on the path of the analysts more interviews can be conducted to increase the sample size of the study. By doing so it will allow for more interpretation of what FGM looks likes to all parties. It also allows for more points of views for example views from women who will still consider cutting to be a good thing for the future generations, health professionals who have never seen or experienced a patient with FGM and perhaps parents who have made the decision to participate in the FGM procedures. The expansion of the sample size can allow for more information to be gathered and updated in the tailored culturally competent guide.

The questions asked in the interviews between the participants who have undergone FGM and the health professionals who have clients who have undergone FGM were a good start at the beginning to understand FGM. However, more in-depth questions could be asked to both parties to get a better understanding, to find more common themes and barriers to quality care. Such questions can include: how does FGM affect you mentally? Or how does it affect your sexual experience? Or how can we introduce Expand the education during their doctorate education and residency? By expanding these interview questions it gives a better insight to what needs to be changed in regards to the healthcare setting for patients who have undergone FGM.

Furthermore, to increase the solidness of the study it would be helpful for future researchers to go into further detail for the FGM participants in regards to what type of cutting they received. Like mentioned earlier there are four types of FGM. Some of which can be cosmetically altered to help reverse the original cutting. However, not all of the circumcision is reversible thus can cause more of a psychological reaction than the other types. By adding the question to the interview of what type of circumcision was received. It allows a better understanding of the health consequences of the spectrums of FGM. It also allows the researchers to conclude if they need to focus on a specific type of FGM more than others based on the severity.

Conclusion

Culturally competent guides benefit areas with high refugee and immigrant populations by providing health professionals with a tool that will allow them to offer better care to those that have undergone female genital mutilation. Providing a guide results in a better understanding of what the procedure is, how it affects women, and how to treat women in a more culturally competent manner, health professionals will hopefully be less uncomfortable when meeting with a patient that has undergone the procedure, in turn allowing her to be more comfortable as well. Based on the results found, it was indicated that cultural competency and knowledge regarding FGM is lacking and is needed in order to better serve the high volume of refugee and immigrants that have undergone this procedure and are currently living in San Diego. By increasing knowledge and cultural competency, health professionals will be able to better serve an underserved demographic. Overall, the research conducted and the guide created will

help improve health care that women with FGM receive, it will also reduce disparities, as well as the stigma surrounding FGM, and help increase the overall health and well being of those affected by FGM.

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Themes
Attitudes & Beliefs
Barriers to Healthcare
Cultural Beliefs
Education
Health Consequences
Laws Regarding FGM
Psychological Consequences
Religious Beliefs

Table 1: Qualitative Interview Coding Themes Used for Research Study

Health Professionals	Attitudes & Beliefs	Barriers to Providing Healthcare	Cultural Beliefs
HP 1	1	3	1

HP 2	0	0	1
HP 3	0	1	1
HP4	0	2	2
HP5	0	3	5
HP6	0	6	2
Totals	1	15	12

Table 2: Number of quotes found for each theme, separated by interview for healthcare professionals

Health Professionals	Education	Health Consequences	Laws Regarding FGM
HP 1	4	5	3
HP 2	0	0	0
HP 3	3	1	1
HP4	4	2	3
HP5	5	8	0
HP6	7	0	2
Totals	23	16	9

Table 3: Number of quotes found for each theme, separated by interview for healthcare professionals

Health Professionals	Psychological Consequences	Religious Beliefs	Totals from All Themes
HP 1	2	0	19
HP 2	0	0	1
HP 3	0	0	7
HP4	0	0	13
HP5	0	0	21
HP6	0	0	17
Totals	2	0	78

Table 4: Number of quotes found for each theme, separated by interview for healthcare professionals

FGM Participants	Attitudes & Beliefs	Barriers to Healthcare	Cultural Beliefs
FGMP1	3	3	9
FGMP2	1	5	4
FGMP3	27	3	9
FGMP4	0	3	10
FGMP5	0	1	10
FGMP6	0	2	10

Totals	31	17	52

Table 5: Number of quotes found for each theme, separated by interview for FGM participants

FGM Participants	Education	Health Consequences	Laws Regarding FGM
FGMP1	1	7	0
FGMP2	2	7	0
FGMP3	1	3	0
FGMP4	3	3	0
FGMP5	4	8	0
FGMP6	9	1	0
Totals	20	29	0

Table 6: Number of quotes found for each theme, separated by interview for healthcare professionals

FGM Participants	Psychological Consequences	Religious Beliefs	Totals for ALL Themes
FGMP1	1	2	26
FGMP2	2	0	21
FGMP3	1	2	46
FGMP4	0	3	22
FGMP5	5	1	29
FGMP6	3	1	26
Totals	12	9	170

Table 7: Number of quotes found for each theme, separated by interview for healthcare professionals

California State University
SAN MARCOS

Informed Consent

Title of Project: Understanding Female Genital Mutilation and Related Complications

Investigators: Nehmo Hassan, Umulqayr Moalin, Judy Hernandez, and Chelsea Tidwell

Invitation to Participate

Dear Participant:

Nehmo Hassan, Umulqayr Moalin, Judy Hernandez, and Chelsea Tidwell are graduate students in the Master of Public Health (MPH) program at California State University San Marcos (CSUSM). You are invited to participate in a study on "Understanding Female Genital Mutilation (FGM) and Related Complications." Before agreeing to participate in the study, please read this form very carefully and ask any questions that you may have or if you need additional information. You must be a female who has had FGM and between the ages of 18 and 55 years to participate in the study.

The information provided during the interview will only be used by the investigators to gain understanding of FGM) and its related complications, a public health issue of significant importance. None of the information provided will be used to identify the respondents. By signing this Consent Form, the participants are giving their implied consent.

PURPOSE OF STUDY:

You are being asked to take part in a research study. The purpose of this study is to gain a better understanding of FGM and its complications by developing a culturally competent guide for health care providers working with affected patients. If you agree to participate, you will be one of six participants in this research study that aims to understand FGM and its complications.

STUDY PROCEDURES:

1. We will be conducting interviews with women affected by FGM. You will be asked to participate in the interview, which is anticipated to be completed during one visit. The interview will take approximately 30-45 minutes to complete.

2. Audio tape recordings will be conducted during the interview.

3. Interviews will be conducted in private rooms or areas at community or religious centers. However, the tape recording will be confidential and responses to the interview questions will be anonymous.

If you agree to participate in the study, you will be required to do the following:

1. Complete and sign this Consent Form stating that you agree to participate in the interview.

2. Answer questions about your knowledge/attitudes related to FGM as well as your personal experiences with FGM, barriers when attempting to access healthcare and/or the provision of healthcare services.

RISKS AND INCONVENIENCES:

There are minimal risks and inconveniences associated with participating in the study. These may include

·Recall of any past experience that may be unpleasant to the participant.

·Some inconvenience of time required to complete the interview.

SAFEGUARDS:

In order to minimize the risks and inconveniences, the following measures will be taken:

1. At any time during the interview, the participants may skip any questions that make them uncomfortable or decline to answer any or all questions.

2. Participants may terminate their involvement in the study, if they choose to do so.

Participants may be directed to counseling or social support services.

BENEFITS:

There will be no direct benefit to you for your participation in this study. However, the information obtained from this study will allow participants to gain knowledge of FGM and its complications by developing a culturally competent guide for health care providers.

CONFIDENTIALITY:

Your responses to the interview questions will be anonymous. None of the information provided will be used to identify the respondents.

Each participant will be assigned an identification number or code. The investigators will not collect names, birthdates, addresses, phone numbers, and social security numbers from participants. The data collected will only be used for research purposes. All notes, interview transcriptions, and any other identifying participant information will be kept in a locked file cabinet in the possession of the investigators.

The results of this study may be used by the investigators to generate reports, presentations, and/or publications as part of the requirement for an integrative learning experience in the MPH program at CSUSM.

CONTACT INFORMATION:

If you have questions at any time about this study, or you experience adverse effects as a result of participating in this study, you may contact Dr. Emmanuel

Iyiegbuniwe at eiyiegbuniwe@csusm.edu o r (760) 750-8499with any further questions. In addition, if you have any questions regarding your rights as a participant in this research, please contact CSUSM's Institutional Review Board (IRB) office at irb@csusm.edu or (760) 750-4029.

VOLUNTARY PARTICIPATION:

Your participation in this study is voluntary. It is up to you to decide whether or not to take part in this study. Withdrawing from this study will not result in any penalty and will affect your relationship with the investigators or the MPH program at CSUSM.

INCENTIVES FOR PARTICIPATION:

There are no incentives for participating in this study.

PARTICIPANT'S CONSENT:

·I have read and understand the provided information and have had the opportunity to ask questions.

·I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without cost and that I will be given a copy of this consent form.

·I voluntarily agree to take part in this study (please check the option that applies to you and sign):

☐ I give permission for my interview to be to be audio (or video) taped.

☐ I do not give permission for my interview to be audio (or video) taped.

Printed Name _____ Participant's Signature

_____ Date_____

California State University
SAN MARCOS

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(OB-GYN) and Experience working with a diverse group of patients, especially immigrant females of African descent who have undergone FGM will be.

The information provided during the interview will only be used by the investigators to gain understanding of FGM) and its related complications, a public health issue of significant importance. None of the information provided will be used to identify the respondents. By signing this Consent Form, the participants are giving their implied consent.

PURPOSE OF STUDY:

You are being asked to take part in a research study. The purpose of this study is to gain a better understanding of FGM and its complications by developing a culturally competent guide for health care providers working with affected patients. If you agree to participate, you will be one of six participants in this research study that aims to understand FGM and its complications.

STUDY PROCEDURES:

1. We will be conducting interviews with Medical Doctors and/or Nurse Practitioners who specialize in Obstetrics and Gynecology (OB-GYN). You will be asked to participate in the interview, which is anticipated to be completed during one visit. The interview will take approximately 30-45 minutes to complete.

2. Audio tape recordings will be conducted during the interview.

3. Interviews will be conducted in private rooms or at clinics. However, the tape recording will be confidential and responses to the interview questions will be anonymous.

If you agree to participate in the study, you will be required to do the following:

1. Complete and sign this Consent Form stating that you agree to participate in the interview.

2. Answer questions about your knowledge/attitudes related to FGM as well as your personal experiences with FGM, barriers when attempting to access healthcare and/or the provision of healthcare services.

RISKS AND INCONVENIENCES:

There are minimal risks and inconveniences associated with participating in the study. These may include

·Some inconvenience of time required to complete the interview.

SAFEGUARDS:

In order to minimize the risks and inconveniences, the following measures will be taken:

1. At any time during the interview, the participants may skip any questions that make them uncomfortable or decline to answer any or all questions.

2. Participants may terminate their involvement in the study, if they choose to do so.

Participants may be directed to counseling or social support services.

BENEFITS:

There will be no direct benefit to you for your participation in this study. However, the information obtained from this study will allow participants to gain knowledge of FGM and its complications by developing a culturally competent guide for health care providers.

CONFIDENTIALITY:

Your responses to the interview questions will be anonymous. None of the information provided will be used to identify the respondents.

Each participant will be assigned an identification number or code. The investigators will not collect names, birthdates, addresses, phone numbers, and social security numbers from participants. The data collected will only be used for research purposes. All notes, interview transcriptions, and any other identifying participant information will be kept in a locked file cabinet in the possession of the investigators.

The results of this study may be used by the investigators to generate reports, presentations, and/or publications as part of the requirement for an integrative learning experience in the MPH program at CSUSM.

CONTACT INFORMATION:

If you have questions at any time about this study, or you experience adverse effects as a result of participating in this study, you may contact Dr. Emmanuel Iyiegbuniwe at eiyiegbuniwe@csusm.edu o r (760) 750-8499with any further questions. In addition, if you have any questions regarding your rights as a participant in this research, please contact CSUSM's Institutional Review Board (IRB) office at irb@csusm.edu or (760) 750-4029.

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INCENTIVES FOR PARTICIPATION:

There are no incentives for participating in this study.

PARTICIPANT'S CONSENT:

·I have read and understand the provided information and have had the opportunity to ask questions.

·I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without cost and that I will be given a copy of this consent form.

·I voluntarily agree to take part in this study (please check the option that applies to you and sign):

☐ I give permission for my interview to be to be audio (or video) taped.

☐ I do not give permission for my interview to be audio (or video) taped.

Printed Name _____ Participant's Signature _____ Date_____

Interview Questions for FGM Participants

1. Have you undergone FGM?

☐ Yes ☐ No ☐ Don't know

2. Why was FGM performed on you?

3. How common is FGM in your community?

4. Does being circumcised affect your willingness to see a doctor for health issues?

5. Are you comfortable talking to your healthcare provider about FGM?

6. What do you want healthcare providers to know and discuss with you about FGM?

7. What can healthcare providers do to make it easier for you to receive medical care?

8. Do you think FGM can cause health problems (choose all that apply)?:

☐ menstrual problems ☐ sexual problems ☐ fertility problems

☐ problems with labor ☐ none of the above

9. Do you think FGM will (choose one):

☐ Increase your chances of marriage ☐ Reduce your chances of marriage

☐ Don't know

10. Do you have any concerns about FGM that you would like your healthcare provider to address?

11. Do you think the practice of FGM should continue? Why?

☐ Yes ☐ No ☐ Don't know

12. Would you have FGM performed on your daughter? Why?

☐ Yes ☐ No ☐ Don't know

Interview Questions for Medical Doctor

1. Do you know the laws related to FGM?

2. How do you approach patients that have had FGM?

3.Do you/would you feel comfortable working with patients that have undergone FGM?

4. Do patients normally feel comfortable to speak candidly about the procedure or is there hesitation?

5. Are certain types of circumcision more common than others?

6. What are some of the challenges when dealing with a patient who has undergone FGM?

7. What type if any training have you received regarding this topic?

8. With regards to the FGM procedure, what would you like to learn more about that would allow you to treat patients in a more culturally sensitive manner?

9. Will a culturally competent practical guide regarding FGM be beneficial for you as a healthcare provider?