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Examining Associations Between Female Genital Mutilation and the Human Immunodeficiency Virus

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Abstract

The potential association between Female Genital Mutilation (FGM) and the incidence of Human Immunodeficiency Virus (HIV) has been a part of academic discourse for three decades. By considering the mixed reports on the association between FGM and HIV so far, this dissertation contributes to the current state of research by providing new information, first through a systematic review of existing research, and then through two secondary analyses of a nationally representative sample of women residing in Sudan. Taken together, the three studies show that within a complex and nuanced relationship is a positive social association between FGM and HIV, where social factors within a given geographic location influence rates of FGM as well as HIV literacy. The findings demonstrate that confounders such as education, wealth, and living in urban (or modernized areas) contribute to which form of FGM women experience (medicalized or traditional). Additionally, the dissertation demonstrates different levels of HIV literacy and testing activity among women who experience medicalized and traditional FGM.

The systematic review showed mixed findings on the association between FGM and HIV. Among studies examining the association between FGM and HIV, studies reported either positive, negative or no association between FGM and HIV. Among those reporting positive and negative associations, researchers discussed the potential for "indirect positive associations" where other factors independently associated with FGM and HIV may create a bridge to connect the two. There were contradictory reports from studies that examined the associations on different populations within the same country. I concluded that these findings were mixed due to heterogeneity in samples and multiple contextual factors (e.g., the age of participants, sample source and sample size) that may have been specific to the location of each study. Furthermore, the systematic review revealed multiple gaps in current knowledge specifically on medicalized

(vs. traditional) FGM, data outside the continent of Africa, data from women older than age 50, and data on the type of FGM potentially associated with HIV. More high-quality studies (guided by conceptual frameworks and demonstrating reasons for chosen methodology) are necessary to provide strong evidence for conclusions within the reviewed studies.

Studies 2 and 3 were secondary data analyses of nationally representative data from the sub-Saharan nation of Sudan. Sudan was selected for its high prevalence of FGM (medicalized and traditional) as well as it's vulnerable position for increased HIV incidence. The data source (Multiple Indicator Cluster Surveys) did not include HIV status of their participants. Instead, it included responses to survey questions that addressed HIV literacy and HIV testing activity among Sudanese women of reproductive age. Despite the lack of data on HIV status, examining the association between FGM and HIV literacy and testing is important because women who have undergone FGM may be less likely to seek out sexual health information and services due to cultural taboos and stigma surrounding discussions of sexuality and reproductive health. Additionally, due to traditions and social norms (similar to those surrounding FGM in Sudan), women may lack agency in navigating safer sexual options for themselves, potentially increasing vulnerability to HIV transmission. Given these possibilities, social and cultural factors can cause FGM and health literacy to travel together, resulting in an increased risk of HIV transmission and limited access to HIV prevention and treatment services. Higher levels of HIV literacy are often associated with a reduced risk of HIV infection because people who are more knowledgeable about HIV are better equipped to protect themselves from the virus. For its place within the HIV care continuum, examining FGM groups enables future interventions to target those who are at risk of failure to follow through with HIV testing, adherence to Highly Active Antiretroviral

Therapy (HAART) or engagement in HIV care by virtue of the social stigma and lack of empowerment present among those who are of a traditionally cut versus medically cut group.

Study 2 of this dissertation focused on FGM group and HIV literacy (i.e., HIV knowledge and toward people living with HIV) in Sudan. The sample selected were women who reported traditional or medicalized FGM, and those who were uncut at the time of data collection. Examining HIV knowledge and attitudes among women of different FGM cut groups served to provide information on the potential norms surrounding FGM that impact HIV-specific health literacy. After controlling for other potential explanatory variables (i.e., age, wealth, education, and location), results indicated that FGM group was significantly correlated with knowledge of HIV among women in Sudan. Specifically, those in the medicalized cut group reported the most accurate knowledge of HIV in the study sample, and those of traditional cut reported the least. Furthermore, those in the medicalized cut group were also among the wealthiest and most educated in the population and were more represented in urbanized areas. Attitudes toward people living with HIV did not differ across the three FGM cut groups, as they all reported highly stigmatizing views toward HIV. As a result of their wealth, education, and proximity to care (i.e., urban residence), those of medicalized cut were able to afford the more expensive form of FGM (i.e., medicalization) and had access to more HIV-specific information. By viewing the findings in this study along with other reports on criminalization, I concluded that medicalized FGM is contributing to slowing down progress toward eradicating FGM in its entirely, especially as criminalization (as reported in other studies) has resulted in increased prices of the medicalized form, allowing the wealthier to promote continuation. Additionally, considering that those that were traditionally cut are most represented in the poorest quintile and

among the least educated in rural areas, efforts to increase HIV knowledge must target those of traditional cut as these additional confounders contribute to their low knowledge of HIV.

Extending the findings from Study 2, Study 3 further explored the association of stigmatizing views and HIV testing activity in the same sample. HIV testing is important because it informs intervention efforts on the prevalence of the virus in a population and advances informed self-care for the infected individual(s). Based on other studies that report stigma as a predictor of HIV testing, this analysis aimed to determine if despite general stigmatized views, belonging to an FGM group could show differences in HIV testing activity. Results indicated that Sudanese women who experienced medicalized FGM had higher odds of having been tested for HIV when compared with the uncut. Those in the traditional cut group reported no statistically significant difference from the uncut in the odds of having been tested. Furthermore, while the traditionally cut group reported no statistically significant difference in knowing where to test compared to the uncut, those in the medicalized cut group were *less* likely to know where to test for HIV compared to those in the uncut group (but more likely to test as noted above). The result on odds of knowing where to test among the medicalized group contradicts other findings reported up until this point, as it should seem obvious that if those of medicalized cut had higher knowledge of HIV and higher odds of ever testing for the virus, they should report higher odds of knowing where to test. One possible explanation for this unexpected finding might have been miscommunication at the point of data collection, where participants assumed that they were asked about HIV-specific testing centers outside of hospitals and clinics.

The results in these studies create a foundation for examining power dynamics within FGM-practicing communities that also influence HIV literacy and likelihood of testing. For instance, the majority of participants in the sample for Studies 2 and 3 were cut by medical

professionals. Although medical professionals are in trusted positions to provide the best possible care for their patients, those who provide FGM services are contributing to a slower rate of eradication by providing a seemingly safer option for FGM to their patients without knowledge on the long-term health consequences. Thus, efforts to eradicate HIV among Sudanese women should begin with and be directed toward medical professionals. Interventions must also include those in positions of authority (like religious leaders) who contribute to the social norms surrounding female sexual and reproductive health. On another level, society-wide stigmatized views of HIV, compounded with silence surrounding FGM practices have the power to subjugate a woman's reach in accessing necessary services along the HIV continuum of care.

Taking this intersectional view, those of traditional cut (who are also the poorer and least educated in FGM practicing communities) can be the focus for comprehensive HIV education. Additionally, I recommend caution in making blanket statements regarding the association of stigmatizing attitudes and HIV testing activity, as contextual factors (such as residence location and education level) likely influence associations across different FGM-practicing communities. Building upon this dissertation, future research has the potential to create directional hypotheses on the type of FGM potentially associated with incidence of HIV, examine long-term effects of medicalized FGM, conduct similar comparative studies on data from countries outside Africa, examine potential pathways between medicalized FGM and HIV, and examine medical provider knowledge and attitudes toward the association between FGM and HIV.

Acknowledgment

I have a theory that at heart, Jesus was a Public Health professional. Afterall, in Matthew chapter 25, verses 35 and 36, he encouraged his listeners to address food and water insecurity, provide kindness and shelter to migrants, give clothing and medicine to the poor and sick, and demonstrate genuine concern for the incarcerated. In his time on Earth, he never did those things alone, and for my decision to be his hands and feet in the field of Public Health, he has provided just the right people at the right time, with the right resources, and the right dose of affirmation to keep me going.

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To my mother and father, Martha and Ibrahim Puri, I can spend a lifetime trying to repay you for your sacrifices, and only scratch the surface. Instead, I will strive to continue to honor

you by living the life that you've worked for, knowing that just being your daughter is and has always been enough.

List of Abbreviations

FGM	Female Genital Mutilation
HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
DHS	Demographic Health Surveys
MICS	Multiple Indicator Cluster Surveys
PLWHA	People Living with HIV/AIDS
WHO	World Health Organization
SES	Socioeconomic Status
UNICEF	United Nations Children's Fund
UNFPA	United Nations Population Fund
UNAIDS	Joint United Nations Programme on HIV/AIDS
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
DfiD	Department for International Development
ANCOVA	Analysis of Covariance
SPSS	Statistical Package for the Social Sciences

This dissertation is dedicated to the survivors of female genital mutilation.

Your strength, resilience, and perseverance in the face of unimaginable pain and trauma inspire me to work towards a world where FGM is no longer practiced.

To the survivors who have shared their stories with me and have given me permission to use their experiences in the course of my career, I am deeply grateful. Your bravery in speaking out about your experiences has been instrumental in raising awareness about the devastating effects of FGM and in advocating for change.

To the survivors who have not yet found their voice or who continue to suffer in silence, I dedicate this work to you. Your experiences are valid, and your pain is real. I hope that this research will contribute to a greater understanding of the physical, emotional, and psychological toll of FGM and will help to create a world where all women can live free from harm and discrimination.

Finally, I would like to acknowledge the activists, advocates, and organizations around the world who are working tirelessly to end FGM. Your dedication, passion, and commitment to this cause inspire me every day, and I am honored to be part of this movement for change.

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CHAPTER ONE: INTRODUCTION

This chapter provides a comprehensive introduction to the practice of Female Genital Mutilation (FGM), the trends toward medicalization, the gendered experience of the Human Immunodeficiency Virus (HIV) among women and a rationale for examining the association between FGM and HIV.

Both FGM and HIV are significant public health concerns affecting women worldwide. FGM is a global practice (often viewed as a rite of passage into womanhood) that involves the partial or total removal of the external female genitalia, and it affects millions of women.[1] HIV is a viral infection that attacks the immune system, leading to severe illness and death if left untreated.[2] While these two issues may appear unrelated at first glance, there is a growing body of evidence suggesting a link between them.

1.1 Female Genital Mutilation

What is Female Genital Mutilation and Why is it practiced?

The practice of female genital mutilation (FGM) involves several forms of genital alterations without medical benefits. In multiple parts of the world, it is a traditional rite of passage that ranges from cutting (or nicking) the clitoris to sewing up the vulva and covering the urethra, leaving a small opening for the vaginal canal.[3,4] This dissertation refers to these procedures as FGM, adopting the official terminology used by United Nations Children's Fund (UNICEF), World Health Organization (WHO) and United Nations Population Fund (UNFPA).[5] However, some researchers refer to this procedure (and its various forms) as “cutting” or “circumcision” as they are sometimes used by the communities that practice FGM, and therefore, these terms are also present in literature.[6] Additionally, “circumcision” and “cutting” are seen as

more culturally sensitive and neutral,[7] since they do not carry the negative connotations that the term "mutilation" implies.

However, it is important to note that “circumcision” often implies a parallel to male circumcision- a procedure that is different from FGM in both process and outcome. FGM involves the partial or total removal of external female genitalia, which can cause serious physical and psychological harm, while male circumcision involves the removal of the foreskin of the penis, which is a much simpler and less invasive procedure. Terminology notwithstanding, there are four classifications of FGM provided by WHO.[8]

WHO Definitions

Type 1: *Clitoridectomy* is the partial or total removal of the prepuce (or the skin covering the clitoris) and/or partial or total removal of the clitoral glans.

Type 2: also known as *excision*, this type involves the partial or total removal of the clitoral glans and labia minora (or inner folds of the vulva), with or without removal of the labia majora (or outer folds of the vulva).

Type 3: Also known as *infibulation*, this is the narrowing of the vaginal opening through the creation of a covering seal. The seal is formed by cutting and repositioning the labia minora, or labia majora, sometimes through stitching, with or without removal of the clitoral prepuce/clitoral hood and glans.

Type 4: This includes all other harmful procedures to the female genitalia for non-medical purposes, including pricking, piercing, incising, scraping, and cauterizing the genital area.

Additionally, other FGM procedures provide include:

Defibulation: referring to the surgical procedure of unsealing the vaginal opening of an infibulated woman to improve sexual health outcomes and childbirth.[9]

Reinfibulation: referring to the postpartum resealing of a *deinfibulated* vagina. Some medical professionals report that patients have requested this procedure for cultural purposes[9].

Communities practice FGM for a number of cultural, social, religious, and economic reasons. Some of the reasons commonly cited for the practice of FGM include:

1. Social acceptance and pressure[10]: FGM is often seen as a rite of passage and a way for girls to gain social acceptance and status within their community. Failure to undergo the procedure can lead to social exclusion and stigmatization.
2. Religious beliefs: Some communities believe that FGM is required by their religion as a way to preserve virginity and promote chastity. FGM predates Abrahamic religions and neither Christian nor Catholic Bible, Jewish Torah, nor the Islamic Quran support FGM as a religiously mandated practice. [11]
3. Tradition and customs: In several societies, FGM is honored as a traditional practice that has been passed down from generation to generation and is therefore deeply ingrained in cultural beliefs and practices. However, the traditions are rooted in controlling female sexual behavior, as several practitioners cite the preservation of virginity as cause for cutting.[12,13]
4. Perceived health benefits[14]: Some communities believe that FGM has health benefits, such as reducing the risk of infection or making childbirth easier.

Despite differences in rationale for the practice of FGM, studies confirm that survivors across FGM-practicing societies suffer physical (such as excessive bleeding, urine retention, and genital tissue swelling)[15] as well as mental health harm (such as anxiety, depression and post traumatic stress disorder (PTSD)) resulting from FGM.[16,17]

Who experiences FGM? When and where do women experience FGM?

FGM is typically performed on girls between infancy and age 15, although it is sometimes also performed on adult women.[18] It is practiced in communities in Africa, Asia, and the Middle East, as well as in immigrant communities from these regions who have settled in other parts of the world.[19] Globally, it is estimated that more than 200 million girls and women have undergone FGM.[20]

National level estimates of the prevalence of FGM are subject to underreporting, due to the stigmatized nature of the practice.[21] Nevertheless, there is growing evidence of survivors who require a wide range of medical services ranging from defibulation surgery to specialized gynecological care[22] and mental health treatment[17]among others. Short-term outcomes include excessive bleeding, damage to other organs, sepsis, and shock.[1] Some girls have reported broken bones because older women hold down the young, unanesthetized person during the procedure.[4] In rural areas where blood transfusions are not readily available, death can result from excessive hemorrhage during or after an error in FGM procedure.[4] Long-term negative sequelae include scarring, sexual dysfunction, chronic pelvic pain, and intrapartum complications.[23,24] In response to these outcomes, there was a shift toward medicalization of FGM.

1.2 Trends toward Medicalization of FGM

In most Asian and African societies with high FGM prevalence, the procedure is carried out by traditional birth attendants, local barbers, traditional practitioners, and family matriarchs.[25,26] A Kenyan study published in 2004[27] described an increase in young women reporting to the hospitals for tetanus toxoid injections shortly after experiencing FGM. These occurrences were the result of FGM performed with crude and often unsterile instruments, in

unsterilized environments. Similar findings were reported in Egypt, Nigeria, and Sudan.[28] The Kenyan report was important because it presented viable proof that the traditional procedure was harmful to the female body. With the goal of harm reduction for girls and women undergoing the procedure, medical professionals (including doctors, nurses and nurse-midwives) in multiple countries began to provide what is now known as medicalized FGM - any type of FGM conducted by a medical professional in a home or clinic.[28] Consequently, institutions like WHO consider *reinfibulation* (post-partum resealing of a *deinfibulated* vagina) as a form of medicalized FGM.[8] In some cases, medicalized FGM involves the use of local anesthesia to reduce the immediate pain experienced by the female.[29]

For now, there is no research providing data on long-term physical and psychological consequences of medicalization of FGM. Proponents of this from of the practice suggest that it reduces initial harm compared to the traditional form as incidences of infections, severe bleeding, and even death can be reduced.[28] Advocates for medicalization also propose that healing is faster under this form,[30] and it can relieve fears attached to the practice.[31]

Due to the involvement of medical professionals, medicalized FGM in some societies is more expensive, creating implications for socioeconomic status (SES) as predictor of FGM. In some societies, those of higher SES opt for medicalization as they can afford what is viewed as potentially safer for their daughters.[32] The aforementioned Kenyan study[27] also found that financial or material gifts are used as incentives for medical professionals to perform FGM, as the cost of the procedure ranged from 150 to 500 Kshs (US$ 1.90 – 6.25) per patient.[27] By comparison, the minimum wage for an average worker in Kenya is 48.6 Kshs (US$ 0.39) per hour.[33] Studies have reported that medicalized FGM is now offered as part of routine neonatal

care in Indonesia and Nigeria.[34,35] Some medical professionals who provide this service as routine care argue that medicalization reduces the odds of health complications and will eventually lead to eradication.[36] They maintain that the road to eradication must happen in gradual steps beginning with medicalization. Consequently, the social acceptability of medicalized FGM is on the rise, especially among those of higher SES, because patients respect the opinion of their medical care providers and, therefore, view this form as a safer option for their daughters.[37,38]

However, medicalized FGM is not accepted by all. Some public health professionals have argued that medicalization slows down the United Nations Sustainable Development Goal of eradicating FGM by 2030.[36,39] Some traditional cutters are also in opposition to medicalization as they lose income and clients.[36]Additionally, some argue that the full traditional experience is diminished by using anesthetics or other clinical tools.[40]

Given the growing social acceptance surrounding medicalization, and the lack of information on the long-term effects of this form, more research comparing characteristics of those of medicalized FGM to their traditionally cut and uncut counterparts would add value to public health interventions. That is, where research can identify ways in which those of medicalized cut differ from their traditionally cut and uncut counterparts, we can tailor health interventions to the specific needs of women with different FGM experiences.

1.3 FGM, Male Circumcision and HIV

In 2007, WHO and UNAIDS released a joint statement recommending male circumcision as an additional HIV prevention strategy in settings with high HIV prevalence and low levels of male circumcision.[41] The statement was based on evidence that indicated that male circumcision could reduce the risk of HIV acquisition by up to 60%. Since then, several countries in sub-

Saharan Africa have adopted policies promoting male circumcision for HIV prevention. For example, the government of Kenya launched a national voluntary medical male circumcision (VMMC) program in 2008 aimed at circumcising 80% of uncircumcised men by 2022. [42] Tanzania also launched a national VMMC program in 2010, with the goal of circumcising 80% of uncircumcised men by 2015.[43]

Given these findings and subsequent policies, some researchers extended the findings from male circumcision and hypothesized that the association between FGM and HIV is similar to that of male circumcision and HIV.[44,45] However, statements from WHO, UNICEF and other international bodies state that there is no evidence that FGM has medical benefits, and, furthermore there is no evidence to support FGM as a means of HIV prevention.

1.4 Human Immunodeficiency Virus (HIV)

Women are disproportionately affected by HIV, making it a gendered epidemic. This is evident as women account for more than half of all people living with HIV/AIDS (PLWHA) worldwide.[46] In sub-Saharan Africa, where HIV is most prevalent, women account for approximately 60% of all new infections.[47] In some countries, the HIV prevalence among young women aged 15-24 is up to three times higher than that of their male counterparts.[48] This is due to biological, social, and economic factors that put women at higher risk of HIV acquisition; specifically transactional sex, lack of access to prevention and treatment, stigma and discrimination, and economic vulnerability.[49-53] Additionally, women who experience gender-based violence are at a higher risk of HIV infection due to forced or unprotected sex.[54] For instance, sexual violence can lead to genital trauma, which increases the risk of HIV transmission. These social and economic factors contribute to a lack of autonomy over one's health, subsequently contributing to delayed diagnosis and treatment, and poorer health

outcomes. Finally, women living with HIV have unique reproductive health needs, including preventing mother-to-child transmission (MTCT) of HIV during pregnancy, delivery, and breastfeeding.[55] Access to antiretroviral therapy (ART), pre-exposure prophylaxis (PrEP) and other reproductive health services is essential to prevent HIV transmission to their partners and their children. Where cultural and societal norms prevent women from negotiating safer sex and accessing HIV prevention and treatment services, the burdens only increase. [56]

1.5 Social and Structural Determinants of Health connecting FGM and HIV

FGM and HIV are interconnected through social and structural determinants of health. That is, social factors that surround FGM can also contribute to the spread of HIV. Some of the determinants that are relevant to both FGM and HIV include:

1. Gender inequality: Gender inequality and the subordination of women can contribute to both FGM and HIV.[233] In communities where women are not given equal status and opportunities, they may have limited power to negotiate safer sex practices, access health care, or resist the practice of FGM.
2. Cultural and religious beliefs: Cultural and religious beliefs that support FGM can also contribute to the spread of HIV.[234] For example, in some communities, the practice of FGM is linked to the belief that women should be chaste and abstinent,[4] which can discourage them from using condoms or seeking HIV testing and treatment. Where religious leaders encourage abstinence through FGM, they may also contribute to a system of stigmatization where HIV is viewed as a punishment for the lack of abstinence before marriage.
3. Poverty and lack of education: Girls from poor families or those who do not have access to education may be at higher risk of FGM,[235] which can increase their vulnerability to

HIV. Poverty can also limit access to HIV prevention and treatment services, making it harder to control the spread of the virus.[192]

4. Migration and displacement: Girls and women who are displaced or forced to migrate may be at increased risk of polyvictimization [236] including, but not limited to mental health challenges, FGM and HIV. Through forced migration, they may be exposed to different cultural norms and practices or may feel pressure to conform to the traditions of their new community.

1.6 Purpose of the study

FGM and HIV are both stigmatized conditions[57,58] that lead to underreporting and adversity in physical and mental health. Multiple studies examining the association between FGM and HIV have reported on the biological plausibility of FGM resulting or protecting against HIV. While some report that FGM is a risk factor for HIV,[59] others report that like male circumcision, FGM provides a protective effect against HIV transmission during intercourse.[44] This dissertation examines reports on said associations and provides information on the social plausibility of an association between FGM and HIV.

This dissertation utilizes a 3-study format to examine the association between FGM and HIV through three approaches. The first approach is a systematic review to identify the current state of the evidence on associations between FGM and HIV, the second is a secondary data analysis on the association of FGM and HIV-specific health literacy, and the third is a secondary data analysis on FGM and HIV testing.

The systematic review (or Study 1) is significant for synthesizing existing evidence on the association between FGM and HIV. By summarizing the evidence, evaluating the quality of

evidence and identifying gaps in knowledge, this review will contribute new information that will inform discussions on predictors of HIV in the context of FGM.

For the two secondary analyses of nationally representative data (Studies 2 and 3), this dissertation focuses on the sub-Saharan nation of Sudan. Sudan is relevant for its high rates of medicalized FGM and vulnerability to increased incidence of HIV. While 87% of the female population have experienced FGM,[60] reports show that requests for medicalized FGM have increased by 67% in the last two decades.[30] Additionally, the HIV epidemic in Sudan was influenced by sociopolitical shifts after the 2011 secession,[61] which included the reduction of states from 25 to 18 and significant population displacement within and outside the country.[62] Moreover, the limited awareness about HIV and highly stigmatized views among the general population further exacerbate the situation.[63] According to the Sudan Health and Household Survey (SHHS), comprehensive knowledge about HIV among the general population was found to be remarkably low, at 6.7%.[64] This lack of knowledge can lead to stigma and discrimination towards people living with HIV, as well as hinder efforts to prevent new infections. Given the high FGM rates and associated vulnerability to HIV, Sudan provides relevant data for examining the association between FGM and HIV.

Using secondary data analyses, studies 2 and 3 examine HIV knowledge, attitudes and testing activity to expand on current knowledge on the of the social impact of FGM on HIV in Sudan. Two significant risk factors for HIV are poverty and illiteracy.[65] Given high poverty and illiteracy rates in Sudan,[66] the questions of knowledge and attitudes toward PLWHA are essential for public health education efforts, as more targeted interventions can identify specific groups and tailor interventions to their needs. Additionally, comparisons in HIV testing activity will

provide knowledge on factors influencing testing and targeted interventions to improve testing rates among specific groups.

1.7 Research Aims

The studies for this dissertation are guided by three aims:

Aim 1a: To conduct a systematic review examining studies on associations between FGM and HIV

Aim 1b: To identify gaps in current knowledge regarding associations between FGM and HIV.

Aim 2: To examine HIV literacy among Sudanese women of medicalized cut, traditional cut and uncut FGM status

H_0: There is no statistically significant difference in knowledge on HIV/AIDS and attitudes toward people living with HIV/AIDS among Sudanese women of different FGM cut groups, after controlling for age, wealth, education and location.

H_1: There is a statistically significant difference in HIV/AIDS knowledge and attitudes toward people living with HIV/AIDS among Sudanese women of different FGM cut groups, after controlling for age, wealth, education and location.

Aim 3: To compare self-reported HIV testing activity across FGM groups (medicalized, traditional, or uncut)

H_0: When compared to their uncut counterparts, Sudanese women of medicalized and traditional cut groups will report no differences in HIV testing activity after controlling for age, marital status, wealth, education and location of residence.

H_1: When compared to their uncut counterparts, Sudanese women of medicalized and traditional cut groups will report significant differences in HIV testing activity after controlling for age, marital status, wealth, education and location of residence.

CHAPTER TWO: A Systematic Review of the Evidence of HIV Infection among Survivors of Medicalized and Traditional Female Genital Mutilation

2.1. Introduction

Female genital mutilation (FGM) is a harmful cultural practice that has been reported to affect an estimated 200 million women and girls worldwide.[67] The World Health Organization (WHO) identifies four types of FGM, ranging from partial to complete removal of the clitoris and labia, and in some cases, narrowing of the vaginal opening.[67] The practice is deeply rooted in cultural and social beliefs and is often performed without medical supervision or anesthesia.[5,68] It also has severe short-term and long-term physical and psychological consequences for women and girls, including chronic pain, infertility, and sexual dysfunction.[1,69] In addition to these challenges, several researchers report that FGM predisposes women to viral infections with lifelong implications.[70,71] One such lifelong affliction is the onset of HIV.

In the process of investigating associations between FGM and HIV, several studies have reported mixed findings, [44,72,73] and the underlying factors contributing to these mixed findings are not well understood. Some researchers propose that FGM can cause tissue damage and scarring, leading to increased susceptibility to HIV infection during sexual activity.[74] Some also propose that the removal of external genitalia can lead to painful vaginal sex, leading to reliance on anal sex instead, which has a higher risk of HIV transmission.[75] However, other researchers have proposed that like male circumcision, FGM serves a protective effect against HIV infection. Therefore, a systematic review is needed to synthesize the existing evidence and provide a comprehensive understanding of the relationship between FGM and HIV.

This systematic review aims to identify and critically appraise the available literature on the association between FGM and HIV. It will also explore the factors that contribute to this association and the challenges of addressing FGM and HIV in affected communities. This review also builds upon two existing systematic reviews of similar aims. Although they both also examined literature on the association between FGM and HIV across various databases, one of them[70] was published ten years ago, and broadened its scope to all infections giving limited space to HIV-specific discussion. The second[76] only presented a summary of previous findings without identifying gaps in current knowledge and relied on a single individual for article screening. The review for this dissertation improves on the previous reviews, by including more recent literature focused specifically on HIV. In addition, the present review included a second screener for the articles and benefitted from comprehensive guidance from a librarian with expertise in systematic reviews and literature searches. Finally, the present review addresses the research gaps and their implications for future research.

2.1.1 Rationale for the review

Male circumcision has been reported to have a protective effect against HIV transmission in several studies.[77,78] WHO and UNAIDS recommend male circumcision as a public health intervention in areas with high HIV prevalence, where the procedure can be safely provided.[79,80] The exact mechanism by which male circumcision provides protection against HIV is not fully understood, but it is thought to be related to the fact that the foreskin is more susceptible to HIV infection than other areas of the penis.[81] Removing the foreskin reduces the amount of tissue that can be infected and also removes cells that are more susceptible to HIV infection. Based on these findings, some researchers have theorized that FGM has a similar protective effect against HIV

transmission. However, others have proposed the opposing viewpoint, stating that FGM is a risk factor for HIV.

In a 1997 publication on FGM and HIV, K.E. Kun provided four theoretical pathways through which FGM may result in HIV infection among women. Table 2.1 outlines the four proposed pathways (see Table 2.1).[75]

The first pathway proposes that lacerations from FGM can promote scar tissue formation that eventually obstructs the vaginal canal. This obstruction increases the chances of inflammation, abrasion, and bleeding during intercourse, increasing the risk of HIV transmission. Kun's argument is supported by a cross-sectional study conducted in Nigeria that found that survivors of FGM/C were four times more likely to report Genital Ulcer disease (GUD) from a break in the vaginal mucosa.[82] This breach also increases the risk of other viral infections like HIV. Another study supporting this proposed pathway identified type 3 FGM/C (infibulation) as a precursor to tearing and bleeding during intercourse.[74] In this case, the potential for blood sharing between partners increases along with the risk of HIV transmission. The second proposed pathway states that FGM/C has been reported to lead to painful vaginal intercourse,[83,84] increasing the practice of anal intercourse. Anal intercourse has been identified in multiple studies as a mode of efficiently transmitting HIV due to the anal canal's thin epithelial layer.[85-87] A 2007 study also supported this pathway as they discussed painful intercourse as a result of FGM/C.[74] They also argue that the couple may practice anal sex if the infibulated female (i.e., a survivor of type 3 FGM/C) experiences too much pain. Anal sex is still a taboo topic of discussion in multiple African societies,[88] which may explain the lack of studies vigorously examining the role of anal sex in HIV transmission among FGM/C survivors. Nevertheless, the potential association is also considered an indirect causal link between FGM and HIV.[89]

The third proposed pathway highlights obstructed labor and tearing resulting from some forms of FGM/C.[90-92] The pathway proposes that excessive hemorrhage from obstructed labor and tearing may lead to the need for blood transfusion at the time of delivery. While HIV antibody testing reduces the rate of contaminated blood transfusions, human, as well as testing errors, are feasible. [93-95] Therefore, this association is also considered an indirect causal link between FGM and HIV.[88]

Table 2.1 Hypothetical Mechanisms of HIV transmission through FGM/C
FGM ⇒Infection/scarring ⇒Partial/complete occlusion of the vagina ⇒ Greater risk of inflammation/bleeding during intercourse⇒ Disruption of the genital epithelium/exposure to blood/penile abrasions which have been reported to enhance risk of HIV infection
FGM⇒ Painful/difficult vaginal penetration⇒ Increased practice of anal intercourse, which has been shown to enhance the efficiency of HIV transmission
FGM⇒ Higher incidence of obstructed labor and tearing⇒ Hemorrhage⇒ Higher risk of blood transfusion; blood supply may not be optimally screened for HIV
Use of unsterilized instruments to perform the FGM procedure⇒ Exposure to blood contaminated by the virus
Source: Rebecca Y. Stallings, x^2 Statisticus Consultoris, USA and Emilian Karugendo, National Bureau of Statistics, Tanzania

Finally, the fourth pathway highlights what studies have described as a direct causal link between FGM/C and HIV.[88] In this pathway, unsterilized instruments shared among survivors make them increasingly vulnerable to HIV infection. This is made possible by communal cutting practices, where young women simultaneously experience the cut in a group.[96] If a participant was born with HIV or contracted it through sexual intercourse, others involved in the communal cut are more vulnerable to infection.

Despite the plausibility of these hypothesized pathways, not all peer-reviewed studies find support for a positive association between HIV and FGM.[88] Others have argued for a negative association suggesting that, like male circumcision, FGM/C protects against HIV.[44,97 77,78] In light of these opposing views, this dissertation implemented standardized guidelines to conduct a systematic review.

2.2 Methods

2.2.1 Study selection

We identified citations for review through a systematic search of Medline (Ovid), Embase, Cochrane Library, CINAHL, PsycINFO, Scopus, Web of Science and Global Health. The search included a combination of the terms "female genital cutting", "female genital mutilation", "circumcision", "Sunna circumcision" (as it is called in several predominantly Muslim communities),[98] "infection" and "HIV". This search was conducted with help from a Feinberg Librarian. On separate occasions, we also conducted a search of Google Scholar with the same search terms. To limit bias in article selection, a second reviewer was invited for the screening stage of the review. As a medical student with prior experience in research, the second reviewer provided additional screening assistance with support and training from a Feinberg Librarian.

Articles were excluded if they were editorials or opinion pieces, studies with no clinical data (i.e., those with no participant data on HIV and FGM diagnosis, exposures and demographics) and studies outside of the English language. Although we included conference presentations (marked as gray literature)[99] conference abstracts were excluded when we were unable to find the full presentation. The process of reporting data from this systematic review was guided by a checklist of items provided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).[100] A detailed protocol for this review is registered with PROSPERO (ID:CRD42023391491). Figure 2.1 provides a PRISMA chart of the article sources and review stages.

2.2.2 Methodology for rating selected studies

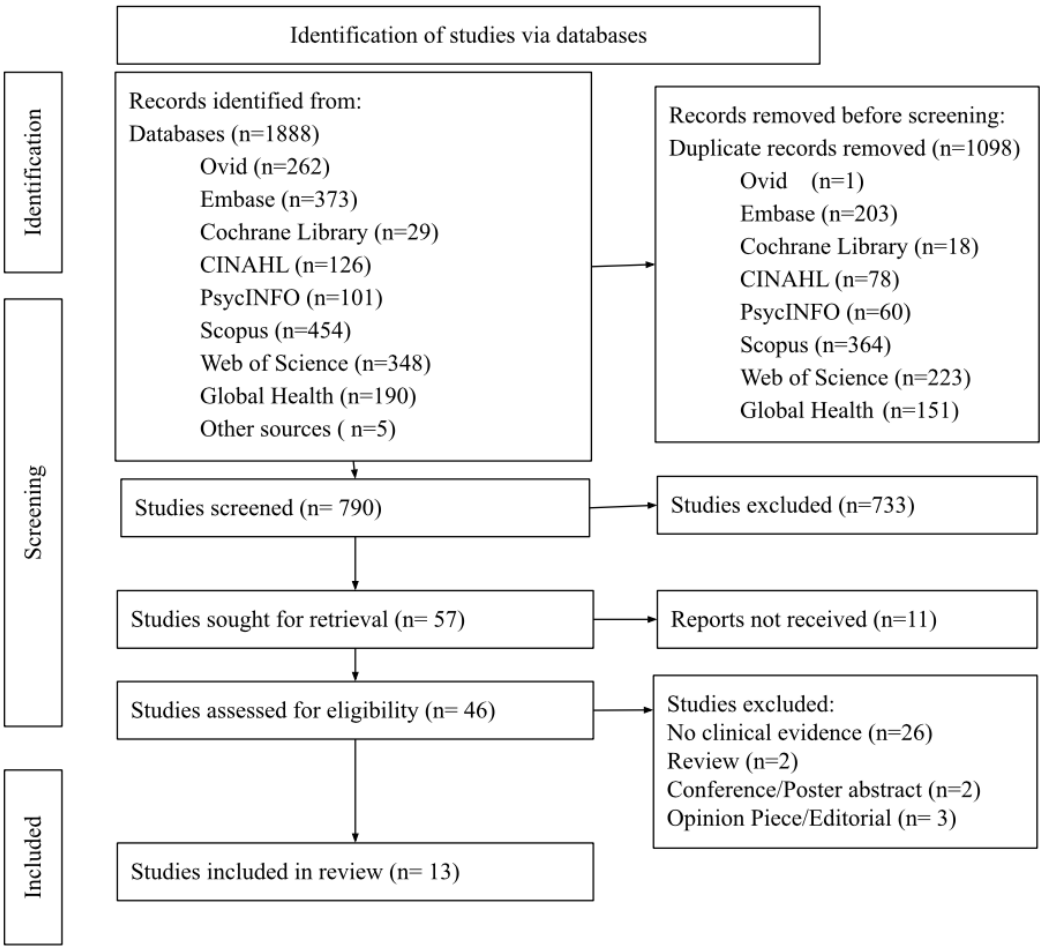
After selecting the studies for inclusion based on criteria provided in the protocol, we began appraisal on each study by identifying study participant's country of origin, sample source (and year), study design, prevalence of HIV and FGM, age of participants, type of FGM reported, person performing FGM, and results of positive, negative, or no association. The tabular form (see Table 2.2) allows a visual comparison between studies.

In addition to each study characteristic, we appraised individual studies for quality using the seven "principles of high-quality research studies" provided by the Department of International Development (DfiD). Published in 2014, DfiD's "How to Note: Assessing the Strength of Evidence"[101] was developed to provide a thorough and uniform system for assessing individual studies. Below are the seven principles used to evaluate the quality of each study:

1. Conceptual framing: Does the study acknowledge existing research? Does the study construct a conceptual framework? Does the study pose a research question? Does the study outline a hypothesis?
2. Openness and transparency: Does the study present or link to the raw data it analyses? - Does the author recognize limitations/weaknesses in their work?
3. Appropriateness and rigor: Does the study identify a research design? Does the study identify a research method? Does the study demonstrate why the chosen design and method are good ways to explore the research question?
4. Validity: Has the study demonstrated measurement validity? Is the study internally valid? Is the study externally valid?
5. Reliability: Has the study demonstrated measurement reliability? Has the study demonstrated that its selected analytical technique is reliable?

6. Cogency: Does the author 'signpost' the reader throughout? Are the conclusions clearly based on the study's results?
7. Cultural sensitivity: Does the study explicitly consider any context-specific cultural factors that may bias the analysis/findings?

Figure 2.1 PRISMA 2020 Flow Diagram for Systematic Review Study Selection



The seven principles according to DfiD standards were addressed using the questions above and reported in Table 2.3. A detailed definition of each quality is provided in the *How to Note*.[102] The document encourages reviewers to assign a particular grade to a study based on their judgment. In this dissertation, a numeric value is assigned to each qualifying question, with

1 indicating that the qualifying question was answered in the study, 0 for those not answered, and 0.5 when the qualifier was partially found in the study (see Table 2.3). This allowed for a maximum of 20 points. High-quality studies received scores greater than 15 points. Moderate-quality studies received 11-14.5 points, and low-quality studies were those with less than 11 points. The DfiD document also recommends directional arrows that may be used to signify quality in evidence papers. Therefore, results in Table 3 also include directional arrows indicating high-quality (↑), moderate quality (→), and low-quality (↓) studies.

2.3 Results

2.3.1 Search Results

A total of 790 citations were screened after deduplication (See Fig. 1). Following the patients/population, intervention, comparison, and outcome (PICO) principle recommended by the Cochrane Collaboration,[103] 733 studies were excluded after the title and abstract review and 57 studies were sought for full-text review. Finally, 13 articles were included for systematic review. 4 of the 13 articles 44,72,73,104 [77,85-87] were sourced from other review articles. One study delivered as a conference presentation[105] was found through Google Scholar.

Table 2.2. Studies Reviewed for Association between FGM and HIV

Authors, Year	Country of study	No. of participants	Sample Source	Study design	Prevalence of HIV among participants	Prevalence of FGM among participants	Age of participants	FGM measured by	Person performed FGM (%)	Most common FGM type (%)	Results (95% confidence interval)
Bouare et al., 2013	Mali	1,000	6 reference health centers (2009)	Prospective Study	4.10%	90%	<50yrs	Self-report	NR	Type 2 (Excision)	No statistically significant association [HIV+, cut women=4.3%; HIV+, uncut women=4.4%]. *p* value=0.97, CI not reported
Brewer et al., 2007	Kenya, Lesotho, Tanzania	3,268	Demographic and Health Surveys (DHS) (2003)	Retrospective study	0.10%-10.80%	18%	15-49	Self-report	NR	Type 1 (Clitoridectomy)	No statistically significant association; OR 2.38 (0.59-9.69)
Kanki et al., 1992	Senegal	435	STD Centers in Dakar, Ziguinchor and Kaolack (1992)	Prospective Study	HIV-1: 0.4%-4.1%; HIV-2: 10%-38.1%	Dakar (15.5%), Ziguinchor (20%), Kaolack (14.7%)	20-69	Self-report	NR	Type 2 (Excision)	Negative association OR 0.47 (0.27-0.85)
Kapiga et al., 2002	Northern Tanzania	312	Bar and hotel workers in Moshi (2002)	Prospective Study	26.30%	27.7%	16-55	Self-report	NR	NR	No statistically significant association OR 1.41 (0.82-2.44)
Klouman et al., 2005	Tanzania	399	Temporary survey center established in Tanzania Highlands (1993)	Cross-sectional survey	81.40%	72.5% from pelvic exams, 65.5% from self-reports	15-44	Self-report & pelvic exam	NR	Type 1 (Clitoridectomy) and 2 (Excision)	No statistically significant association; Self-reported FGM/C OR 1.0 (0.5-2.3); Pelvic exam FGM/C OR 1.2 (0.4-3.4)
Magadi & Desta, 2011	Sub-Saharan Africa: 20 countries	95759	Demographic and Health Surveys (DHS) Data (2003-2008)	Retrospective study	0.7%-31.1%; 5% (All *SSA)	NR	15-49	Self-report	NR	NR	Negative association OR 0.37 (0.22-0.52)

Maslovsaya et al, 2009	Kenya	3114	Kenya Demographic Health Surveys (KDHS)(2003)	Retrospective study	8.80%	30.9%	15-49	Self-report	NR	NR	Positive association OR 2.2(1.13-4.32)
Mauri 2022	Switzerland	387	HIV-infected migrants from 30 high FGM-risk countries (2016-2018)	Prospective Study	100%	20.7%	18+	Self-report	NR	**Type 2 (Excision) & 3 (Infibulation)	Positive association; OR 2.34 (1.98,2.62)
Msuya et al., 2002	Tanzania	379	3 largest government healthcare clinics in Kilimanjaro (1999)	Prospective study	Cut, 7.90% Uncut, 12.30%	16.6%	6-18yrs	Pelvic exam	NR	Type 1 (Clitoridectomy)	No statistically significant association OR 0.64(0.26-1.57)
Pepin et al., 2006	Guinea-Bissau	1608	Areas of Bissau: Pluba, Cupelom, Luanda, Santa Luzia, Penha, Pefine, Calequir, Bairro Militar, Amedalai, Rossio, Antula and Reno	Cross-sectional survey	13.5% HIV-2 only, 1.6% HIV-1 & 2	18.4%	>50	Self-report	NR	Type 2 (Excision)	Positive association OR 1.54 (1.08-2.18)
Smolak, 2014	Mali	4219	Demographic and Health Surveys (DHS)	Retrospective study	1.64%	83% of total sample	15-49	Self-report	NR	NR	Positive association OR 2.10 (1.84-2.39)
Stallings & Karugendo, 2005 (gray literature)	Tanzania, Kenya	6061 (interviewed and tested for HIV)	Tanzania HIV/AIDS Indicator Survey (THIS)	Retrospective study	2%-15.2%	3%-73% across ethnicities and regions	15-49	Self-report	Medicalized: 6.9%, Traditional:74%-91% across regions	NR	Negative association OR 0.51(0.38-0.70)
Yount et al., 2007	Kenya	3167	Kenya Demographic Health Surveys (KDHS) (2003)	Retrospective study	33.80%	8.5%	15-49	Self-report	NR	NR	No statistically significant association OR 0.81 (0.50-1.33)

***SSA: Sub Saharan Africa**
**** hypothesized by authors**
OR= Odds Ratio

Table 2.3. Study Ratings Outlined According to DfiD Principles of Quality (2014)

	Conceptual Framing			Transparency			Appropriateness			Cultural Sensitivity	Validity				Reliability			Cogency			Overall rating score	
Authors, Year	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	Out of 20	Quality
Bouare et al., 2013	1	0	0	0	1	0	1	1	0	1	1	1	1	0	1	1	1	0.5	0	0	11.5	→
Brewer et al., 2007	1	0	0	1	1	0	0	0	0	1	1	1	1	1	1	1	1	1	0	0	12	→
Kanki et al., 1992	1	0	1	0	1	1	0	1	0	1	1	1	0.5	1	1	1	1	1	0	0	12	→
Kapiga et al., 2002	1	0	0	0.5	1	1	0	1	0	0	1	0.5	1	0.5	1	1	1	1	1	0.5	13	→
Klouman et al., 2005	1	0	0	1	1	0	1	1	0	1	1	1	1	1	1	1	1	1	0	1	15	↑
Magadi & Desta, 2011	1	1	1	1	1	0	1	0.5	0	0	0.5	1	1	1	1	1	1	1	0	0	14	→
Maslovsaya et al, 2009	1	0	1	1	1	1	1	0	0	1	0	0	1	0	1	1	1	0.5	1	1	13.5	→
Mauri, 2022	1	0	0	1	1	1	1	1	0	0.5	0	0	0	0	1	0	0	1	1	1	10.5	↓
Msuya et al., 2002	1	0	0	1	1	1	0	0	0	1	0.5	0	0	0	0.5	0	1	1	1	1	10	↓
Pepin et al., 2006	1	0	1	0.5	1	0	0	0	0	1	1	0.5	1	1	1	1	1	0.5	1	0.5	13	→
Smolak, 2014	1	1	1	1	1	0	0.5	1	0.5	0	1	1	1	1	1	1	1	1	1	0.5	16.5	↑
Stallings & Karugendo, 2005 (gray literature)	1	0	0	0.5	1	0	0	1	0	0	1	1	1		1	1	1	1	0	0.5	11	→
Yount et al., 2007	1	1	1	1	1	0	0	1	0.5	1	1	1	1	1	1	1	1	1	0	0	15.5	↑

1= Present, 0.5= Partially present, 0= Missing;

↑= high quality, →= moderate quality, ↓= low quality

A= Acknowledge existing research? B= Construct a conceptual framework? C= Pose a research question or hypothesis? D= Present or link to the raw data it analyzes? E= Geography/context of study? F= Declare sources of support/funding? G= Identify a research design? H= Identify a research method? I= Demonstrate why the chosen design and method are well suited to the research question? J= Cultural sensitivity? K= Measurement validity? L= Internal validity? M= External validity? N= Ecological validity? O= Stability? P= Internal reliability? Q= Reliable analytical technique? R= Signposting included? S= Study's limitations included? T= Clear and cohesive conclusion(s)?

2.3.2 Study Participants

As seen in Table 2.2, most participants in the reviewed studies were women of reproductive age (approximately between 15 and 49 years). One study specifically focused on women above 50 and another limited participant age to 6-18yrs. All participants were from African countries with FGM. They reported FGM prevalence ranging from 3% to 90% and HIV prevalence ranging from 0.1% to 81.4%. FGM in the reviewed studies was measured by self-report (n= 11), and pelvic exam (n=2). Person performing medicalized or traditional FGM on participants was reported in 1 study and type of FGM among participants was reported in 7 studies.

2.3.3 Associations between FGM and HIV

As shown in Table 2.2, 6 studies [77,104,106,107-109] found no statistically significant association between FGM and HIV, after controlling for multiple explanatory variables. The most commonly controlled variables across the 6 studies were age, religion, location of residence, education, and wealth. 4 studies in this category (no association) were prospective in nature, 1 was cross-sectional and 1 was retrospective.

Four studies[59,73,110,111] included in this review found positive associations between FGM and HIV (see Table 2.2). There was insufficient data on FGM type among the four studies reporting positive association as 2 of the studies did not report FGM type among their population of interest and 1 study assumed the FGM types based on the predominant type of FGM in their participant's country of origin. All four studies were correlational and thus causality was not explicitly evaluated. One study reported that HIV-2 (a less common strain compared to HIV-1) was independently associated with FGM. The other 3 studies make no such distinction between

HIV-1 and HIV-2 . Finally, no studies in this category tested the 4 potential transmission pathways outlined in Table 2.1.

3 studies in this review[44,45,105] reported that FGM provided a protective effect against HIV. Two studies in this category[45,105] stated that unobserved factors potentially explained the negative association. One study. reported that type 2 FGM (or excision) was prevalent in their population of interest. The other two did not report FGM type.

2.3.4 Quality of included studies

Based on my appraisal by DfiD quality standards, I rated 3 studies to be of high quality, 8 studies of moderate quality and two studies of low quality. Specifically, the overall quality of eligible studies ranged from 10-16.5 out of a possible 20 points. It was also notable that of the 3 high quality studies, 2 reported no association between FGM and HIV and 1 reported no association Moderate to low quality studies fell short on a few criteria including conceptual framing, demonstration of appropriateness of the study design and including study limitations (see Table 2.3).

2.3.5 Gaps in Current Research

Using data extracted and provided in Table 2.2, I identified 5 significant gaps in the literature including:

1. Lack of data on medicalized vs traditional FGM: Based on extracted data in Table 2.2, it is evident that there is a significant gap in research on medicalized FGM. 12 of the 13 studies did not report on who performed FGM on their participants. One study provided in a 2005 conference presentation by Stalllings & Karugendo[105] (gray literature) provided data on the percentage of medicalized FGM and traditional FGM among their population.

2. Literature is focused primarily on data from northern African countries. Among the small number of studies examining FGM and HIV meeting inclusion criteria, there is a gap in knowledge from southern Africa (where HIV is a significant burden) and countries outside of Africa. It was previously mentioned that only one study in our review (by Mauri et al.) was conducted outside of the continent of Africa. However, Mauri limited participants to non-Swiss migrants from FGM-practicing countries, most of whom were from countries in sub-Saharan Africa.
3. Exclusion of women older than 50: Based on data in Table 2.2, women older than 50 are largely excluded from FGM and HIV discourse. One study by[73] focused on women older than 50 specifically because at 15%, HIV-2 became highly prevalent in individuals born before 1962, and they aimed to identify risk factors contributing to this prevalence. Another study simply included everyone above age 18.[110] However, 10 studies had participants within 15-49 years of age, as they utilized nationally representative data sources that typically women of this age group. Bouare et al. demonstrated cultural sensitivity, stating that they made this exclusion because based on societal norms, it seemed culturally inappropriate to discuss FGM with women who are older than 50.[72]
4. Incomplete information on type of FGM: Six of the 13 studies reported a predominant type of FGM experienced by their population of interest. Based on data in Table 2.2, it is evident that there is unclear (and limited) information about the type of FGM that may be associated with HIV, as some studies assumed the FGM type experienced by their participants, based on the prevailing type in the participant's country of origin.

5. Contextual and behavioral factors that may confound association of FGM and HIV:

   Several contextual and behavioral factors that likely influence the association between FGM and HIV were not included in most of the eligible articles. Potential explanatory factors like history of blood transfusion, religion, age of sexual debut, number of sexual partners, knowledge of HIV status and use of contraceptives were reported in less than half of the included studies.

2.4 Discussion

This systematic review examined studies that researched associations between FGM and HIV. I found few eligible studies possibly because of the taboo nature of the subject, distrust of researchers among community members or lack of preserved data. Using DfiD's *How to Note* criteria for technical quality,[102] I rated most studies as moderate to low quality, and 3 as high quality. I also identified several gaps in current knowledge on the association between FGM and HIV, including lack of research on medicalization, limited data outside of African countries, limited information on which types of FGM are most strongly associated with HIV, and the exclusion of women older than 50 in study samples.

It was not unexpected that all of the studies included in this review originated from African countries as African countries carry the heaviest burden of the HIV epidemic and the highest FGM prevalence. However, it is also notable that countries with the highest FGM rates (Somalia (98%), Guinea (95%), Djibouti (94) and Sudan(87%))[112] and those with the highest HIV rates (like Eswatini (27.9%), Botswana (18.6%) and South Africa (18.3%))[113] were largely absent in the studies examining FGM and HIV associations. One may conclude that the distribution of FGM in countries with high HIV prevalence may be low, however, stigma may contribute to underreporting of FGM in those countries, hence impacting our understanding of

the association between FGM and HIV in those countries. For instance, while Eswatini has one of the highest HIV rates, there is no national-representative data reporting on the prevalence of FGM at the time of this dissertation. However, in 2019, a national campaign to end FGM was added to the Maputo Protocol with aims to eradicate both traditional and medicalized FGM in Eswatini.[114] The existence of this legislature indicates a significant prevalence of FGM that is not available in publicly available, nationally representative data. Including countries like Eswatini in studies on FGM and HIV may yield a fuller picture of the ingrained systemic factors that may have kept FGM and HIV prevalence high. Additionally, studies outside of African countries have the potential to add information that may otherwise be absent in the African context. For instance, Indonesia has a national-level data on the prevalence of FGM.[115] According to a study from the National Institutes of Health (NIH), Indonesia is also one of a few countries with an increasing incidence of HIV every year.[116] Therefore, from a country like Indonesia (whose gross national product indicates a healthier economy than most African countries), research on the association between FGM and HIV may provide new information.

Information on medicalized FGM was also missing in the existing literature. This was significant because data on medicalized FGM has been systematically extracted through surveys as early as year 2000. Nationally representative data sources like Demographic Health Surveys (DHS) and Multiple Indicator Cluster Surveys (MICS) have asked eligible participants who performed their FGM and that of their daughters. Responses have included traditional practitioners as well as doctors, nurses and nurse-midwives who constitute medicalized FGM practitioners. Countries like Egypt, Sudan, Nigeria and Kenya have practiced medicalization for decades.[28] However, studies examining its long-term effects or potential associations with infections (like HIV) are yet to be published.

Another notable gap is the exclusion of women older than 50 years of age. One explanation for this may have been out of cultural sensitivity to prevailing social norms. As one study reported, female sexuality and discussions on sex are often taboo topics of discussion in African spaces.[117] Another explanation is the common theme that several studies in this review performed retrospective analyses of existing data that only included women from the approximate ages of 15-49. In this instance, the researchers were working within the constraints of limited data. Nevertheless, women over 50 remain at risk of HIV potentially linked to FGM, as survivors of FGM may not experience the full extent of its health consequences until later in life. Given this exclusion, we may lack an understanding of specific health needs and experiences of older women living with FGM. Although no authors explicitly state this, an additional potential reason is that between approximately 15 and 49 years, women are most likely to become pregnant, give birth, and experience maternal and child health issues.[118] This age group is also at higher risk for sexually transmitted infections, including HIV.[119] Therefore, by focusing on women of reproductive age, studies have informed policies and programs to address their unique health needs. Nevertheless, considering that HIV was first declared an epidemic in 1981,[120] those above age 50 at the time of data collection (2014), who were living with FGM, would have been newly exposed to the HIV epidemic and could potentially provide data on the cultural trends of FGM over decades and how those trends contributed to or thwarted HIV incidence in their communities.

Despite the important difference in FGM types that may drive differential risk for HIV, type of FGM is largely excluded in 6 of the 13 articles in this review (see Table 2.2). Indicating the type of FGM when discussing HIV is important as they differ in reported outcomes. Reports have shown that those with type 3 FGM have reported higher rates of complications and birth

and bladder infections [121-123] compared to women with other types. Additionally, it has been proposed that through some types of FGM, particularly type 1, where the clitoral hood and part of the clitoris are removed, sexual sensation and desire can decrease.[124] I surmise that with a reduction in sexual desire, survivors of FGM are less likely to have multiple sexual partners, effectively reducing risk of HIV transmission. This would be supported by studies that report a negative association between FGM and HIV. Given the four types of FGM, further research into which types are more closely related to studies on positive, negative or no association, would contribute significantly to current knowledge. Additionally, among the 6 studies that reported a positive association between FGM and HIV, 3 indicated type 1 FGM as the most prevalent in their study samples. This could be the indication of a pattern that informs directional hypothesis for future research. That is, one can examine type 1 as potentially more associated with HIV than the other types.

Regarding quality, a few things are notable among the included studies. First, only 3 of the 13 studies included a conceptual framework. Conceptual frameworks aid in first identifying and then clarifying the critical elements of a study and then making connections with other influences on one's research.[125] They provide a common language and understanding for researchers and readers, facilitating the communication of relevant findings and promoting greater clarity and understanding of the results. A consistent theme across the frameworks in the 3 studies is the interaction between human behavior (like risky sexual activity, timing of marriage, timing of sexual debut and condom use etc.) and environmental or societal factors (including HIV stigma, education and media exposure among others). It was also observed that of the three studies that included a conceptual framework, one reported a positive association

between FGM and HIV, one reported no association and the third reported a negative association.

Cultural sensitivity was included in DfiD principles of quality and thus included for appraisal. This quality is critical in research because it acknowledges the influence of cultural beliefs, values, and practices on individuals and communities. A culturally sensitive approach recognizes the diversity of human experiences and respects the differences that exist between cultures. Without cultural sensitivity, researchers risk overlooking important factors that may affect the research outcomes. This can lead to incomplete or inaccurate results and compromise the validity and reliability of the study (both of which were also qualities included during appraisal). Additionally, a lack of cultural sensitivity can cause harm to participants by perpetuating stereotypes, marginalizing certain groups, or exploiting vulnerable populations. Culturally sensitive research requires an understanding of the social, historical, and cultural context in which the study is conducted. 8 out of 13 studies demonstrated cultural sensitivity by including local and cultural factors that might explain their results. For instance, after reporting a positive association between FGM and HIV in Kenya, one study[59] further discusses increasing urbanization and local modernization that may have influenced changes in sexual and marital relationships. In this instance, the reported positive association between FGM and HIV was evident in the presence of an interaction effect- age of first spouse. The women with FGM and a young or same age spouse were at higher risk of HIV and their counterparts with older spouses were at lower risk of HIV. The authors theorize that this result is explained by behavioral factors like sexual liberation and the choice of whom to marry- both of which result from modernization. Modernization in this context was neither reported as negative nor positive, but simply an explanation for behavioral factors. Similarly, while another study[107] reported no association

between FGM and HIV, they discuss the local state of HIV, as the epidemic was prevalent but not as widely researched in Tanzania at the time of their study.

Among the high-quality studies, 2 studies mention possibilities of indirect positive associations such that FGM caused a change in one or more intermediate variables, which resulted in increased vulnerability to HIV. One of the two studies[107] discussed this possibility as a positive association between FGM & bacterial vaginosis (BV) and FGM & genital ulcer disease (GUD). Given established research that GUD and BV may increase susceptibility to HIV-1, [126-127] they argue that women who experience FGM may be more susceptible to HIV infection, implying a possible indirect positive association. The second study,[109] reported that there is potential for an indirect positive association because women with FGM/C were 27% less likely to have multiple sexual partners and women with multiple sexual partners were 2.63 times more likely to test positive for HIV.[109] While the authors discuss the latter as an indirect positive association, one could argue that this is a negative association, as FGM, in this context, has protected women from HIV by forcing a limited number of sexual partners.

Unlike studies on association between HIV and male circumcision, researchers reporting that FGM has a protective effect against HIV report that "unobserved contextual factors" would explain their findings.[105] I therefore conclude that male circumcision and FGM do not have similar protective effects against HIV. Instead, social norms (or other contextual factors) related to female sexuality in some communities may have contributed to reports of the protective effect of FGM against HIV. For instance, it is possible that diminished sexual desire caused by FGM can contribute to having fewer sexual partners, which in turn limits vulnerability to HIV.

Limitations

Some limitations within this review include:

1. Heterogeneity of studies: Eligible studies varied in terms of their methodology, location, data source, sample size, and population studied. This heterogeneity can make it challenging to compare results across studies and draw definitive conclusions about the association between FGM and HIV. To limit the impact of heterogeneity, I documented odds ratios where they were reported.
2. Limited information on FGM type: There are different types of FGM, with varying degrees of severity and associated health risks. However, studies on the association between FGM and HIV have predominantly focused on type 2 and type 3 FGM, which are the most severe forms. As a result, this study is limited in its capacity to speak to precise connections between FGM type and risk of HIV.
3. Potential for underreporting among studies: Both FGM and HIV have documented stigma attached to them, so there is potential for underreporting in HIV and FGM prevalence across all the reviewed studies
4. There is a potential lack of data covered by this review through the selection of English-only articles.

2.5 Conclusion

Given the general quality of studies on FGM and HIV as well as the gaps in literature identified by this review, there is a need for additional research that limits heterogeneity by narrowing geographic location and comparing differences in health outcomes among those who experience traditional FGM, medicalized FGM, and those who remain uncut. This direction would provide data on whether or not medicalized FGM limits harm to the extent that it becomes a suitable alternative rite of passage into adulthood. Additionally, since there are several potential variables (or behavioral pathways) that may contribute to the interaction between FGM

and HIV (including religion, age of sexual debut and number of sexual partners), studies aiming to examine association between FGM and HIV in any given location must include said factors to provide more precise results. That way, reports on indirect positive associations (like that of FGM, BV, GUD and HIV) would provide precise and relevant interventions for disease prevention. Finally, including research in studies outside of the continent of Africa (like Indonesia) could potentially provide new information that is unavailable within the African context.

CHAPTER THREE: Examining HIV Literacy Among Sudanese Women of Traditional and Medicalized FGM.

3.1 Introduction

Female Genital Mutilation/cutting (FGM/C or FGM) is a traditional rite of passage that affects 87% of women in Sudan.[128] It is practiced in several forms across the 18 states and ranges from nicking or cutting off the clitoris (type 1) to the partial or total removal of the clitoris and the labia minora (with or without excision of the labia majora) (type 2), and Sudan's most common form,[129] (type 3), involving a combination of types 1 and 2 and the creation of a seal that covers the urethral opening and most of the vaginal opening. The invasive practice has caused physical and psychological harm to survivors, including chronic pain, infections, difficulties with urination and menstruation, and psychological trauma.[130]

The prevalence of FGM in Sudan varies by region, with the highest rates found in the northeast regions such as North Kordofan (97.7%), North Darfur (97.6%), and Northern State (97.5%).[131] The lowest prevalence is found in Central Darfur, in the southwest, at 45.4%. International campaigns against FGM deemed it a form of abuse and a violation of human rights, and the practice has been banned in several countries, including Sudan. Nevertheless, the practice persists through traditional cutters who may use crude instruments in unsanitary conditions.

Some of the most commonly used instruments among traditional cutters are the razor blade, scissors, broken glass, thorns or needles.[132-133] These instruments are cheap and readily available, making them attractive choices for the cutter. The razor blade is used to cut the clitoral hood, clitoris, and labia minora, often without anesthesia or proper sterilization. This process is categorized as type 1 (clitoridectomy) or type 2 (excision). Thorns and needles are typically used

to create a small hole in the clitoral hood, through which the practitioner can insert a small stick or piece of wood. The stick is left in place for several days, causing the clitoris to shrink and eventually disappear.[134] This form is, classified under infibulation (or type 3 FGM). These practices have led to immediate significant pain, bleeding, and infection.[135] In some cases, they have inflicted lifelong physical and psychological trauma.[1]

Medicalized FGM is defined as any form of the practice performed by a medical professional (i.e., doctor, nurse, nurse-midwife) in a home or clinic. Movements to end FGM in Sudan highlighted health complications caused by the traditional form, including infection, hemorrhage, and even death. Instead of leading to eradication, the fear of health complications from traditional FGM drove many families to seek FGM from medical professionals who could provide what is now known as medicalized FGM.[136] The shift was likely based on the belief that medicalized FGM was safer because a medical professional is trained to use sterile instruments with more and provide solutions to immediate excessive pain.

The shift to medicalized FGM is especially prevalent in Sudan. In the last decade, reports of medicalized FGM (as opposed to the traditional form) have increased by 67% among women of reproductive age in Sudan.[39] This is the highest global increase in medicalized FGM nearly doubling the rates from Egypt, which reports the second-highest increase in medicalized FGM at 38%.[28] This trend in Sudan has been attributed to several factors, including the belief that medicalized FGM is safer and more convenient than traditional forms,[137] the endorsement of medical professionals, and the perception that medicalization legitimizes the practice.[138]

The social environment in Sudan has fostered (both traditional and medicalized) FGM through a combination of tradition, social pressure, religious beliefs, lack of education, and poverty.[139] In terms of tradition and culture, it is believed to preserve a female's virginity and purity and ensure that she is eligible for marriage.[140] The pressure to conform to social norms and traditions is strong in Sudanese culture. Many women and families feel compelled to continue the practice of FGM because they fear being stigmatized or ostracized if they do not. In some cases, even those who are opposed to FGM may feel pressure to have their daughters undergo the procedure to avoid social isolation. [141] Additionally, while FGM is not explicitly required by Islam, it is often justified in Sudan as a religious practice.[142] Consequently, several Sudanese communities believe that FGM is necessary to fulfill Islamic requirements for modesty and purity, making the influence of religious leaders a significant factor in its continuation. In terms of education and awareness, particularly in rural areas, many have limited access to education and healthcare leading to gaps in knowledge about the harmful effects of FGM,[143] and many families continue to believe that it is a harmless and necessary practice. Finally, poverty has contributed to the continued practice of FGM in Sudan as families see FGM as a way to secure their daughters' future and improve their chances of financial success through marriage, as they may not have the resources to provide other forms of education or support that would help their daughters achieve said success.[144]

Based on the realities of the social environment (including religious requirements, traditional rites of passage and cultural views surrounding female sexuality), most women in Sudan experience FGM. However, it is unclear if these factors associated with FGM create an association between FGM and other stigmatizing experiences like HIV.

3.1.1 HIV in Sudan

International migration has placed Sudan in a vulnerable position for increased HIV incidence and prevalence. As of 2021, Sudan reported a 0.2% prevalence of HIV among people aged 15-49,[145] making it lower than the current global average of 0.7%. However, this prevalence is subject to underreporting as multiple studies report high levels of stigma toward PLWHA in Sudan.[146-149] From low governmental investment to individuals who refuse to work with, shop from, or live with PLWHA,[150] it is possible that PLWHA do not report their status or, those of unknown HIV status may not seek HIV testing, leading to an underestimated national prevalence. Additionally, Sudan's proximity to neighboring countries with higher HIV prevalence (Kenya (4.2%), Malawi (8.1%), Zambia (11.1%) and South Sudan (2.3%))[151] make it consistently vulnerable, especially in times of sociopolitical unrest and forced migration.

Women who have undergone FGM may be less likely to seek out sexual health information and services due to cultural taboos and stigma surrounding discussions of sexuality and reproductive health.[152-153] Additionally, due to traditions and social norms (similar to those surrounding FGM in Sudan), women may lack agency in navigating safer sexual options for themselves, potentially increasing vulnerability to HIV transmission. Given these possibilities, social and cultural factors can cause FGM and health literacy to travel together, resulting in an increased risk of HIV transmission and limited access to HIV prevention and treatment services.

A study on Sudanese women living in the North American diaspora found that participants reported low knowledge of HIV as indicated by a poor understanding of how it is transmitted, self-reported lack of safe sex practices, and a belief that HIV/AIDS is a punishment from God.[154] A study among medical professionals, teachers, and religious leaders (from where?) found high rates of stigma toward PLWHA.[155] They also found that stigmatizing

attitudes were not only directed toward people living with “full-blown AIDS” but also toward public health efforts like HIV testing facilities and community education. This is supported by another study in Sudan that states that people with AIDS are viewed as disgraceful.[156] The authors argue that this stigmatizing view results from ignorance and misconceptions about how the disease spreads such as the belief that the condition only affects homosexuals, sex workers, and drug users. Such views contribute to lack of investment in HIV education for the general population.

Stigmatizing attitudes toward PLWHA in Sudan are high. A 2014 nationally representative survey of Sudanese people aged 15-49 on their attitudes toward PLWHA. In this report, 65% of respondents responded “No” to the questions: "Would you buy fresh vegetables from a shopkeeper or vendor if you knew that this person had HIV?"; and "Do you think that children living with HIV should be able to attend school with children who are HIV negative?"[157] A growing body of research has demonstrated that stigmatized views serve as a hindrance to seeking care and maintaining low viral loads among PLWHA. At least two studies demonstrate that stigma has contributed to increased depressive symptoms among PLWHA- a phenomenon that may be twice that of the general population.[158-159]

Given the common determinants of FGM and HIV literacy, in the present study, I examine differences in attitudes toward PLWHA and HIV knowledge by women’s cut status. Through secondary data analysis of Sudan-specific data, I compare responses to questions regarding HIV awareness and attitudes across three groups of Sudanese women—the uncut, the medically cut, and the traditionally cut. This will add to knowledge on the social impact of medicalized and traditional FGM on HIV knowledge.

3.1.2 Conceptual Framework

Figure 3.1 Conceptual Framework of Association between FGM Cut Group and HIV Knowledge and Stigmatizing Attitudes

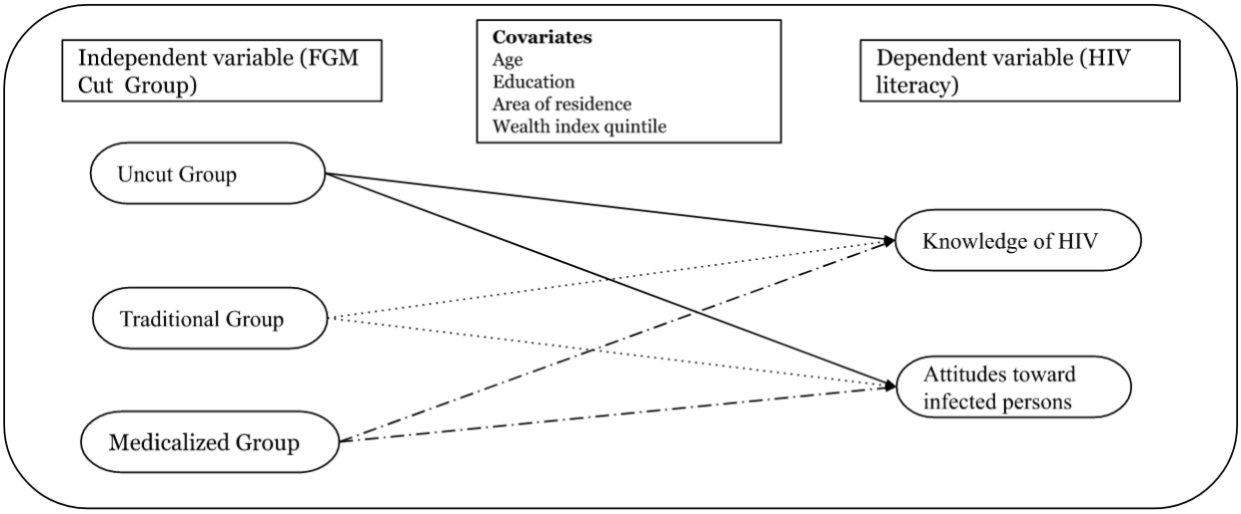


Figure 3.1 demonstrates a conceptual framework that reflects the alternative hypothesis of the current study. That is, it indicates that if there is a statistically significant difference in HIV literacy between groups, belonging to an FGM cut group can determine higher or lower HIV knowledge and attitudes after controlling for several covariates (age, location, education and wealth). Covariates I considered include participant age, area of residence (urban or rural), wealth and level of education. These covariates were selected based on their identification as significant factors in multiple HIV literacy studies[160-163] and their availability in the dataset.

3.2 Methods

This study uses data from Multiple Indicator Cluster Surveys (MICS), developed with technical support from the United Nations Children's Emergency Fund (UNICEF). Key indicators measured through MICS provide a unique opportunity to examine population based FGM/C and HIV data. The most recently available MICS for the nation of Sudan is from 2014.

To collect nationally representative data, researchers calculated a sample of 25 households per cluster (or census enumeration area) by considering the available budget and time needed to complete one cluster. They calculated that 40 sample clusters would need to be chosen in each of Sudan's 18 states by dividing the total number of households by the number of sample households per cluster.[157] Researchers arrived at the equation below to determine a nationally representative sample:

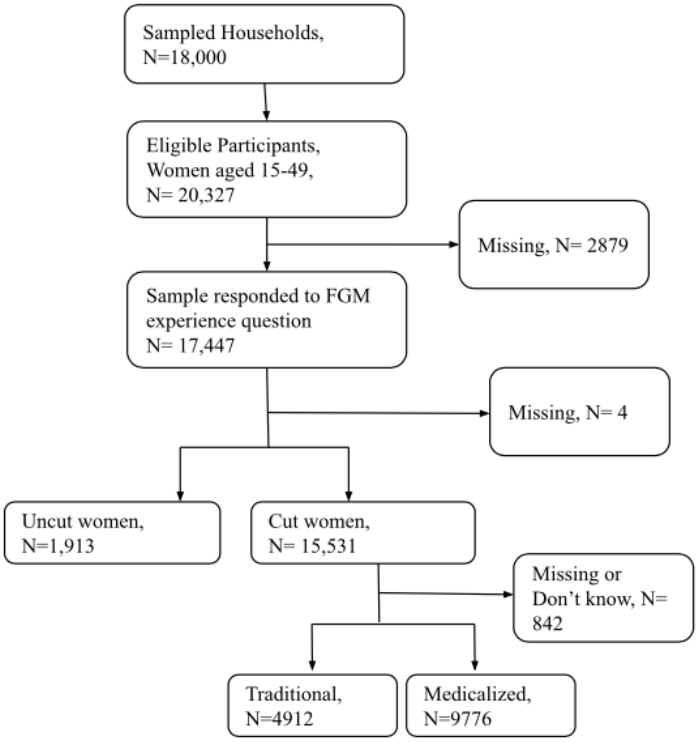
25 sample households per cluster (×) 40 clusters (×) 18 states of Sudan = 18,000

3.2.1 Data Collection

Based on the above equation, the survey sample included 18,000 households. 17,142 were occupied, and adults from 16,801 households were interviewed between in 2014, for a 93% household response rate. The average household size was 5.9, with 15% of the population under age 5 and 51% above age 18. Within the households, 20,327 women were eligible for interviews, and 18,302 were interviewed, giving a 90% response rate. This study's sample included 16,601 women who responded to questions on their FGM/C status. A total of 14,688 women reported experiencing FGM, 9,776 of whom were cut by medical professionals, 4,912 were cut by traditional cutters. 1,913 women reported being uncut. Based on these self-reported numbers,88.5% of participants experienced FGM/C. This aligns with the 87% national estimate of FGM/C in Sudan. [128]

In the relevant modules for this study, women of reproductive age (15-49) were questioned about their knowledge of HIV, attitudes toward PLWHA, FGM status, the type of FGM they experienced, and by whom the procedure was performed. The question of who performs FGM on them indicates medicalized or traditional FGM/C.

Figure 3.2 Flow chart of sample size selection from Sudan Multiple Indicator Cluster Surveys, 2014 among women 15-49yrs



3.2.2 Study Variables

To examine the association between FGM/C and HIV attitudes and knowledge among Sudanese women, we identified the independent variable as participant FGM/C group: uncut women, the traditionally cut, and the medically cut. Uncut women were identified as those who responded "No" to the question "Have you yourself ever been circumcised?." The groups of traditionally and medically cut women were originally coded into one variable represented by the question "Person circumcising respondent." Labels for this variable included Doctor, Nurse/Midwife, Health Visitor, Trained Midwife, Medical Assistant, Other Health Person, Traditional Circumcisor, and Other Traditional Circumcisor. To aid in secondary analysis, this variable was re-coded into two groups–Medical Professional (Doctor, Nurse/Midwife, Health Visitor, Trained Midwife, Medical Assistant, Other Health Person) and Traditional Practitioner (Traditional Circumcisor, and Other Traditional Circumcisor) to represent medically cut and

traditionally cut participant groups, respectively. Thus, the independent variable was created with three groups: uncut, medicalized cut, and traditional cut.

The dependent variables for this study are knowledge of HIV and stigmatizing attitudes/views toward PLWHA. Participants answered "Yes", "No" or "Don't know" to all survey questions regarding HIV knowledge and attitudes. Knowledge questions addressed local myths regarding HIV transmission (i.e., transmission through mosquitoes or supernatural means), knowledge of mother-to-child transmission (MTCT) and whether not the correct use of condoms reduces the risk of transmission. For this study, a Knowledge Scale was created as a discrete numeric variable based on the sum of correct responses to knowledge items. During analysis using SPSS, outliers (1.3% of the sample, N= 67) were removed to reduce their influence on the data. Outliers were identified as those to answered less than 3 questions. A similar process was used to create the Attitude Scale with one item re-coded to allow uniformity. Survey questions regarding attitudes asked participants if they would shop from, work or live with PLWHA. A discrete numeric variable for Attitude Scale was also created based on the sum of positive responses to attitude items. That is, "Yes" responses to whether they would be willing to shop from, work or live with PLWHA were regarded as positive attitudes, and vice versa. During analysis, outliers were removed as they accounted for only 1.9% (N= 229) of the sample. Here, outliers were identified as those to answered less than 2 questions.

3.2.3 Covariates

Covariates were selected based on availability in MICS data and prior published literature that showed they were likely to influence the associations between FGM group and HIV literacy. The covariates included in this study are the participant's area of residence, wealth, age, and level of education. As seen in Table 4.4 participants' areas of residence were either urban or

rural, participants' self -reported level of education ranged from no formal education to primary, secondary and tertiary education. All variable responses were collected via in-person interviews. For this study, age was divided into those below age 30 and those above, as seen in other literature that used the MICs age variable for analysis.[164] Wealth was reported in five categories from poorest to richest using a household's asset-based index. Sample weight calculations are available in the 2014 Sudan MICS report.[157]

3.2.4 Statistical Analysis

All analyses for this study were conducted using SPSS v.28. We tested the null hypothesis that there is no statistically significant difference in knowledge on HIV/AIDS and attitudes toward people living with HIV/AIDS among Sudanese women of different FGM cut groups, after controlling for age, wealth, education and location. Analysis of covariance (ANCOVA) produced an F- value that indicated whether to reject the null hypothesis that the group means are equal, after controlling for the covariates. Adjusted groups means are provided in tabular form. Post hoc comparisons were also provided in tabular form to report pairwise comparisons and the effect of covariates on the dependent variables. As a post-hoc test, pairwise comparisons compare pairs of groups (i.e., uncut and medicalized cut, uncut and traditional cut, traditional and medicalized cut) to determine if there is a statistically significant difference between them. ANCOVA was particularly useful as a statistical technique as the covariates (i.e., age, area of residence, wealth and education), have reported statistical significance on HIV knowledge and attitudes in prior studies.[165-167] Thus, ANCOVA reduced bias and increased the accuracy of the estimated effect of the independent variable (FGM cut groups) on the dependent variables (knowledge of HIV and attitudes toward PLWHA).

3.2.5 Power analysis

Given a sample size of N=16,601, this study was powered to detect a small association between FGM cut group and HIV literacy by a small effect size of 0.12. Justification of sample size for an ANCOVA of three levels (traditional, medical, and uncut) and at least five covariates (two areas of residence, multiple age groups, wealth index quintile and four levels of education) was determined using power analysis previously performed by Faul et al. through G*Power Version 3.1.7.[168] Power analysis was conducted using alpha 0.05, power 0.80, and a small effect size (f = 0.10), justifying a minimum total sample size of 1443. As seen in Figure 3.2, the sample size for this analysis exceeds the minimum requirement, with the uncut group N=1913, traditional cut group N= 4912, and medically cut group N= 9776.

3.3 Results

3.3.1 Descriptive Statistics

Table 3.1 Sociodemographic characteristics of study sample

Variables	*N*	%
Age		
15-29	9292	55.4%
30-49	7255	44.3%
Not reported	54	0.3%
Location		
Urban	5528	33.30%
Rural	11073	66.70%
Education		
None	5586	33.70%
Primary	5458	32.90%
Secondary	3899	23.50%
Tertiary	1653	10.00%
Wealth Index Quintile		
Poorest	16596	18.30%
Second	3508	21.10%
Middle	3492	21.00%
Fourth	3117	18.80%
Richest	3441	20.70%

Survey results showed an 88.5% prevalence of FGM/C among women aged 15-49, similar to other estimates of the national prevalence of 87%. Based on their responses to ever being cut, the number of 15 to 49-year-old Sudanese women eligible for inclusion in this study was 16,601. Most participants were under the age of 30 (55.4%) and 67% of participants lived in rural areas. Participants also reported low education levels with 67% reporting primary education or less. Table 3.1 contains general sociodemographic characteristics of study participants.

Overall, among participants eligible for this analysis, there were moderate to low levels of HIV knowledge especially when questioned about condom use and the physical appearance of PLWHA (see Table 3.2). Most participants (75.5%) had heard of HIV/AIDS. The most correctly answered questions were on chance of transmission by having one infected partner (60% answered correctly) and transmission through supernatural means (57% answered correctly). Attitudes toward PLWHA were largely negative as 31.2% reported that they would buy vegetables from a shopkeeper with HIV and 47.5% would be comfortable with PLWHA teaching in schools (see Table 3.3).

Table 3.2 Number and percentage of HIV-specific correct answers among women among eligible study participants

	Correct Answers	
	N	%
Ever heard of HIV/AIDS	12533	75.5%
Can avoid AIDS virus by having one uninfected partner (Yes)	9958	60%
Can get AIDS virus through supernatural means (No)	9396	56.6%
Can reduce their chance of getting the AIDS virus by using a condom correctly every time they have sex (Yes)	4679	28.3%
Can get the AIDS virus from Mosquito bites (No)	7546	45.5%
Can get the AIDS virus by sharing food with a person who has AIDS (No)	8298	50%
Is it possible for a healthy-looking person to have the AIDS virus (Yes)	5614	33.8%
Can the AIDS virus be transmitted from mother to child during pregnancy (Yes)	7829	47.1%
Can the AIDS virus be transmitted from mother to child during delivery (Yes)	7698	46.4%
Can the AIDS virus be transmitted from mother to child during breastfeeding (Yes)	6537	39.4%

Table 3.3: Number and percentage of accepting/positive attitudes toward PLWHA among eligible study participants

	Accepting/Positive Answers	
	N	%
Should female teacher with AIDS virus be allowed to teach in school? (Yes)	5530	47.50%
Would you buy fresh vegetables from shopkeeper with AIDS virus (Yes)	3731	31.20%
If household member became infected with AIDS virus, would you want it to remain a secret (No)	6677	56.10%
Willing to care for person with AIDS in household (Yes)	10773	90.60%

Among the FGM cut groups, those of traditional cut reported lower levels of education with 89.9% reporting primary or no formal education (see Table 3.4). Those of the medically cut group reported the highest levels of formal education compared to their uncut and traditionally

cut counterparts. The medically accounted for 30.7% of those in the richest quintile. Those of traditional cut were least represented in the richest quintile (4.5%) and most represented among the poorest (35.5%). Additionally, while most in all three groups lived in rural areas, those in the traditionally cut group had the most representation in rural areas at 83.7%.

Table 3.4. Crosstabulation of Education, Wealth Index Quintile, Age and Area of residence across FGM cut groups

	Uncut	Traditionally Cut	Medically Cut
Education Level			
None	56%	61.4%	15.4%
Primary	23.8%	28.5%	36.8%
Secondary	14.8%	8.6%	32.7%
Higher	5.4%	1.5%	15.1%
Wealth Index Quintile			
Poorest	18.6%	35.5%	9.7%
Second	26.6%	32.7%	14.3%
Middle	30.2%	19.1%	20.2%
Fourth	13.3%	8.2%	25.2%
Richest	11.3%	4.5%	30.7%
Area of residence			
Urban	33.2%	16.3%	41.8%
Rural	66.8%	83.7%	58.2%
Age			
Below 30	64.6%	41.8%	61.4%
Above 30	35.4%	58.2%	38.6%

3.3.2 ANCOVA Results

Table 3.5 Mean HIV knowledge & attitudes among Sudanese women of different FGM/C experiences

FGM Cut Groups	Knowledge Scale		Attitude Scale	
	Mean HIV knowledge	Std. Deviation	Mean HIV Attitudes	Std. Deviation
Uncut	7.4524	1.57118	2.0863	0.93385
Traditionally Cut	7.0361	1.57793	1.9968	0.90078
Medically Cut	7.6999	1.49161	2.2560	0.95216

Table 3.5 indicates the adjusted mean values of Knowledge Scale and Attitude Scale across the FGM cut groups. At first glance, those who experienced a medicalized cut reported higher knowledge of HIV ($\bar{x}$ = 7.70), followed by the uncut group ($\bar{x}$ = 7.45) and traditionally cut group ($\bar{x}$ = 7.04). Additionally, traditionally cut women showed the least positive attitudes toward PLWHA ($\bar{x}$ = 1.997) and the medically cut showed the most positive attitudes toward PLWHA ($\bar{x}$ = 2.256). The uncut also showed relatively higher positive attitudes ($\bar{x}$ = 2.086) although it was lower than that of the medically cut group. Despite visual differences in the mean values, ANCOVA indicates through post-hoc pairwise comparisons that there is no statistically significant difference between uncut and medically cut.

Knowledge of HIV

Table 3.6. ANCOVA Results for HIV Knowledge among Participants

Test of Between Subject Effects										
	Unadjusted					**Adjusted**				
	SS	*df*	F	*p*	Partial Eta^2	SS	*df*	F	*p*	Partial Eta^2
Corrected Model	401.105[a]	2	87.398	<.001	0.029	1237.146a	6	95.661	<.001	0.088
Intercept	152584.566	1	66494.406	0	0.918	7760.986	1	3600.664	0	0.378
FGM Group	401.105	2	87.398	<.001	0.029	49.228	2	11.419	<.001	0.004
Area of residence	-	-	-	-	-	31.716	1	14.715	<.001	0.002
Age	-	-	-	-	-	16.21	1	7.52	0.006	0.001
Education	-	-	-	-	-	135.22	1	62.734	<.001	0.01
Wealth	-	-	-	-	-	203.04	1	94.199	<.001	0.016
Error	13602.968	5928				12766.622	5923			
Total	352357	5931				352308	5930			
Corrected Total	14004.073	5930				14003.767	5929			
SS = Sum of Squares										
***Mean difference is significant at the 0.05 level**										

ANCOVA test results indicated a significant difference in knowledge between FGM groups [$F(2,5923) = 11.42$, $p<0.001$] even when adjusted for area, age, household wealth and

education level. Additionally, pairwise comparisons reported significant differences in HIV knowledge between the uncut and traditional cut group ($p<0.05$), as well as the traditional and medically cut group ($p<0.001$). In both significant comparisons, HIV knowledge among those of traditional cut was significantly lower compared to their uncut and medically cut counterparts. Finally, there was no statistically significant difference in HIV knowledge between the uncut and medically cut group ($p=0.65$). Per Cohen's guidelines (0.2-small effect, 0.5-moderate effect, 0.8-large effect),[169] FGM group effect size was small, ($eta^2= 0.004$). That is, 0.4% of the difference in knowledge among the study population is explained by FGM group membership.

Table 3.7. Pairwise Comparisons in HIV knowledge among FGM Cut Groups

		Mean Difference (I-J)	SE	*p*	95% CI	
					Lower	Upper
Uncut	Trad Cut	.235*	0.082	0.013	0.038	0.433
	Med Cut	-0.023	0.072	1	-0.197	0.15
Trad Cut	Uncut	-.235*	0.082	0.013	-0.433	-0.038
	Med Cut	-.259*	0.054	<.001	-0.389	-0.128
Med Cut	Uncut	0.023	0.072	1	-0.15	0.197
	Trad Cut	.259*	0.054	<.001	0.128	0.389

ANCOVA results also indicates that all four covariates (area of residence, household wealth, age and education level) are significantly related to the self-reported knowledge HIV among Sudanese women in the three FGM groups. However, household wealth was the most significant confounder at 1.6% (see Table 3.6).

Attitudes toward PLWHA

Table 3.7 ANCOVA Results for Attitudes Toward PLWHA

Test of Between Subject Effects										
	Unadjusted					Adjusted				
Source	SS	*df*	F	*p*	Partial Eta^2	SS	*df*	F	*p*	Partial Eta^2

Corrected Model	136.292[a]	2	77.277	<.001	0.014	526.620a	6	103.659	<.001	0.053
Intercept	25216.358	1	28595.198	0	0.722	1193.974	1	1410.119	<.001	0.114
FGM Group	136.292	2	77.277	<.001	0.014	5.282	2	3.119	0.044	0.001
Area of residence						34.767	1	41.06	<.001	0.004
Age						1.816	1	2.145	0.143	0
Education						182.646	1	215.71	<.001	0.019
Wealth						4.824	1	5.697	0.017	0.001
Error	9709.046	11010				9317.288	11004			
Total	62278	11013				62273	11011			

When adjusted for area, age, wealth and education, ANCOVA indicated significant FGM group differences in attitudes toward PLWHA [F(2, 11004) = 3.119, p = 0.044] . However, pairwise comparisons indicate that there were no significant differences in attitudes toward PLWHA between the three groups (uncut & traditional cut, p=1; uncut and medical cut, p= 0.12; traditional cut and medical cut p= 0.19). Per Cohen's guidelines effect size of FGM group membership was small, (eta^2= 0.014). That is, 1.4% change in attitudes among the study population is explained by FGM group membership.

ANCOVA results also indicated that education level had the largest influence of the covariates, as it explained 2% of the difference in attitudes between the groups. Wealth had the least influence accounting for 0.1% (see Table 3.7). Age did not have significant influence on the attitudes of Sudanese women in the three FGM groups.

3.4 Discussion

In this study, I examined the difference in HIV knowledge and attitudes among women of medicalized, traditional and uncut FGM groups. Among this study sample, those of medicalized cut reported the highest level of HIV knowledge but was not significantly different from that of

the uncut group. Both groups reported significantly higher HIV knowledge than their counterparts with traditional cut. Additionally, participants across the three FGM groups reported highly stigmatizing views toward HIV. Because no other studies have examined differences between uncut, medically cut and traditionally cut women, there was no evidence in literature to justify a directional hypothesis. However, given these findings along with descriptive statistics, we can better understand differences within the three groups that have contributed to HIV literacy

Differences in HIV knowledge among FGM groups may be partially explained by differences in SES. Crosstabulation in Table 3.4 indicates that that those who experienced medicalized FGM/C also reported higher SES (i.e., urban residence, increased wealth and higher levels of education). This is similar to a 2020 study conducted to examine the motivators of medicalized FGM in 13 African countries,[170] some of which were in close geographic proximity to Sudan. This study found that those who experience medicalization came from higher socioeconomic status. Similar to the present study, the authors noted that a limitation to their analysis is that they had no information on what led the women to have medicalized instead of traditional FGM. One possibility (as seen in a report from Egypt) is that medical professionals supplement their income through performing FGM.[171] In this case, the report from Egypt states that when FGM was made illegal, the prices increased. While not explicitly stated in the report, we can infer that these price increases could make medicalized FGM too expensive for the poor, who in turn would continue in the traditional form instead.

This also supports our finding in Table 3.4, that those who experienced traditional FGM were often poorer and living in rural areas. Therefore, I conclude that due to their higher SES, those of medicalized FGM status have more access to medical professionals and therefore more

access to HIV-specific information, causing them to report higher knowledge of HIV. By virtue of these other factors, they are in a comparatively favorable position, but still potentially suffering from long-term effects of FGM. Additionally, those of traditional cut lack access to medical professionals by comparison (both geographically and financially) and are therefore at continued risk of misinformation on HIV.

More positive attitudes toward PLWHA are expected from those who present more knowledge on HIV transmission, since knowledge often dispels the fear that stigma creates, as reported by studies on stigma-reduction strategies.[172-173] However, despite the relatively higher average knowledge of HIV among those of the medicalized group (see Table 3.5), the results show that overall positive views toward PLWHA are low among Sudanese women of reproductive age. This finding is also supported by several Sudan-specific studies that found national-level high rates of stigma toward PLWHA.[174-176] One study argued that the stigma on the governmental level has deterred political leaders from taking immediate and effective action against the HIV [160] and on the individual level, negative attitudes toward PLWHA resulted in underutilization of testing sites in Sudan. This failure to address knowledge and stigmatization of HIV among Sudanese women could contribute to increased incidence of the infection.

Limitations

Limitations of this study included several relevant variables that were not measured. The variables include:

1. Participant HIV status: Data utilized in this study did not measure participant HIV status. Given this limitation, I was unable to examine FGM (medicalized or traditional) as a potential risk factor for HIV. Participant HIV status would also provide knowledge on the differences in disease progression and care among those of medicalized, traditional and

uncut groups in Sudan, as well as HIV knowledge and attitudes among people living with both HIV and FGM.

2. Risky sexual health behavior: The present study did not include variables on risky sexual health behavior as it was not available in the data. Studies including number of sexual partners and age of sexual debut have reported these variables as significant factors affecting HIV knowledge.[177-178] Measuring differences in sexual health behavior among women of different FGM groups could inform researchers on norms that have been established (regarding sexual health) and how those norms differ across FGM groups. This, in turn, could inform health education efforts supporting women living with FGM and HIV.
3. Access to care Data utilized in this study also lacked information on proximity to medical care. This could expand our understanding of the impact of residential areas on HIV knowledge and attitudes. The current study demonstrated that area of residence was significantly associated with HIV knowledge among women of different FGM cut groups. Data on proximity to care within residential areas could expand our understanding of how residential area is associated with HIV knowledge.

3.5 Conclusion

With this chapter, I build a foundation for future studies that contribute to our collective understanding of medically and traditionally cut women compared to the uncut. I demonstrate a social relationship between FGM and HIV literacy where factors within SES contributed to the form of FGM experienced (i.e., traditional or medicalized) as well as HIV-specific knowledge. Additionally based on findings in this chapter, those who experience traditional FGM in particular might benefit from avenues for comprehensive HIV-specific

education, since unlike those of medicalized cut, they are often poorer and have lower levels of formal education. Overall, attitudes toward PLWHA must be addressed across the general population. Finally, taking the descriptive results of this chapter along with the report from Egypt, I conclude that medicalized FGM is slowing down the progress toward the UN sustainable development goal of eradicating FGM in its entirety by 2030. Attention must be brought to medical professionals who provide FGM as they lack the data on long term effects of medicalized FGM to justify continuation. Additionally, social norms that surround the taboo of conversations around female sexuality and reproductive health must be addressed to allow women reject FGM for themselves and their daughters while also maintaining access to resources that encourage health literacy.

CHAPTER FOUR: Examining the Role of Medicalized FGM/C in HIV Testing Activity Among Sudanese Women

4.1 Introduction

Female Genital Mutilation (FGM) is an ancient traditional practice in Sudan that has resulted in adverse health outcomes for several women. At the time of this study, the country reports an FGM prevalence of 87% among women of reproductive age.[128] The World Health Organization (WHO) has classified FGM into four types (see Table 4.1), each of which has severe and long-lasting consequences. Physical pain, infections, hemorrhage, infertility, psychological challenges and complications with childbirth, are a few of the adverse outcomes reported by several survivors of FGM.[3]

In Sudan, there are various crude instruments commonly used for traditional FGM. These instruments include knives, razor blades, scissors, and even broken glass.[132] In many cases, the instruments used are unsterile, leading to infections and other health complications.[135] The use of crude instruments can also lead to excessive bleeding and tissue damage, which can have long-term consequences for women's health. The use of crude instruments for FGM reflects the deeply ingrained cultural and social norms that support the practice. It is also common to perform the procedure in unsanitary and unsafe conditions, [179] with little regard for women's health and wellbeing. Despite efforts to eradicate the practice, FGM continues to be performed in many communities in Sudan, with devastating consequences for women's health and human rights.

FGM has been rejected by various groups in Sudan, and there have been calls from the United Nations and other international human rights organizations to eliminate the practice globally.[180-181] To achieve this goal, research, legislation, education, and community leaders

continue to bring awareness to the subject matter.[182] However, despite efforts to encourage communities to abandon the practice, progress has been slow.[183]

Table 4.1. Types of FGM according to the WHO

Type 1	Removal of the prepuce/clitoral hood and/or the clitoral glans. The following subdivisions are employed to help differentiate between the main types of Type I FGM: Type Ia. Only the prepuce and clitoral covering are removed. Type Ib: Using the prepuce/clitoral covering to remove the clitoral glans.
Type 2	Type II. Removal of the labia minora (the interior folds of the vulva) and the clitoral glans, either completely or partially, along with or without removal of the labia majora (the outer folds of skin of the vulva). The following subdivisions are employed to help differentiate between the main types of Type II FGM: Type IIa. Only the labia minora are removed. Labia minora and the clitoral glans may be completely or partially removed in Type IIb; the prepuce or clitoral hood may also be impacted. Type IIc: partial or complete excision of the clitoral glans, labia minora, and labia majora (possibly affecting the prepuce/clitoral hood).
Type 3	(Often referred to as infibulation). a covering seal is formed, narrowing the vaginal orifice. The labia minora or labia majora are sliced and repositioned to create the seal. The clitoral prepuce/clitoral hood and glans may or may not be removed when the vaginal orifice is covered. (Type I FGM). The following subdivisions are used to separate Type III FGM variants when necessary: The labia minora are taken out and repositioned in type IIIa. Labia majora are taken out and repositioned in Type IIIb.
Type 4	Refers to all other harmful procedures to the female genitalia for non-medical purposes, for example pricking, piercing, incising, scraping and cauterization.

Source: WHO, Sexual and Reproductive Health and Research (SRH)

4.1.1. Trends toward medicalization

Researchers and advocates have theorized that the slow pace of eradicating FGM is due, in part, to the medicalization of the practice.[183] Medicalized FGM is defined as any form of the

practice performed by a medical professional (doctor, nurse or nurse-midwife) in a home or clinic setting.[39] It differs from the traditional form primarily through the person performing it. Additionally, where the traditional form does not involve the use of anesthetics or analgesics, the medicalized form includes the use of localized anesthesia and sterilized instruments.[36] However, while medicalized FGM may reduce the risk of immediate complications such as bleeding and infection, it can still lead to long-term health problems, including chronic pain, sexual dysfunction, and psychological trauma.[184-185]

In the last few decades, Sudan has reported the highest rate of global medicalized FGM (67%). Other countries that report increasing rates are comparatively lower with Egypt at 38%, Guinea and Kenya at 15% and Nigeria at 13%.[39] Despite these increases, the World Health Organization (WHO) and other international health organizations do not recognize any form of FGM, including medicalized FGM, as a legitimate medical practice. The negative health consequences of FGM in Sudan extend far beyond immediate physical and psychological harm. Multiple studies have reported that FGM can also indirectly contribute to the spread of infections like HIV by increasing women's vulnerability through unsterilized instruments.[74,106]

As an ongoing epidemic, HIV has resulted, not only in high morbidity and mortality rates on the African continent, but highly stigmatized views toward people living with HIV/AIDS (PLWHA).[186] Multiple studies report that Sudan reports highly stigmatizing views toward HIV.[187-189] A 2021 study reported that stigma contributes to low testing rates and underreporting HIV status, eventually resulting in misinformation on national-level estimates of HIV.[190] Given the high prevalence of FGM in Sudan, as well as the potentially underreported nature of HIV

incidence, it is critical to examine the ways in which these two issues intersect and to develop strategies that address them holistically.

4.1.2 HIV Testing in Sudan

HIV testing is a prerequisite for the early identification of effective care and therapy. It supports initiatives and services aimed at lowering rates of risky health behavior and mother-to-child transmission (MTCT). Ideally, consistent HIV testing and counseling has the potential to decrease global HIV incidence at a faster rate than we are currently experiencing.[191] However, given several debilitating factors (like poverty and systemic oppression) HIV continues to affect several communities. Despite the efforts made by the Sudanese government and its partners to address the HIV epidemic, underutilization of HIV testing remains a challenge to public health efforts. According to UNAID, only 30% of people living with HIV in Sudan are aware of their status as of 2019, which was significantly lower than the target set by UNAID[192] that 90% of all people living with HIV would know their status by 2020. This target was meant to be achieved at the national level. Other targets aimed to increase the number of people who are aware of their HIV status, who are receiving treatment, and who have viral suppression. This in turn would improve the health outcomes of people living with HIV. These targets have since been revised, and the new targets are known as the 95-95-95 targets. They aim to achieve 95% of people living with HIV knowing their status, 95% of people diagnosed with HIV receiving treatment, and 95% of people receiving treatment having viral suppression by 2030.[193]

Underutilization of HIV testing in Sudan can be attributed to several factors, including a lack of awareness about the benefits of testing, fear of stigmatization, and limited access to testing services, especially in rural areas.[194-196] One study conducted among 2,224 university students in Sudan found that, while 34% of participants expressed interest in voluntary HIV

testing, only 10% actually visited the testing facilities.[197] The students reported that the fear of being stigmatized was the reason for their lack of follow through. Another study among Sudanese women of reproductive age found that HIV testing sites were underutilized as several participants were fearful of receiving and potentially disclosing a positive HIV status.[198] In this case, it was not sufficient that testing sites were established and functional when the fear of stigmatization posed a significant barrier to use despite the availability of the facilities. Another study examining HIV testing activities among pregnant women in Eastern Sudan reported that 617 out of 1017 participants refused testing. The authors report stigma and ignorance of HIV's effects as the main reasons for declining.[199] Other studies identify inter-group differences in voluntary testing and counseling, with one reporting that older women from Muslim communities utilized HIV testing services more than their younger and non-Muslim counterparts.[200]

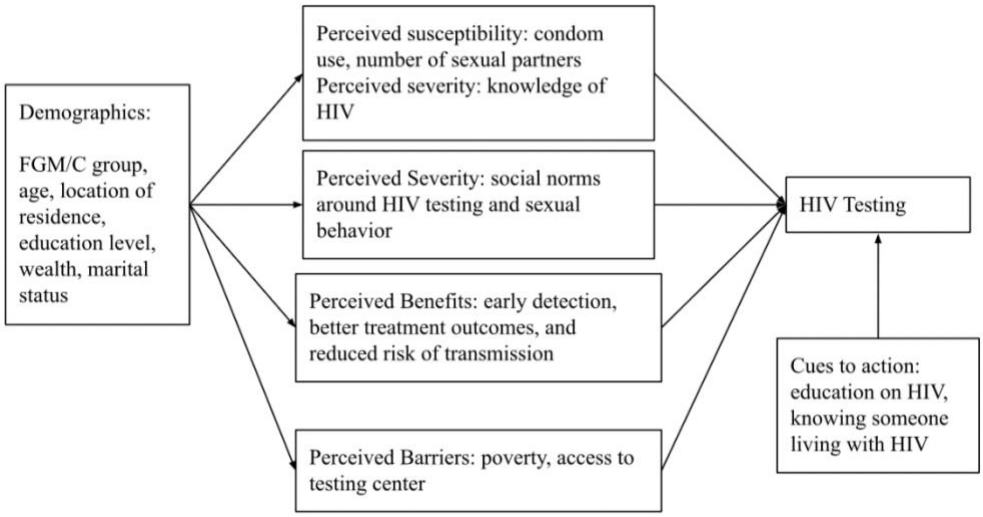
This present study is a secondary data analysis of nationally representative data in Sudan, that examines the association of HIV testing activity among uncut, traditionally cut and medically cut women of reproductive age. Using binary logistic regressions, I tested a null hypothesis that when compared to their uncut counterparts, Sudanese women of medicalized and traditional cut groups will report no differences in HIV testing activity after controlling for age, marital status, wealth, education and location of residence (rural/urban). This hypothesis is based on data from the previous study that showed those of medicalized cut reporting the highest knowledge of HIV among the three FGM groups, and those of traditional cut reporting the lowest. Testing activity for this study included testing history, knowledge on where to test and whether or not they knew the results for their last test.

The control variables for this study were selected based on availability in the data and significance in literature on HIV testing.[201-209] Age is a key factor in HIV testing and treatment, as younger people and older adults may face different barriers to accessing HIV services.[210] Wealth is also an important factor, as poverty and economic disadvantage have been associated with higher HIV prevalence and lower access to HIV testing and treatment.[211] Education level has reported significance where those of higher levels of education were more knowledgeable about HIV and more likely to seek testing and treatment.[212] Marital status can also influence HIV risk and testing behavior, as individuals who are married or in long-term relationships may have different risk factors than those who are single or sexually active outside of a committed relationship.[213] Finally, location of residence is important because access to healthcare services, including HIV testing and treatment, can vary widely depending on whether an individual lives in a rural or urban area, and in which country or region they reside.[214]

4.1.3 Conceptual Framework

The Health Belief Model (HBM) is a widely used theoretical framework in health behavior change research.[215] It posits that individual's health behaviors are determined by their beliefs and attitudes about their susceptibility to poor health, the severity of the condition, the benefits of and barriers to taking preventive measures, and cues to action for the target behaviors.[216] Several studies have adapted HBM to examine HIV testing among different groups of people.[217-220] Similarly, using Sudan-specific literature, this study adapts the HBM model to better understand HIV testing among Sudanese women.

Figure 4.1 Adapted Health Belief Model for HIV testing-



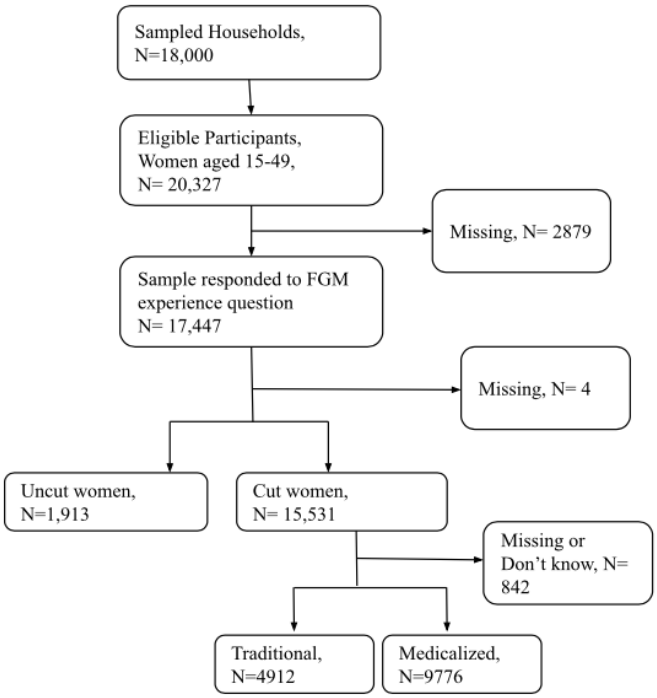
Using the health belief model adapted for this study from a 2015 study on HIV testing [221] I identified which factors are present in the available data, which ones are missing, and how future research would benefit from addressing the missing factors. The first construct, *Perceived Susceptibility* means that people who believe they are at risk for HIV infection are more likely to get tested.[222] This perception of risk can be influenced by factors such as marital status, condom use, knowledge of HIV status, and number of sexual partners.[223] *Additionally,* people with other health complications report higher *perceived severity* of HIV compared to others.[224] *Perceived Benefits* like early detection, better treatment outcomes, reduced risk of transmission and social costs potentially move people toward increased testing activity.[225] Additionally, the fear of stigmatization, lack of access to testing sites (in rural areas), lack of confidentiality and financial (and social) cost of testing all constitute *perceived barriers* to HIV testing.[226] Health care providers can address these barriers by providing confidential testing, offering free or low-cost testing, and using mobile testing units to reach underserved populations. The fifth component of the Health Belief Model is *Cues to Action*. People who receive reminders or encouragement from

health care providers, peers, or the media are more likely to get tested for HIV.[227] Health care providers can use reminder systems such as text messages or emails to encourage patients to get tested, and they can provide information about testing sites and resources.

4.2 Methods

4.2.1 Data Source & Study Participants

Figure 4.2 Flow chart of sample size selection for Study 3



The present study examines nationally representative data on FGM and HIV using Multiple Indicator Cluster Surveys (MICs). For Sudan, the most recent MICS available is from 2014. Other publicly available, nationally representative data on Sudan that include the subjects of relevance for this study are Demographic Health Surveys (DHS) that are limited to 1989 and 1990. 18,000 households were included in the survey sample. Between August and November 2014, 16,801 in-person interviews were performed in 17,142 homes, yielding a 93% household

response rate. 15% of people were under the age of five, and 51% were over the age of 18, with an average household size of 5.9. 18,302 of the 20,327 women who qualified for interviews did so, yielding a 90% response rate. 29.8% of people reported living in urban areas, while 70.2% lived in rural areas. 16,601 women who replied to the questions about their FGM/C status made up the sample for this study (see Figure 4.2). 9,776 women reported being cut by medical professionals, 4,912 by traditional cutters, and 1,913 were uncut. These self-reported data indicate that 88.5% of participants had experienced FGM/C. Therefore, this study sample is representative of the larger Sudanese female population as it closely reflects 87% prevalence in Sudan's national estimates of FGM/C.

4.2.2 Study Variables

Table 4.2. Dependent Variables for HIV/AIDS Testing Activity among Sudanese Women (15-49yrs)

Dependent Variable	Questions
Testing Activity	1. Ever been tested for AIDS virus. 2. Received results of AIDS virus test 3. Know a place to get AIDS virus test

Source: Sudan MICS, 2014

Three dependent variables for this analysis are collectively called "testing activity" as seen in Table 4.2. The larger sample was asked if they had ever tested for the AIDS virus. Those who responded "Yes" were asked if they received their test results. The larger sample was also asked if they know a place to get a HIV test.

The independent variable was FGM Group (i.e., uncut women, traditionally cut women and medically cut women). The independent variable was created through re-coding in SPSS. The groups of traditionally and medically cut women were originally coded into a single variable, represented by the question "Person circumcising respondent." Labels for this variable included Doctor, Nurse/Midwife, Health Visitor, Trained Midwife, Medical Assistant, Other Health Person, Traditional Circumcisor, and Other Traditional Circumcisor. We re-coded the variable into two groups, namely Medical Professional and Traditional Practitioner, to represent

medicalized and traditional participant groups, respectively. Uncut women were identified as those who responded “No” to the question “Have you yourself ever circumcised?”. The independent variable was finally created by creating a dummy variable of the three groups.

4.2.3 Power Analysis

A power analysis was conducted using G*Power Version 3.1.7.[168] to determine the appropriate sample size for binary logistic regression between a three-group independent variable (traditional, medical, and uncut) and at least five covariates (two areas of residence, multiple age groups, four levels of education, marital status and wealth index quintile). The analysis, which used alpha 0.05, power 0.80, and a small effect size (f = 0.10), showed that a minimum sample size of 1443 was necessary. As seen in Figure 4.2, the sample size for this analysis is larger than the minimum requirement, with N=1913 for the uncut group, N= 4912 for the traditional cut group, and N= 9776 for the medically cut group, indicating a relatively large sample size. Additionally, SPSS was used to calculate a small effect size of 0.12.

4.2.4 Data Analytic Plan

To examine HIV testing differences among women in the three FGM groups, I tested a null hypothesis that there is no difference in HIV testing activity among uncut women compared to those of the medicalized and traditional cut groups. Using binary logistic regression, adjusted odds ratios are reported with the uncut as a reference group. This test indicates the strength of association between medicalized and traditional FGM and HIV testing activity relative to the uncut after accounting for age, location of residence, wealth, education and marital status.

4.3 Results

4.3.1 Descriptive stats

Table 4.3 Crosstabulation of HIV testing activity among Sudanese women of different FGM Groups (N=16,601)

	Ever Tested for HIV				Received HIV Results*				Know Where to Test for HIV			
	No		Yes		No		Yes		No		Yes	
	N	%	N	%	N	%	N	%	N	%	N	%
Uncut	998	94%	64	6%	17	26.6%	47	73.4%	827	83.5%	164	16.5%
Traditional Cut	2944	97.2%	84	2.8%	20	23.8%	64	76.2%	2623	89.4%	312	10.6%
Medical Cut	7566	94.1%	472	5.9%	82	17.4%	390	82.6%	5965	79%	1584	21%
Total	11508	94.9%	620	5.1%	119	19.2%	501	80.8%	9415	82%	2060	18%

*Responses to Received HIV Status were asked when participants responded "Yes" to Ever Tested for HIV

Overall, HIV testing activity is low among participants included in this analysis (see Table 4.3). 5.1% reported that they had ever been tested for HIV (N=620). Among those who had ever tested for HIV, 80.8% (N=501) knew their results. Additionally, only 18% (N=2060) of the larger sample knew where to test for HIV. In terms of FGM cut groups, the uncut and medically cut reported higher likelihood of HIV testing (6% and 5.9%, respectively). The medically cut reported the highest rates of knowing their test results (86.6%, N=390). The uncut reported the lowest numbers for receiving test results (78.4%) and traditionally cut participants and the lowest percentage knowing where to test for HIV (XX%).

4.3.2 Binary Logistic Regression Results

<u>Ever Tested for HIV/AIDS</u>

Table 4.4. Odds of Ever Testing for HIV among Sudanese women of different FGM group **(N=16,601)**

	Model 1 (Unadjusted Odds Ratios)			Model 2 (Adjusted Odds Ratios)		
	Odds Ratio	95% C.I.		Odds Ratio	95% C.I.	
		Lower	Upper		Lower	Upper
Uncut (ref.)	-	-	-	-	-	-
Traditional Cut	0.973	0.743	1.273	0.799	0.604	1.057

Medical Cut	2.186**	1.727	2.768	1.444**	1.112	1.875
Area				2.495**	2.064	3.016
Age				0.708**	0.586	0.856
Education level				0.785**	0.706	0.873
Wealth				0.98	0.9	1.067
Marital Status				1.024	0.925	1.133

**= p<0.05
C.I., Confidence Interval
Model 2 controlled for age, location, education, wealth index and marital status

Table 4.4 shows results for binary logistic regression outlining the odds of testing for HIV among traditionally and medically cut participants compared to the uncut. In Model 1, we did not control for other explanatory variables in order to observe initial odds for testing for HIV in women with FGM compared to the uncut. The model indicated that the odds of ever testing for HIV are 118.6% higher for those in the medical group than in the uncut reference group (OR 2.186; 95% CI 1.727, 2.768). After adjusting for other variables (see Model 2, Table 4.4), the odds ratio of ever testing for HIV is still significant for differences between FGM groups (with $p < .05$). Specifically, odds of testing for HIV are 44.4% higher for those in the medical cut group compared to those in the uncut group (OR = 1.444; 95% CI 1.12, 1.875). This shows that membership in the medical group compared to the uncut is significantly related to the odds of testing for HIV even when controlling for area, age, education, wealth and marital status.

Received Results of HIV/AIDS Test

Table 4.5 Odds of Receiving HIV Test Results among Sudanese women of different FGM group who Reported Ever Testing (N=620)

	Model 1 (Unadjusted Odds Ratios)			Model 2 (Adjusted Odds Ratios)		
	Odds Ratio	95% C.I.		Odds Ratio	95% C.I.	
		Lower	Upper		Lower	Upper
Uncut (ref.)	-	-	-	-	-	-
Traditional Cut	0.552**	0.315	0.966	0.666	0.369	1.201
Medicalized Cut	0.649	0.386	1.093	0.823	0.455	1.488
Area				0.64**	0.415	0.987
Age				1.01	0.647	1.577

Education	1.47**	1.133	1.907
Wealth	0.864	0.698	1.068
Marital status	0.86	0.663	1.117

**= p<0.05
C.I., Confidence Interval
Model 2 controlled for age, location, education, wealth index and marital status

As seen in Table 4.5, among those who had ever tested for HIV (N=620), 80.8% (N=501) reported knowing their HIV status (i.e., received results of HIV test). Model 1 indicates that belonging to the traditional cut group significantly influences the odds of receiving results for HIV testing (p<.05). The odds of receiving results for HIV tests are 44.8% lower for those in the traditional group than in the uncut reference group (OR 0.557; 95% CI, 0.315, 0.996). In Model 2, after controlling for area of residence, age, education, wealth and marital status, the odds of receiving HIV test results are no longer statistically significant (p= 0.649), meaning that belonging to the traditional group is not significantly related to the likelihood of receiving HIV Test Results when controlling for age, area, education, wealth and marital status.

Knowing where to Test for HIV/AIDS

Table 4.6 Odds of knowing where to test for HIV among Sudanese women of different FGM groups **(N=16,601)**

	Model 1 (Unadjusted Odds Ratios)			Model 2 (Adjusted Odds Ratios)		
		95% C.I.		Odds Ratio	95% C.I.	
	Odds Ratio	Lower	Upper		Lower	Upper
Uncut (ref.)	-	-	-	-	-	-
Traditional Cut	0.747**	0.626	0.891	0.947	0.786	1.14
Medicalized Cut	0.448**	0.393	0.51	0.767**	0.662	0.888
Area				0.527**	0.472	0.587
Age				1.332**	1.188	1.494
Education				1.493**	1.399	1.593
Wealth				1.034	0.985	1.086
Marital status				1.059	0.997	1.125

**= p<0.05
C.I., Confidence Interval
Model 2 controlled for age, location, education, wealth index and marital status

Table 4 outlines odds of knowing where to test for HIV among Sudanese women of reproductive age compared to the uncut. As seen in Model 1, compared to the uncut (reference) group, the odds of knowing where to test for HIV are statistically significant with odds 55.2% lower among those in the medical cut group (OR 0.448, 95%; CI 0.393, 0.510) and 25.3% lower among those in the traditional cut group (OR 0.747, 95%; CI 0.626, 0.891).

In Model 2, after adjusting for age, area, education, wealth and marital status, belonging to the traditional cut group is no longer statistically significant in the odds of knowing where to test compared to the uncut. However, belonging to the medically cut group is still statistically significant. In this model, the odds of knowing where to test for HIV are 23.3% lower for those in the medically cut group compared to the uncut reference group (OR 0.767, 95% CI 0.662, 0.888).

4.4 Discussion

In this study, I examined HIV testing activity among women of traditional and medicalized cut compared to their uncut counterparts. Binary logistic regressions indicated that after controlling for potential confounders, the odds of ever testing for HIV were significantly higher among those in medicalized group, as they are 44% more likely to test for HIV compared to the uncut. Those of traditional cut did not report a significant difference from the uncut in odds of ever testing for HIV. These results may be explained by the nature of medicalized FGM- as it is any form of the practice performed by a medical professional, often in a clinic or hospital setting,[28] where HIV testing is usually available. Therefore, given access to medical professionals, those of medicalized cut may be more likely to receive information on HIV in the clinical setting and therefore be more likely to receive HIV testing.

After controlling for confounders, I found that there was no significant difference in the odds of receiving HIV test results among Sudanese women of reproductive age (regardless of cut group). This is potentially explained by the general high rate of follow through among those who test, as descriptive statistics show that 81% of those who tested for HIV, received their results (N=501). However, testing factors contributing to follow-through remain unclear. Depending on the type of HIV test offered (i.e., rapid or traditional), participants can receive their test results without needing to return if they tested negative for HIV. A rapid HIV test can provide results in about 20 minutes while a traditional test could take up to 2 weeks.[228] It is unclear if participants received rapid or traditional HIV tests at the time of data collection. However, it can be inferred that participants received rapid tests because according to UNAIDS, rapid tests became available to Sudan in 2013.[229] MICS data utilized in this study was collected in 2014.

Knowing where to test for HIV was significantly different in both traditionally and medically cut groups compared to the uncut group before I considered other confounders. After including confounding variables (age, location of residence, wealth, education and marital status), I found that only the medical group remained significantly different compared to the uncut (see Table 4.6). I also found that the odds of knowing where to test for HIV are 23.3% lower for those in the medically cut group compared to the uncut reference group. This was an unexpected result given that those of medical cut status are more likely to ever have been tested for HIV within this population. Nothing in the data also explains this finding. Therefore, a possible explanation is that there may have been discrepancies at the point of data collection when it came to the question of knowing where to test. If the interviewer(s) phrased the question in a manner that asked if participants knew HIV-specific testing cites outside the hospitals or clinics for instance, it could have led to inaccurate data collection that skewed this result.

Overall, it is notable from descriptive statistics that a majority of the sample (82%) did not know where to test for HIV. This partially explains why there is little uptake in HIV testing within the sample population. However, a similar study on HIV testing in Northern Nigeria states that knowing where to test is not necessarily enough to encourage HIV testing.[230] Therefore, to ensure successful uptake in HIV testing, there must be concurrent efforts to increase knowledge on where to test and address other contextual factors specific to the nation of Sudan.

Limitations

While the current study provides new knowledge on the odds of HIV testing activity among different FGM status groups, components of the HBM enables us to identify limitations including:

1. Potential underreporting of HIV testing: As with any self-reported data, there may be underreporting of HIV testing activity due to social desirability bias. This may lead to an underestimation of the true prevalence of HIV testing among women of FGM groups in Sudan.
2. Limited information on testing outcomes: The data utilized for this study does not provide information on the outcomes of HIV testing, such as the frequency of testing, number of positive tests among the population, linkage to care, and viral suppression. This information is important for providing more precise results on the differences testing incentive between uncut and cut groups.
3. No information from healthcare facilities: While the data provides information on HIV testing in the community (i.e., through household visits and in-person interviews), it may not fully capture testing activity in healthcare facilities. This information is important for

understanding the role of medical providers (especially those who perform FGM in clinics) in HIV testing and linkage to care.

4. Limited data on other explanatory variables: Based on existing literature, the HIV adapted HBM included condom use as a predictor for HIV testing. While data on condom use was available, it was excluded from the present analyses as there were too many missing entries (i.e., participants reported male condoms N=7 and female condoms N=2, out 20,327 overall interviews.) Other predictors (included in the adapted HBM) like number of sexual partners and age of sexual debut were not provided in the data.

4.5 Conclusion

Given the findings in this study, I conclude that efforts to improve HIV testing activities among Sudanese women of reproductive age would not necessarily benefit from targeting women by FGM cut group. However, given that compared to uncut women, those of medicalized cut were significantly more likely to test for HIV, and reportedly less likely to know where to test, there must be research conducted across other countries to determine what other contextual factors may have contributed to the discrepancy in these results. Additionally, seeing as a vast majority of participants across the three FGM groups neither tested for HIV nor knew where to test, more avenues for testing outside the current status quo would be beneficial for Sudanese women. Admittedly, the presence of more testing sites is not necessarily a prerequisite for utilizing testing services as the previous chapter found that stigmatized views toward PLWHA are high in Sudan. Therefore, efforts to improve testing activities in Sudan must address widespread stigma while simultaneously providing education on the need for HIV testing and increasing access to testing sites.

CHAPTER FIVE: GENERAL CONCLUSIONS

5.1 Summary of Dissertation Findings

Female Genital Mutilation (FGM) and Human Immunodeficiency Virus (HIV) are two gendered issues that have individually received widespread attention in global health discussions. Using a 3-article format, this dissertation addressed the seldom discussed association between the two. Overall, the relationship between FGM and HIV is complex and nuanced, but not indecipherable given understanding of contextual factors like location, education and wealth, among others. This dissertation identifies those contextual factors including those that present as gaps in current knowledge in a systematic review, and confounding (and missing) variables within two secondary analyses. It also contributes information to the under-researched subject of medicalized FGM and provides a foundation for future studies that compare health literacy and health behavior among women of different FGM groups.

Three studies in the systematic review reported a negative association between FGM and HIV such that FGM was associated with a lower risk of HIV. I concluded that this is different from the protective effect of male circumcision against HIV. That is, where FGM is prevalent, community-level factors connected to sexual activity (such as norms around having multiple sexual partners, unprotected sex or young age at sexual debut) or behavioral factors (such as diminished sexual desire) could potentially explain the study results. On the other hand, four studies reported a positive association between FGM and HIV (i.e., FGM was associated with a higher risk of HIV) after controlling for several explanatory variables. However, the potential pathways for HIV transmission proposed by K.E. Kun[75] were not tested in any of the studies

reporting positive association. Most studies reviewed in the systematic review (N=6) found no association between FGM and HIV.

Through the systematic review, I conclude that FGM and HIV are complex issues that cannot be simplified into a single association. While some forms of FGM may reduce the risk of HIV transmission, others may increase it. Therefore, efforts to address FGM and HIV must consider the specific cultural and social contexts within which they occur and should aim to empower women to make informed choices for themselves and their daughters about sexual and reproductive health.

To address gaps in knowledge regarding medicalized FGM, this dissertation also examined the differences between women who experienced medicalized FGM compared to those of uncut and traditional cut status. The overall goal was to contribute new knowledge to understanding of the social impact that FGM potentially has on health literacy- specifically HIV health literacy and the nuances surrounding the trend toward medicalization. Through secondary data analysis of nationally representative data from Sudan, I found that those of medicalized cut reported higher odds of HIV testing compared to the uncut. Those of medicalized cut reported more general knowledge of HIV transmission than their traditionally cut and uncut counterparts. However, stigmatizing views toward people living with HIV where high across all three groups of women and did not differ among the three FGM groups. Those of medicalized cut within the study sample were also wealthier, and more likely to be able to afford medicalization. Based on a report from Egypt,[171] when FGM was criminalized in an effort to eradicate the practice in all forms, several medical professionals increased the price of the procedure and continued to provide the service as routine medical care. Based on findings from this study, those of

medicalized cut (who are wealthier) would be able to afford the higher prices for their daughters, effectively nulling the point of criminalization. Considering the report on the SES of those of medicalized cut along with the fact that criminalization is an effort toward eradicating FGM, I conclude that medicalization is slowing the progress toward eradicating the practice in its entirety.

It is notable that those of medicalized cut were wealthier and more educated than their uncut and traditionally cut counterparts, a factor that may partially explain the differences in HIV knowledge and testing between the groups. They were also over-represented in urban areas. This means that they potentially have more access to health professionals, first by virtue of their medicalized cut status, and also by geographic access to urban health centers and ability to afford relatively costly medical services. Given these findings, I was surprised to find that compared to the uncut group, those of medicalized cut were less likely to know where to test for HIV. This could potentially be explained by miscommunication at the time of data collection.

5.2 Innovation

The three articles comprising this dissertation add new information to literature on FGM and HIV. Two systematic reviews on the association between FGM and HIV were published prior to this dissertation. [70,76] Iavazzo et al [70] was published in 2013 and thus the systematic review in this dissertation updates their findings by including more recent research. The review by Pinheiro [76] was more recent (2019) and it effectively summarized the findings on FGM and HIV associations but stopped short of providing information on (or an analysis of) gaps in current knowledge. This dissertation improves on Pinheiro by following a rigorous process that

included utilizing two trained reviewers. Furthermore, this dissertation went on to analyze gaps in current research and provided recommendations for future research based on said gaps.

At the time of this project, there are no studies examining the HIV knowledge, attitudes and testing activities of women by FGM group. Additionally, in Sudan-specific data, studies on genital cutting and HIV were limited to male circumcision.[230-232] This dissertation addressed both gaps by being the first study to examine HIV literacy and testing activity among women of different FGM statuses in Sudan. This was conducted using analytical techniques in SPSS including ANCOVA, and binary logistic regressions. With access to a large dataset from the UNICEF, this dissertation uses nationally representative data from Sudan to provide a replicable methodology for other countries with high prevalence of FGM.

5.3 Synthesizing the dissertation

Based on these findings, three themes emerge across the three articles that build upon each other, specifically the importance of location (such as a specific country or state within a country), the need for information on long term effects of medicalized FGM and the social factors that affect both FGM and HIV literacy among Sudanese women of reproductive age.

The mixed nature of reports on the association between FGM and HIV is not surprising as there is extensive heterogeneity in the data. As seen in Study 1, the 13 reviewed studies ranged in sample sizes (370-96,000 participants), prevailing types of FGM, countries across the continent of Africa and research methodology. This heterogeneity led to a focus in this dissertation on just one country (i.e., Sudan) for Studies 2 and 3. Despite this concentration in geography in the latter studies, participant location (i.e., urban or rural location within the country) still played a confounding role in HIV literacy and HIV testing activity. It was also evident in the geographic

distribution of women who experienced FGM, as those of traditional cut mostly lived in rural areas and those of medicalized cut were most represented in urban areas. This indicates the importance of geographic specificity in examining any aspect of associations between FGM and HIV.

Likely related to the variable of location exist other factors like the social norms surrounding female sexuality and empowerment. While study 1 reviewed publications that focused on the biological plausibility of FGM's association with HIV, studies 2 and 3 indicate plausible social pathways, where factors that encourage different forms of FGM also contribute to different outcomes in HIV literacy. That is, where higher SES (higher education, more wealth and modernized (or urban) location of residence) contributed to higher rates of medicalized FGM, it was also related to more knowledge of HIV. This potential social pathway is relevant for future research that examines overlapping influences to women's health and vulnerability in any given location.

On biological plausibility, the dissertation also creates a foundation for directional hypothesis on the type of FGM most likely associated with HIV compared to the other types. This is through the finding that three studies on positive association between FGM and HIV reported type 1 as the prevailing type of FGM among their participants. The potential for this association would be possible where a communal cut (i.e. several girls cut at the same event, using the same instrument) is often performed as tradition in the community. This is also supported by the fourth pathway proposed by K.E. Kun [75] and described in study 1. Those pathways were developed based on data on the consequences of traditional FGM and may be less likely with medicalized FGM. However, the lack of data on the long-term effects of medicalized FGM creates its own

possibilities for the pathways of association between medicalized FGM and HIV as seen in Table 5.1

Table 5.1 Potential Pathways of Positive or Negative Association between Medicalized FGM and HIV	
Positive association	Med FGM ⇒ scar tissue/narrow vaginal opening ⇒ painful intercourse ⇒ anal sex
Negative association	Med FGM ⇒ alternative to traditional communal cut ⇒ girl is not exposed to other infected persons
	Med FGM ⇒ decreased sexual desire ⇒ fewer sexual partners ⇒ less chance of HIV infection

Despite the lack of information on medicalized FGM, this dissertation contributes to the discussion on the progress toward eradicating all form of FGM by 2030. My findings do not explicitly dictate that medicalized FGM is slowing down the progress toward eradication, however, when looking at the fact that the criminalization of FGM in countries like Egypt led to increased cost of medicalization, along with my finding that those of medicalized cut are also wealthier, one can surmise that the wealthier can opt for medicalization for their daughters, effectively voiding the point of criminalization and in so doing, slowing down the progress toward eradication by 2030. Addressing these social and structural determinants of health is crucial for preventing both FGM and HIV. This requires a multi-sectoral approach that involves education, advocacy, and community engagement, as well as strengthening health systems and addressing the root causes of gender inequality and poverty.

5.4 Future Research

Based on findings and limitations of this dissertation, future research should

1. Consider ways to reduce heterogeneity in the data such as a focus on social and cultural norms specific to a geographic location when examining associations between FGM and HIV

2. Examine the type of FGM potentially associated with HIV, considering that several studies included in this dissertation reported type 1 as the prevailing type when a positive association was reported.
3. Examine long-term health outcomes among women with medicalized FGM. This will not only contribute to information on potential pathways of the association with HIV, but provide data on whether it is less harmful when compared with long-term health outcomes of traditional FGM.
4. Conduct similar comparative studies in other FGM-practicing countries, including non-African countries like Indonesia, which reports nationally representative data on FGM prevalence and increasing HIV incidences.
5. Examine medical provider knowledge and attitudes toward associations between FGM and HIV to explore the potential to intervene at the medical provider level.

It is important to note that although conversations around female sexuality are often taboo, there is a high level of communal acceptance that comes from experiencing FGM within a community with high prevalence of the practice.[10] That is, a woman who rejects FGM while belonging to such a community risks social exclusion and ostracization from her people. This, in turn, can mean exclusion from valuable resources within the community that may contribute to her health, wellbeing and economic success. Therefore, while considering the findings of this dissertation along with the plans for future research, one must exercise compassion, cultural sensitivity and attentiveness to the social impact of their work. Deeply ingrained beliefs over long periods of time have led to the current state of FGM and the social norms that keep it prevalent. Therefore, it will take thoroughly researched and repeatedly implemented efforts over long periods of time to completely eradicate a practice like FGM.

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