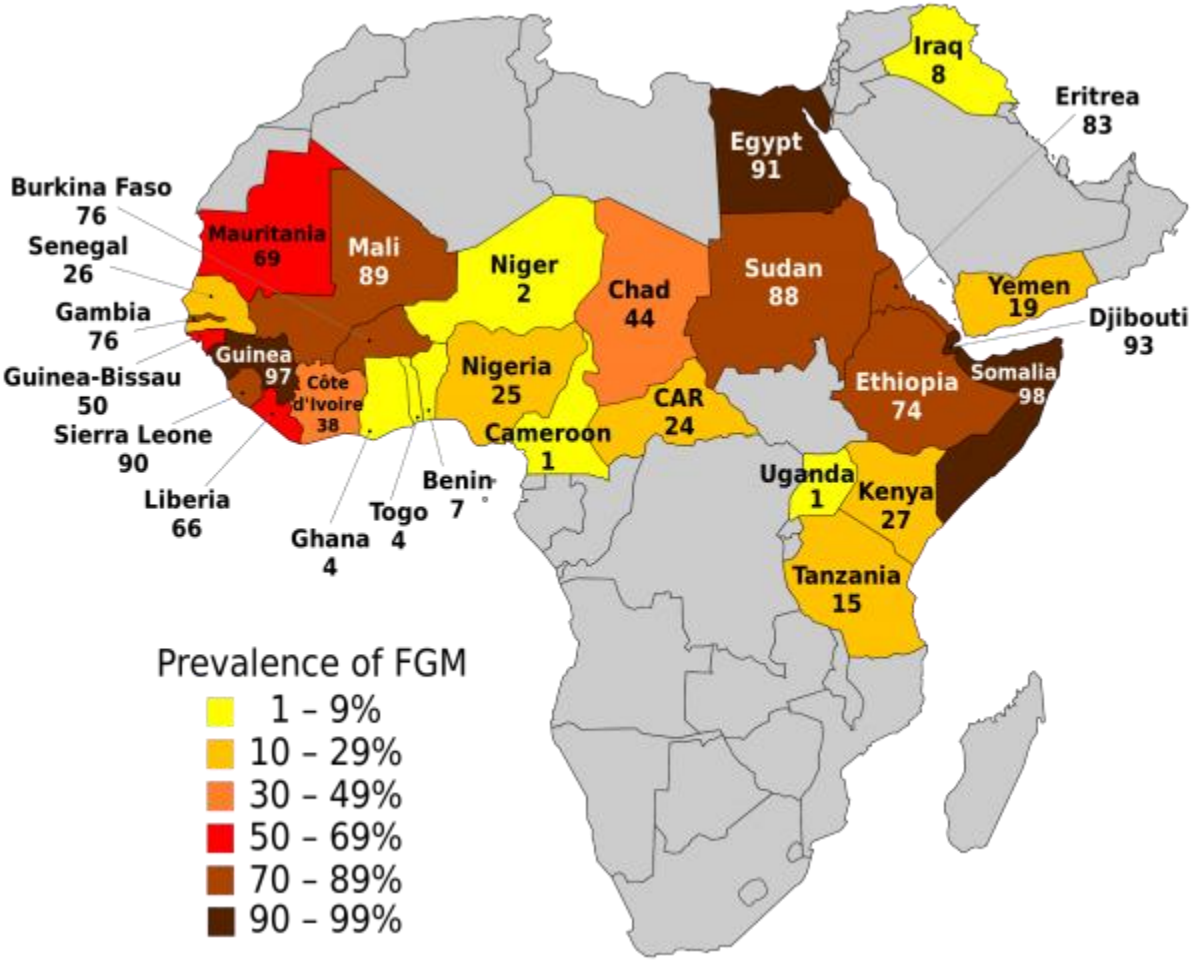
Investigating Experiences and Health Concerns of Female Genital Mutilation among African Women in Toronto



Uzima Women Relief Group International

Giving a new meaning of Life, hope and bright future to all women

WOMEN'S COLLEGE HOSPITAL

Health care for women | REVOLUTIONIZED

2017

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EXECUTIVE SUMMARY

1. Statement of Problem/Topic

Female Genital Mutilation (FGM) is a cultural practice in many cultures in the world particularly in Africa, Asia and Middle East. In 2011almost 29,000 women from Africa and the Middle East became permanent residents of Canada making FGM an important Canadian issue that needs more to be done to augment legislation in order to stop the practice.

FGM is a procedure where girls have some or all of their external genitalia (the labia and clitoris) removed. In some cases the vaginal opening is also sewn and almost closed. FGM is performed on girls from infancy to puberty. It is therefore important to investigate the long term effects of FGM on the lives of survivors. FGM can result in life-threatening health complications including infections, bleeding, and problems during childbirth. The cultural values of FGM in communities where it is practiced include protecting young girls' virginity by preventing them from premarital sex. FGM is illegal in Canada and women who have had FGM illegally may be avoiding health care for fear of being discovered. Uzima works with women from communities where FGM is practiced and therefore understands their fears. This study is therefore urgently needed to address health issues, ignorance and stigma associated with FGM through public education and awareness campaigns.

2. Description of Research Conducted or Program Implemented

Uzima engaged women residing in Toronto and the GTA who originate from 15 African countries where FGM is practiced. Community leaders were both men and women of African descent serving African communities and included community agency leaders, women group leaders and religious leaders. Service providers were both men and women from all racial groups ranging from Caucasian to African and comprised social services agency staff, community health centres staff including managers, counselors and health promoters. Others included clinical staff such as Nurse Practitioners and Doctors.

A Community Advisory Committee (CAC) of seven members was formed to ensure community-based participation. The study used both Qualitative and quantitative methods to collect data. 21 women aged 18 – 55 years participated in the study. Additionally, 8 community leaders and 11 service providers also participated in the study. Key areas covered included demographics: age range, country of origin, year of immigration to Canada, number of Biological children, marital status, and for all women participants, if they had FGM or not. The rest of the questions covered knowledge of FGM and experience, health issues experienced by women e.g medical and psychological complications. Other questions included whether women are receiving adequate services and what women wish to receive to meet their needs in order to understand the harm and risks if FGM as well as what they would like communities and service providers to do to reduce stigma and stop FGM.

3. Key Findings/Outcomes

Health concerns of women
95% (20/21) of the women interviewed have experienced a form of FGM which happened between infancy and adulthood. 47% (10/21) women said that FGM is a stigmatized topic and some women may be afraid to disclose it to their service providers. All women expressed concern about the harm associated with the practice saying most of the injuries are permanent and cannot be reversed, and all who could remember the experience said FGM was done at home rather than in a hospital. All women interviewed have experienced the following: Severe psychological trauma resulting in mental health issues such as stress and depression, reproductive and urinary system complications, bleeding, shock, birth difficulties, decreased sexual satisfaction and painful menstruation.

When women were asked whether they were satisfied with their health care providers, 66% (14/21) said they were not satisfied due to several reasons among them Doctors not taking time to listen to their needs especially not asking about FGM. 57% (12) women responded to whether they had a pap smear. The rest were afraid to disclose FGM to service providers among other reasons. 71% (5/7) women felt FGM was not being addressed by local agencies.

Chronic disease management: Women living with FGM experience need better management of chronic diseases such as diabetes, heart problems, mental illnesses and HIV/AIDS.

Mental Health needs: Women living with trauma experience from their home countries need a lot of counseling services which agencies provide but due to stigma associated with FGM some women do not access such services. There are a lot of taboos on mental health so women need health care support to overcome such barriers.

Management of other FGM related infections and conditions: Urinary tract infections, birth difficulties because giving birth in most cases is traumatic

Social Concerns: Social concerns included talking about FGM outside of cultural group, relationship stigmatization, infidelity and divorce.

4. Unexpected/Unanticipated Outcomes

Law on FGM in Canada: Women now know that FGM is a violation of their Human Rights and they support the law. However, women felt that the law is not open to Canadians and people can take advantage and continue to practice FGM secretly.

Some service providers including some Doctors have only limited knowledge and understanding of the law. Consequently, some community members and service providers may feel the law is interfering with cultural practices and find ways of circumventing the law thus putting more girls and women at risk of FGM and the harm associated with the practice.

5. Recommendations for Policy, Practice or Further Research

More health information/ education for everybody: There is an urgent need to stand up against FGM in all communities. Community leaders, service providers and policy makers need to advocate education in order to bring about positive change.

Training of service providers in cultural competence:

- Main stream service providers particularly those in Health care need to be culturally sensitive, respectful, nonjudgmental and inclusive when providing services to the populations they serve
- Primary care physicians need to be:
    - More sensitive to the needs of African women living with FGM
    - Understanding of the psychological trauma of women living with FGM
    - Prepared to learn how to care for women with FGM to relate better with patients
    - All service providers need to be empathetic towards women living with FGM
    - There is a need for a presence of more African Doctors attending to African women for those living with FGM to be more comfortable as such Doctors will relate better with African culture.

***Anti-racism, anti-discrimination and anti-oppression policies*:** There is a need to address racism and other oppressive practices by service providers.

Fighting Stigma

- Although some organizations have a policy of inclusion, they do not include FGM in subjects addressed openly.
- Such organizations must include FGM in their programs with procedures to de stigmatize FGM
- FGM should be discussed as part of other topics and not as a standalone topic.
- Cultural competence is key in carrying out education. Sometimes when issues that affect marginalized populations are discussed in public and through the media they are derogatory in nature fueling further stigmatization.

Reinforcement of the law against FGM

- Proactive steps should be taken to enforce the law against FGM
- Public education for everybody on the law especially for families from countries where FGM is practiced

Education on nutrition and other health needs: African women need information on healthy lifestyles: better nutrition, exercise and accessing health and social services

Consistent and adequate funding for agencies serving African people:

- Agencies need consistent funding to adequately address unique needs of African women
- When funding is cut service users are forced to change providers and some may be discouraged to seek new providers

ACKNOWLEDGEMENTS

Uzima Women Relief Group International would like to thank the Women College Hospital for funding this project. Our thanks go to the participants who made it possible for the project to succeed. *Uzima* is grateful to the Research team and Research Assistants for working tirelessly and showing exemplary team work in completing the project. Our sincere thanks go to the Advisory committee team who dedicated time and offered useful advice and direction to the research. Without their support the research team would have taken longer to complete the project. We are very grateful to our volunteers and summer students who did the outreach and engagement of research participants. Last but not least we would like to thank the Research Ethics Board for providing the Ethical guidance for the project.

Jacobet Edith Wambayi
Executive Director

INTRODUCTION

This study investigated the experiences and health concerns of female genital mutilation among African Women in Toronto focusing on both women of African descent with FGM experience as well as those without FGM experience such as people who have lived with those who have experienced FGM. Additionally, the study collected information on how the women's health can be improved through education and awareness. In this study, the African women comprised of those who moved to Canada from some of the 29 countries in Africa where FGM is practiced. This study will provide a better understanding of the impact of FGM and the health concerns of affected women specifically barriers to accessing their reproductive health care.

Understanding the sexual and reproductive needs of this population will lead to reduced stigma through sensitized and culturally appropriate information sharing. Recommendations from this study will help to improve the health of women in the participating communities as well the wider Canadian society. It is hoped that the results and outcomes of knowledge collected through this study will contribute to the growing literature that may, in time, benefit the African FGM women who shared their experiences.

FGM Practice

FGM is a procedure where girls have some or all of their external genitalia (the labia and clitoris) removed. In some cases the vaginal opening is also sewn and almost closed. FGM is performed on girls from infancy to puberty. It is therefore important to investigate the long-term effects of FGM on the lives of survivors. FGM can result in life-threatening health complications including infections, bleeding, and problems during childbirth. The cultural values of FGM in communities where it is practiced include protecting young girls' virginity by preventing them from premarital sex. Whereas this is a fundamental value, the harm associated with the practice far outweighs the traditional values of the practice.

Under the Criminal Code, FGM is illegal in Canada and women who have had FGM performed on them illegally may be avoiding health care for fear of being persecuted. This study is an important starting point in addressing the problem in Canada by engaging the women in sharing their experiences. The study will help reduce ignorance and stigma associated with FGM. This study was guided by the following goals, objectives and research question.

Goals: The main goal of this study was to create more understanding of FGM and to spread awareness of the practice. Stigma and ignorance may prevent some women from seeking services for fear of disclosing that they have undergone FGM to their health providers. This project sought the communities' perceptions of FGM and whether the public is aware of the law against FGM. The study aimed at using a culturally appropriate approach to engage participants in the investigation in order to determine the best methods and policies to help reduce the stigma associated with FGM. Since FGM has been imported into Canada by immigrants it is important that Canada addresses the issue without denial. It is important that the public understand the harm associated with FGM.

Research question: What are the experiences and health concerns associated with female genital mutilation among African women in Toronto?

Objectives:

- To learn about the experiences and health concerns of FGM among African women in Toronto
- To create awareness about the health risks of FGM
- To disseminate the results of the investigation to the wider community
- To develop sustainability plans through support and education programs for affected communities

Literature Review

The impact of Female Genital Mutilation

Female genital mutilation (FGM) also known to as female circumcision (UNICEF 2005) is considered to be a harmful traditional practice that has caused a very serious Human Rights issue that is described and defined by UNICEF (2007, 2005) as the complete cutting/removal and alteration of the external genital portions of girls and women. This practice can be done on the girl child or woman without their consent, which indicates a violation of fundamental Human Rights (charter on human rights, article 24) (Zerai, W. 2003). FGM is done on girls at ages ranging between 5 and 12 years. It also might include infant and adult women (Perron, L., et al 2013). According, to Miltenburg, (2010) this practice is still common in 29 African countries. The harmful practice of FGM does not only affect women in their various countries of origin but continues to impact the lives of those who migrated and are living in various migrant communities of countries and cities other than their countries of origin (UNICEF, 2005).

Historical/Background of FGM:

The origin of FGM and how it was primarily performed is difficult to determine even though FGM is practiced in many cultures around the world from the Australian Aboriginal tribes to different African tribes in many countries (Kouba, & Muasher, 1985; Lorenzi, Rossella. 2012). However, according to Kouba, & Muasher, (1985) ancient Egyptian mummies were discovered to have undergone female circumcision referred to as operations performed on girls in Memphis at the age when their dowry is received. These authors have further shown that these operations still exist and that FGM has been found to be more prevalent on the African continent. However, practice differs from country to country with Somalia having the highest prevalence of FGM at 97% and the highest in the world (Gele, Sagbakken, & Kumar, 2015). The authors have reported that FGM came to existence in Somalia in the early 17th century and it is practiced for religious obligations as well as social beliefs that only girls who have undergone FGM are virgins and also socially belonging

In Nigeria just like any other African country, FGM belief is based on traditions, preservation of chastity and purification, other reasons include family honor, protection of virginity and prevention of promiscuity, modification of socio-sexual attitude (away to deny the woman to attain orgasm) but however, increase the sexual pleasure of their husbands (Okeke, Anyaehie, & Ezenyeaku, 2012). Unfortunately, FGM is also used to justify the denial of family inheritance by women (Okeke, et al. 2012).

Countries and experiences of people with FGM

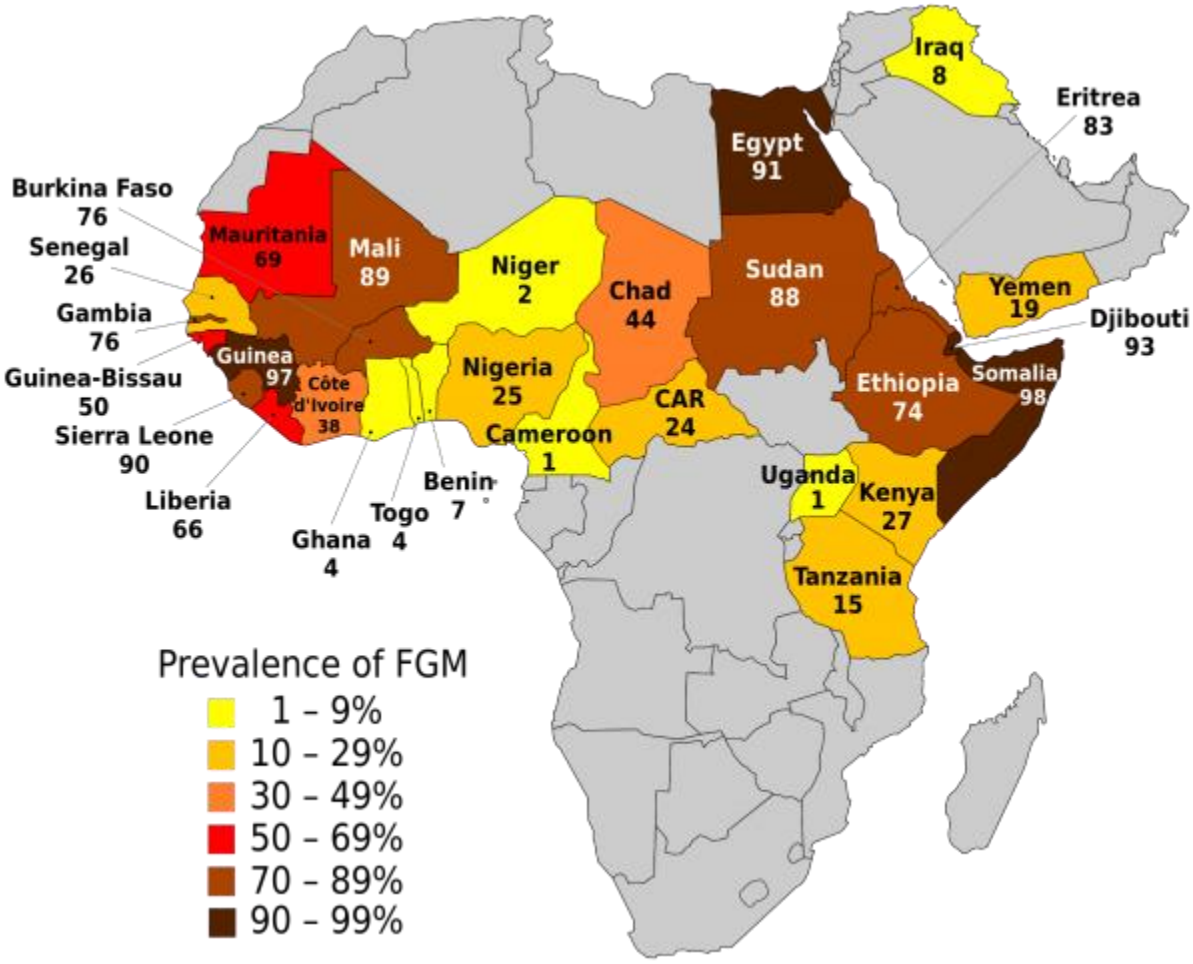
FGM Teachers Guide (2001, 2000) as well as authors like Adan (2016) have estimated that about 100 to 140 million girls and women in Africa have under gone FGM. In addition, more than 2 million girls and women are at risk of undergoing FGM practice each year. Research conducted in Eritrea by Zerai, (2003) revealed that even though FGM comes with health consequences, it has been known to have strong connections or ties to religion and culture. The article further revealed medical problems associated with FGM to include both physical and psychological effects, of much bleeding that can cause shock and death (Zerai, 2003). Others include difficulties in menstrual flow, difficulties during sexual intercourse, problems at and after child birth (Gele, et al. 2015; Zerai, 2003).

Estimated prevalence of FGM by age and country in Africa

Countries	Prevalence by Age (%)		
	15 - 49	15 - 19	45 - 49
Benin	7.3	2	12
Burkina Faso	75.8	57.7	89.3
Cameroon	1.4	0.4	2.4
Central African Rep.	24.2	17.9	33.8
Chad	44.2	41	47.6
Cote d'Ivoire	38.2	31.3	46.9
Dijbouti	93.1	89.5	94.4
Egypt	91.1	80.7	96
Eritrea	88.7	78.3	95
Ethiopia	74.3	62.1	80.8
Gambia	76.3	77.1	79
Ghana	3.8	1.5	6.4
Guinea	95.6	89.3	99.5
Guinea-Bissau	49.8	48.4	50.3
Iraq	8.1	4.9	10.3
Kenya	27.1	14.6	48.8
Liberia	58.2	35.9	78.9
Mali	88.5	87.7	88.5
Mauritania	69.4	65.9	75.2
Niger	2	1.4	1.4
Nigeria	27	18.7	38
Senegal	25.7	24	28.5
Sierra Leone	88.3	70.1	96.4
Somalia	97.9	96.7	99.1
Sudan	87.6	83.7	89.1
Tanzania	14.6	7.1	21.5
Togo	3.9	1.1	6.7
Uganda	1.4	1	1.9
Yemen	38.2		

http://fgm.co.nz/where-is-fgm-practiced/

FGM Prevalence: Percentage of girls and women aged 15-49 with FGM in the 29 African countries



http://fgm.co.nz/where-is-fgm-practiced/

The World Health Organization (WHO) has come out four types of FGM:

"**Type I**, also called **clitoridectomy:** Partial or total removal of the clitoris and/or the prepuce.
Type II also called **excision:** Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora. The amount of tissue that is removed varies widely from community to community.
Type III also called **infibulation:** Narrowing of the vaginal orifice with a covering seal. The seal is formed by cutting and re-positioning the labia minora and/or the labia majora. This can take place with or without removal of the clitoris.
Type IV: All other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, piercing, incising, scraping or cauterization".

See more at: http://www.unfpa.org/resources/female-genital-mutilation-fgm-frequently-asked-questions#sthash.Zsb7yxRh.dpuf

FGM & challenges in immigrant communities

Perron et al, (2013) have reported that even though it is believed that FGM is practiced in Canada, it is yet to be proved although there is concern that some girls may be at risk. The Author further reported that FGM in immigrant communities in Canada has been traced back to the 1990s and those immigrants who arrived between 2005 and 2009 in Canada from FGM countries were documented by Canadian immigration proving that women from these countries had their FGM done from their countries of origin before arrival in Canada. Canada like other United Nation countries has declared FGM illegal. Appendix 1 of The Criminal Code, *Criminal Code,* R.S.C.1985, c. C-46, s.268, as am. S.C. 1997, c.16, s. 5: provides the main section regarding that crime. As well, the Federal Interdepartmental Working Group on Female Genital Mutilation has regarded FGM "a form of child physical abuse. In 2012, the UN General Assembly adopted Resolution L21 revision 1 on female genital mutilation (FGM) led by African countries. The resolution calls upon states to implement laws eliminating FGM among several other recommendations (UN Assembly 2012).

UNICEF (2005) confirmed that there are a lot of immigrant communities that continue the practice even in their new countries. It was first reported in the Netherlands in the 1990s, when Somali women refugees first arrived (UNICEF 2005). The article further reports that even though in 1993 the practice was prohibited under the Netherlands' criminal law, girls in the community continued to experience FGM. According to Gele, et al. (2015) Norway experienced an influx of Somali refugees between the years of 1988-1991 and had to find ways of dealing with the new culture of FGM in this population through implementing policies on criminalization of FGM. Recently there have been reports of FGM being practiced in the USA with perpetrators being prosecuted under the Criminal code. (Free Post, 2017 http://www.freep.com/story/news/local/michigan/wayne/2017/04/17/prosecutors-genital-mutilation-part-incredibly-secretive-ritual/100574696/). It is believed that perpetrators in Canada will be exposed and prosecuted.

Health Care challenges

Studies have revealed that women with FGM from sub-Saharan Africa have experienced various challenges in the countries they migrated to. Some of the challenges reported among Somali women in Ontario include both physical such as difficulties during child birth and psychological trauma (Einstein, 2-12) associated with shame due the feeling of being different from other women who did not experience FGM (Perron et al 2013). These studies reported incidents of improper treatment by service providers who were insensitive to the cultural practice hence the women feeling offended by the ignorance of some service providers. Similar concerns of mistrust of health care providers by the Somali community have been reported in U.S.A (Helm et al. 2014). Other studies have shown that many immigrant women who have experienced FGM prior to immigration into Canada usually do not seek medical health care unless they are sick. Additionally, the women may not seek pre-natal and post-natal care unless there is emergency (Huston, 2012). It is considered taboo to discuss such matters in public by many cultures that practice FGM (Berg et al, 2010).

METHODOLOGY

Population

Uzima engaged women residing in Toronto and the GTA who originate from the following countries where FGM is practiced: Cameroon, Democratic Republic of Congo, Egypt, Ethiopia, Eritrea, Ghana, Kenya, Liberia, Mali, Nigeria, Somalia, Sudan, Tanzania and Uganda.

The African population is widespread in the city with new immigrants still in transit and hence not settled in one neighbourhood. However, the majority reside in the Neighbourhood Improvement Areas with low Neighbourhood Equity Scores like Scarborough Village with a score of 33.9% (City of Toronto). Majority of Africans therefore experience poverty and other social determinants of health which are barriers to their accessing health and social services in Toronto.

Recruitment

Recruitment was by purposeful selection. This model has previously been used in these communities during the HIV/AIDS Stigma study (Lawson et al, 2006). An introductory letter (Appendix I) clearly stating the goals and objectives of the study was sent to community cultural groups and service provider agencies. Publicity was by word of mouth, emails and flyers (Appendix II) distributed at agencies, community events and strategic places such as malls and libraries.

Recruitment criteria were women from African countries where FGM is practiced, residing in Toronto and the GTA and aged 16 years and older. 21 women aged 18 – 55 years participated in the study. Additionally, 8 community leaders and 11 service providers were recruited in the study. Written consent was obtained from all participants (Appendices III – V). When recruiting, researchers went over the study and consent form verbally with all participants prior to participants deciding to participate. Translation and interpretation services were available at recruiting agencies. All participants who could not participate in person had access to email and received the consent forms in advance of the interviews.

Community leaders were both men and women of African descent serving African communities and included community agency leaders, women group leaders and religious leaders. Service providers were both men and women from all racial groups ranging from Caucasian to African and comprised social services agency staff, community health centres staff including managers, counselors and health promoters. Others included clinical staff such as Nurse Practitioners and Doctors.

Methods

A Community Advisory Committee (CAC) of seven members was formed to ensure a community-based participation. The study used both qualitative and quantitative methods to collect data. Two focus groups were conducted with women. One group was held with four women aged 18 – 30 years and the second with six older women aged 31 years and older.

Key informant interviews were held with eleven women, eight community leaders and eleven service providers. Separate questionnaires were developed for each category of participants (Appendices VI – VIII). Key areas covered included demographics: age range, country of origin, year of immigration to Canada, number of Biological children, marital status, and for all women participants, if they had FGM or not. The rest of the questions covered knowledge of FGM and experience, health issues experienced by women e.g medical and psychological complications. Other questions included whether women are receiving adequate services and what women wish to receive to meet their needs in order to understand the harm and risks if FGM as well as what they would like communities and service providers to do to reduce stigma and stop the practice. Questionnaires were pretested with 3 women varying in age and country of origin. They were all survivors of FGM.

Community leaders were asked questions about the organizations or groups that they lead, the issues the organizations address, health needs of African women in the organizations, what the organizations think about the harm associated with FGM, if they were aware of the law banning FGM in Canada and what they thought about the law. Service providers were asked similar questions but with more focus on the health care needs of African women, experiences with clients living with FGM and how they treat them, existing programs on reproductive health and if programs include FGM.

Analysis

Focus groups were recorded and transcribed verbatim. Thematic analysis was done manually. Exemplary quotes are included in the results to qualify responses. Quantitative analysis was done using Excel. Testimonials are reported verbatim.

Dissemination

The research report will be available in electronic and hard copies at the Women Exchange, Uzima and partner agencies and on all websites. Publications for peer reviewed journals will be prepared as well as presentations at forums and conferences. The English fact sheets (Appendix IX) will be translated into the following languages: French, Arabic, Kiswahili, Hausa, Somali, Tigrignya. More translation into other African languages spoken across several countries will continue with availability of future funds.

Workshops, community meetings, seminars, training forums will be conducted to increase awareness. Word of mouth popular among African communities will be used as well to reach members of the community who may not attend forums. Women who are realizing the health risks associated with FGM will educate other women and communities. Culturally sensitive conversations will be encouraged in community groups and at service agencies.

Knowledge users will be all women especially young women and mothers who must be empowered with both health information and Women's Rights, service providers at agencies and health care facilities, policy makers, community leaders, schools, colleges and universities, community groups including parent groups through social media: cell phones, texting, Face book, Whatsapp. A two minute video will be produced as part of this report.

The research team and CAC will develop a sustainability plan with Taibu Community Health Centre to include FGM in their Health Promotion programs. A training tool will be designed for

community health workers to educate them about how to collaborate more effectively and better meet the needs of women from FGM practicing communities. Uzima will develop a bigger research study to follow up on this one and solicit for funding from Women Exchange and other funders.

RESULTS

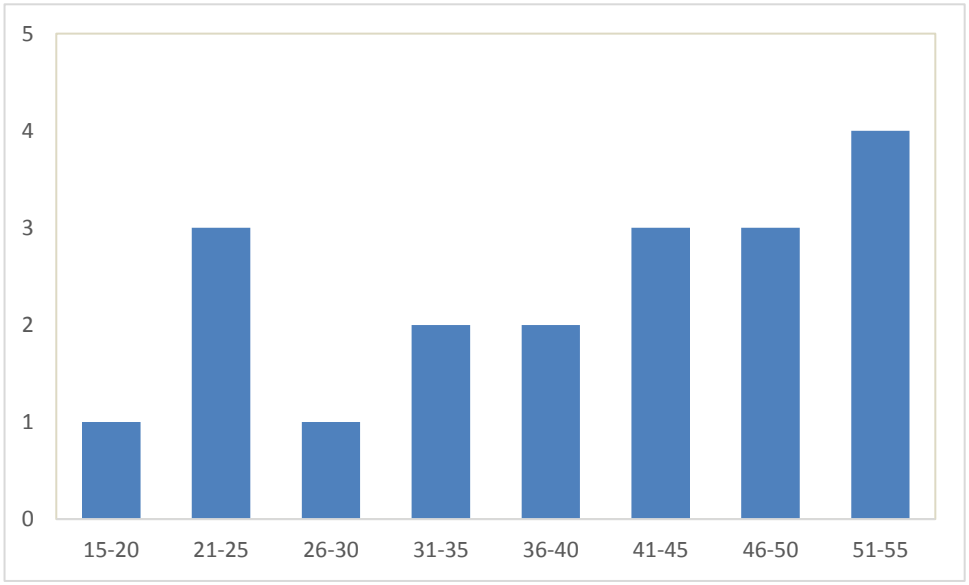
A total of 21 women, 8 community leaders and 11 service providers were interviewed. Demographics of participants as well as responses to the interview questions asked during focus groups and key informant interviews are shown in the following sections. Perceptions of FGM, health and social concerns of participants as well as service gaps were addressed during the consultations. Key themes from focus groups and surveys were identified and exemplary quotes used to emphasize responses. All participants agreed there is serious harm associated with FGM and they expressed concerns on the health of women and entire communities.

DEMOGRAPHICS

Women participants

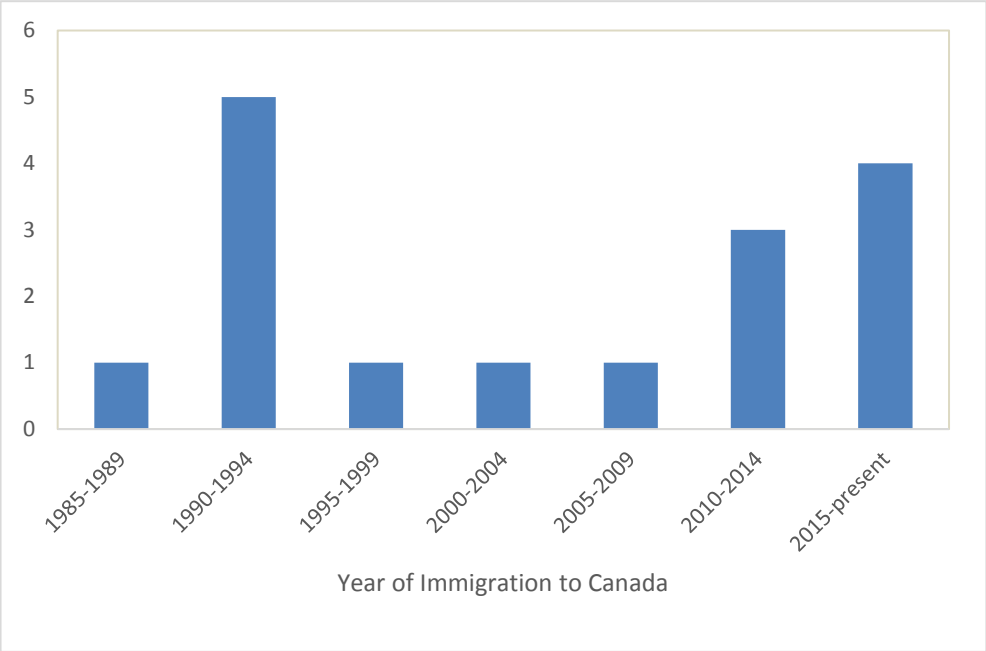
The figures below show the number of respondents per question. Focus group participants were given the questionnaires to fill in their demographic information and some skipped some questions hence the differences in numbers.

Figure 1. Age of Participants (n=19)



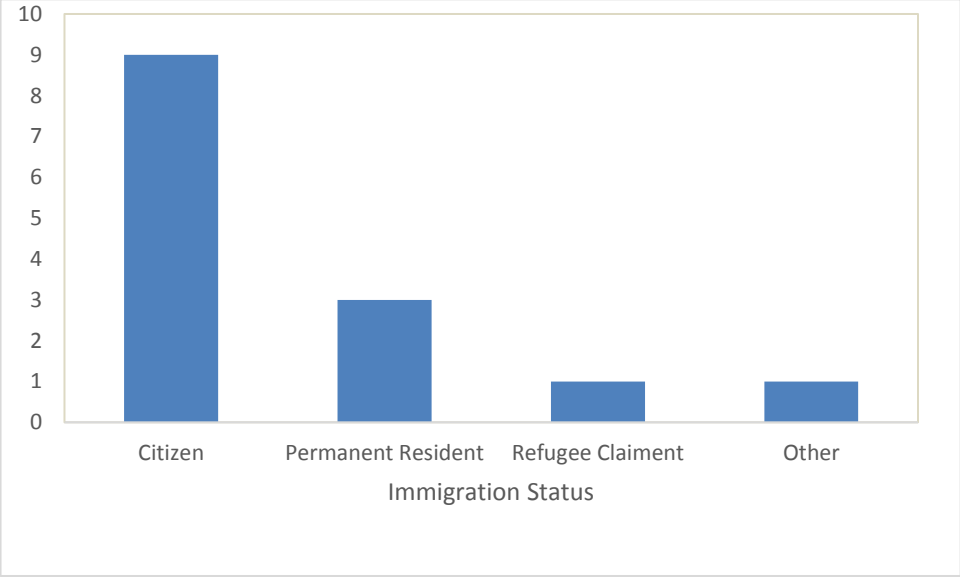
2 participants did not provide age range

Figure 2. Year of Immigration to Canada (n=16)



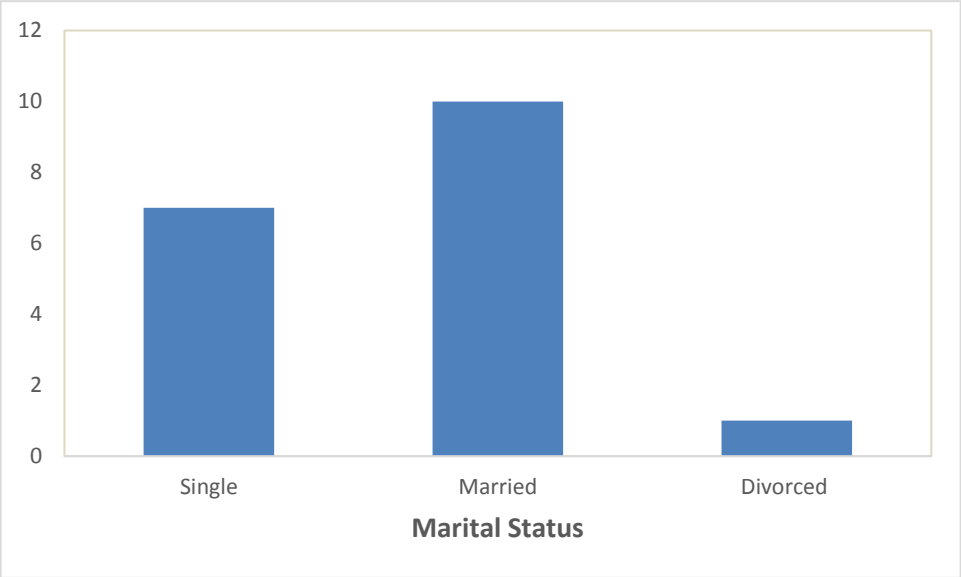
Note: 6 participants were born in Canada

Figure 3. Immigration Status of Participants (n=14)



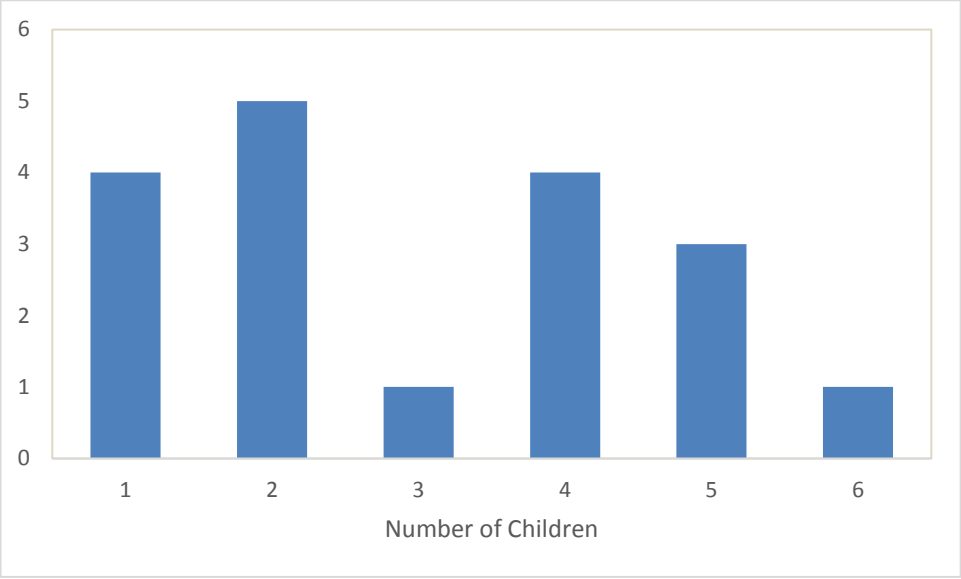
Note: 7 participants did not provide immigration status

Figure 4. Marital Status of Participants (n=18)



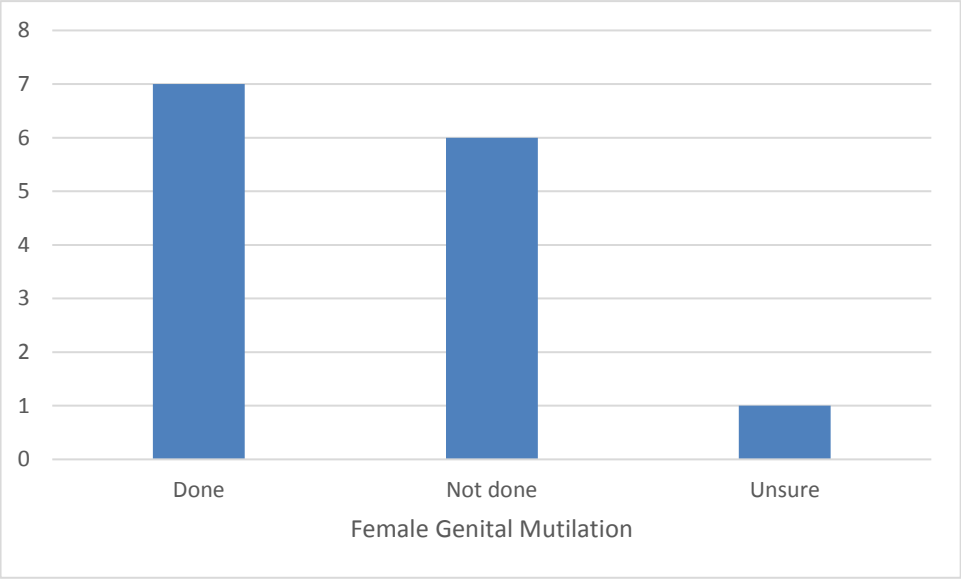
Note: 3 participants did not provide their marital status.

Figure 5. Number of Children of Participants (n=18)



Note: 3 participants did not provide number of children.

Figure 6. Female Genital Mutilation among Study Participants (N=14)



Note: 7 participants did not know say where FGM was performed on them

Community Leaders

Community leaders were all above 30 years of age and all from African communities originating from FGM practicing countries. Most of them are Canadian citizens and all have children.

Table 1. Demographics of Community Leaders

Community Leader	Age Range	Country of Origin	Year of Immigration to Canada	Immigration Status	Marital Status	Number of Biological Children
1 (Male)	45-49	South Sudan	2000	Citizen	Single	1
2 (Male)	50-54	Ghana	1986	Citizen	Married	3
3 (Male)	55-59	Nigeria	2006	Citizen	Married	5
4 (Male)	45-49	Somalia	2005	Refugee Claimant	Divorced	4
5 (Female)	60+	Somalia	1995	Citizen	Married	3
6 (Female)	55-59	Egypt	1997	Citizen	Divorced	1
7(Female)	40-44	Egypt	1995	Citizen	Married	3
8(Male)	30-34	Liberia	2006	Permanent Resident	Single	1

SERVICE PROVIDERS

Service providers were of mixed origin including Canadian born Caucasians

Service Provider	Age	Country of Origin	Year of Immigration to Canada	Immigration Status	Marital Status	Number of Biological Children
1	60+	Canada (Caucasian)	n/a	Citizen	-	1
2	40-44	Uganda	2001	Citizen	Separated	2
3	45-49	Guyana	2001	Citizen	Married	2
4	50-54	Nigeria	2011	Citizen	Married	3
5	55-59	Eritrea	2000	Refugee Claimant	Divorced	1
6	30-34	Canada (Caucasian)	n/a	Citizen	Divorced	0
7	35-39	Kenya	2006	Permanent Resident	Single	1
8	35-39	Kenya	2006	Permanent Resident	Single	1
9	55-59	Kenya	1991	Citizen	Married	4
10	45-49	Dominican Republic	2001	Citizen	Married	1
11	45-49	Dominican Republic (Caucasian)	Born in Canada	Citizen	Single	0

KEY THEMES - RESPONSES FROM WOMEN, COMMUNITY LEADERS AND SERVICE PROVIDERS

Health concerns of women

95% (20/21) of the women interviewed have experienced a form of FGM which happened between infancy and adulthood. 47% (10/21) said that FGM is a stigmatized topic and some women may be afraid to disclose it to their service providers. All women expressed concern about the harm associated with the practice saying most of the injuries are permanent and cannot be reversed, and all who could remember the experience said FGM was done at home rather than in a hospital.

All women interviewed have experienced the following:

- Severe psychological trauma resulting in mental health issues such as stress and depression
- Reproductive and urinary system complications
- Bleeding
- Shock
- Birth difficulties
- Decreased sexual satisfaction
- Painful menstruation

When women were asked whether they were satisfied with their health care providers, 66% (14/21) said they were not satisfied due to the following reasons:

- Long wait times
- Doctors not taking time to listen to their needs especially not asking about FGM
- Hard to relate with Doctors
- Providers are not educated about FGM

"Primary care family physicians need to be aware and learn how to talk to females"
"Impact of racism and other African Women issues to be known by health clinics"
*"**Un-relatable white guy- a black female would be better"***
"I feel that my doctor does not understand my health concerns because he is not an African woman"
***"**Women culture not normal, made to look barbaric so education is important"*
"Doctor should ask about it, should be asked during consultation"
"Yes, providers don't know what they are doing"

57% (12) women responded to whether they had a pap smear. 42% (5) had it in the last 3 years; one had it done more than 3 years ago while 50% (6) had never had it done because they had never heard of the test while one completely refused any invasive procedures done to her including child birth and only undergoes caesarian section. Other reasons reported by women

included: recent immigration to Canada, lack of access to the facility in their country of origin, trauma from rape by husband and being younger than the screening age (25-29 years).

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33% (7/21) responded to whether social agencies address FGM. 71% (5/7) felt it was not being addressed by local agencies. All 7 felt that addressing FGM is beneficial to providing services to women with FGM.

Community organizations

Community organizations serving African women included the following:

- Interdenominational churches providing family support as well as children counseling support in schools
- Umbrella organizations whose membership includes African organizations from different countries with a focus on more vulnerable groups such as women, youth and seniors to get access services such as affordable housing, jobs, education and health care
- Community radio stations and TV networks
- Other agencies providing services to specific communities of immigrants from Africa providing the following services:
    - Advocating for positive change such as addressing youth violence/labor community services, sports etc.
    - National as well as Ethnic language promotion, research, policies specific to ethnic groups
    - Family violence including FGM, physical and sexual abuse, forced marriage,
    - Settlement services through the Social determinants of health lens addressing;
        - Poverty
        - Food security
        - Social isolation
        - Employment
        - Housing
        - Education
        - Immigration process
        - Access to health and social services

Health care agencies

Health care agencies serving African women included the following:

- Sexual health clinics providing:
    - Medical and counseling services on sexual health, reproductive health
    - Education and information on healthy sexuality
    - Education and testing for sexually transmitted diseases including HIV/AIDS
- Agencies providing health care education particularly on prevention of sexually transmitted infections and HIV/AIDS
- Family Health Teams providing services on Family medical care- walk-in patients, one-time encounter

- Clinics providing HIV services, prevention, education and support for people living with and affected by HIV/AIDS
- Primary Health Care agencies including Community Health Centres, providing general family medicine, well-being, chronic diseases, check-ups ”Everything-heart, BP, diabetes, cholesterol, bladder and urinary infection” mental health, sickle cell anemia, among other chronic diseases, health access issues, especially for racialized populations, Health support (applying for government support)

Social and Health Care Organizations' Positions on FGM

All organizations were against FGM and felt it should be eliminated. Organizations identified the following concerns:

- **Long-term Health Complications:**
  - As the women clearly reported, living with FGM makes sexual intercourse painful for women
  - FGM increases chances of infections
  - FGM exposes women to other issues so when not done properly it causes other problems

- **Trauma**
  - FGM traumatizes women and gives them low self-esteem, and causes anxiety
  - Organizations advocate for health, right to choose, inclusion, empowering those with trauma, domestic violence and to do referrals when they cannot provide support for psychologically traumatic for women

- **Oppressive practice**
  - FGM is an oppressive practice inherent within tradition where a woman had no choice not to practice
  - FGM is a violation of Women's' and Girls' Rights

The Meaning of FGM

In response to what FGM means in various cultures most women and community leaders said it is done for cultural or religious purposes. All participants including service providers without FGM experience had good knowledge of why FGM is practiced. FGM is practiced to control female sexuality to prevent women from being sexually active or promiscuous. Women participants said it was a transition to womanhood. They also understood that FGM varies in different cultures.

> *"It was actually something most girls looked up to because it elevated their status from childhood to womanhood" "Indicates they're alive, cleansing, leading for manhood/womanhood"*

The practice is so embedded in some cultures that even though girls/women as well as parents did not like the practice it was still done.

"It is imbedded in you from the time you are circumcised; you will abstain from sexual behaviours"
"Even my parents didn't want to do it but since it was culture…"

Women were forced to go through it because they were made to believe that if they did not do it they would not get married. It slowly became a family's choice as people got more enlightened and recognized the harm associated with FGM.

Health needs of African women

Primary Healthcare Needs

Women, community leaders and service providers identified the following as major health care needs for African women:

- **Chronic diseases management**
  - Some of the women are living with above mentioned chronic conditions and illnesses such as diabetes, heart problems, mental illnesses and HIV/AIDS.
  - Women need to access treatment support while in care

- **Mental Health needs**
  - People living with trauma experience from their home countries need a lot of counseling services which agencies provide but due to stigma associated with FGM some women do not access such services
  - There are a lot of taboos on mental health so women need to overcome such barriers
- **Management of other FGM related infections and conditions**
  - Urinary tract infections transmitted sexually
  - Birth difficulties, giving birth in most cases is traumatic

"When having twins in hospital, I was on display and felt uncomfortable"
"Hard to delivery normally-pushing. I reject FGM because of the pain that one goes through when they give birth" "Many children die because the woman can't push"
"Many people bleeding while giving birth"

  - Decreased sexual satisfaction
  - Complications of FGM at the time of cutting

"Cutting, cutting a sensitive part of the body is harmful"
"If you see the way children cry, the pain is terrible"

  - Bleeding sometimes to death
  - Pain on wedding night for most women

"I didn't enjoy the intimacy of intercourse, orgasm I have never experienced them"

- Painful menstruation

"It is a painful experience when women have menstruation cycle if dealing with FGM"

- **Difficulty accessing health and social support**
  - Many women lack knowledge on how to access health and social support to fight stigma associated with FGM

Experiences of Women with FGM

Experiences reported by women, community leaders and service providers included the following:

- **Social problems and concerns**
  - Talking about FGM outside of cultural group is a problem as women and communities that practice it are viewed as barbaric
  - It is hard for women with FGM to date from other cultures

"In my generation we have been dating. For people with FGM, it is a barrier"

  - Spousal abuse

"If both a man and woman have contracted HIV the same way, the female is treated differently from the male"
"Although my husband blamed me for not satisfying him, he slept with many women before me"
"Men are asking their wives to have tight vaginas by whatever means after giving birth"

  - Lack of income
  - Language barriers
  - Precarious jobs
  - Discrimination due to "Hijab"

"Black females face Islamaphobia and Black discrimination"

  - Isolation and loneliness as a result of some older women brought here to take care of children and when their services are no longer needed are left to fend for themselves
  - Lost self-esteem, not sociable towards community

- **Stigmatization and harm associated with FGM**
  - Women feel shy to the extent of not feeling comfortable being examined by healthcare providers

    "Those who got cut hide it because they don't want people to know"
    "There is a girl who went with me in school. Every time we took showers, she would hide and hesitate"

  - FGM is not discussed openly. It is a private matter not to be discussed because women are ashamed

    "They don't want to be known as victims" "Do not identify themselves"

  - Relationship stigmatization
  - Although some organizations have a policy of inclusion, they do not include FGM in subjects addressed openly

- **Domestic Violence**
  The following are forms of domestic violence that women with FGM are exposed to:
  - Family violence is experienced by many women with FGM but they do not have a forum to address it.
  - Forced marriage
  - Sexual assault
  - Infidelity by husbands
  - Divorce

Law on FGM in Canada

Most respondents were aware that FGM is recognized as a violation of Human Rights in Canada. All women respondents felt the law is appropriate while many wished the laws could be expanded to other countries.

FGM is a violation of Human Rights

Women now know that FGM is a violation of their Human Rights and they support the law.

"No one's Human Rights should be violated, people should have choices not imposed to practice" "I think the law is a step in allowing women to be able to have rights to protect themselves and participate in the process of making choices about their sexuality."

However, women felt that the law is not open to Canadians and people can take advantage and continue to practice FGM secretly.

"The law is good, but it is hidden"
"It is hard because many people may still do it at home and not go to the hospital"
"It needs to come out in education and public health"

As much as women condemned FGM there are still a few people in the community who believe in practicing it on the argument that Canada is a multicultural country and FGM should be allowed the same way male circumcision is allowed.

Unfortunately some service providers including some Doctors have only limited knowledge and understanding of the law.

Some community members and service providers may feel the law is interfering with cultural practices and find ways of circumventing the law thus putting more girls and women at risk of FGM and the harm associated with the practice

Reinforcing the Law

Women felt that the law should be reinforced more in Canada and internationally. Some African countries are taking action in stopping FGM among them Kenya, Somalia, Egypt and Liberia.

"I think Canada should work with the UN to make it an international law especially in 3rd world countries, especially Africa"
"That is excellent very good should be intended to other countries that do this to children so they can change"

TESTIMONIALS

The following are testimonials reported verbatim

Testimonial I

"I was only six years old when my aunt and another female family relative performed the practice that we now call FGM on me. I was living at the time in my homeland, thinking it was a necessary action that my parents imposed on from both a religious and cultural standpoint. To be honest, I was so young during the incident that I didn't make anything of it until my early teens when I started taking health class in grade 7 and 8. I was also unaware of the trauma that was going to follow me well into my early adulthood.

It was a painful experience for me to endure of the physical act being that I was young and had no choice but to tolerate what was happening. I'm also left with a permanent scar that I have to bear. Growing up in my pre-teen years and adjusting to my growing body, I always felt different about my body and never felt feminine. I was curious about my physical appearance more than the health issues I faced. I was also looking to understand what being a "woman" meant, what kinds of things I needed such as personal hygiene products, really interested in what my anatomy is as a female, looking at images to compare myself with the standard of today's media, etc. Looking back at this personal quest to discover who I was as woman, the physical and emotional impact of this practice, I was always feeling embarrassed and timid to seek help when I had questions relating to my health. Not to mention the anxiety and emotional distress I had about potential romantic partners in my life who I feared would leave me or stigmatize my experience. It's no wonder that I lacked confidence in my need for intimacy because it was always in the back of my mind as much as I tried to deny it ever happened to me. I still hate the way I became duped to believing this was a normal practice, even resenting my family for allowing this to happen to me at a young age. It's difficult to accept the outcome when it was never my decision and to figure out my unique situation growing up in Canada with my peers who never experienced this situation. I was left confused and ashamed about my health and physical body appearance, traumatized from the whole ordeal in general. I began asking questions to my sisters and close friends in an attempt to understand what this practice meant for me as a woman in Canadian society.

Most of my ethnic community in Toronto didn't publicly talk about this practice for reasons I personally challenged. The hardest part of growing up in my community was the total denial and scrutiny that I was caught in the middle of, lacking support within women whose culture wasn't open to sharing their experiences and advocating for others to stop it made it hard for me to find avenues of healing and closure for myself. I still face this challenge today of figuring things out on my own to get to a place of feeling optimistic that this practice will be stopped and labeled for what it is; brutally inhumane and barbaric. I hope and encourage my family and community to learn from the past, share all the voices from women who are affected in some way, and to stop accepting the ignorance of those who continue such a practice while inflicting others. I hate with a passion the many people in my extended family as well as community who don't express remorse for the mistakes that they've made in the past. It's difficult to get people to support me when I talk to parents and young girls in my community

about the practice because it seems like to them that I'm trying to move away from our tradition even though it's the opposition. My approach was to keep talking about this issue to help others heal and find peer support. I wish I had more people in my community to discuss this deplorable practice by making it easier to support women instead of shunning them or denying their voices to be heard."

Testimonial II

"Personal story related to Female Gentile Mutilation

My younger sister and I were circumcised around the age of about 4 or 5. A strange and unforgettable older woman executed the ritual of cutting the visible tip of the clitoris and clitoral hood in true cultural orthodoxy.

I hold on to the vivid memory of myself playing happily outside with my siblings until I was called to come inside the house. This peculiar older lady who stayed inside our house for a while carried out the procedure. She opened my two legs apart (maybe pinning me down) and circumcised me with a blade. I don't recall how the procedure went for my sister but I found out she was bleeding heavily.

Looking back, I definitely would imagine I underwent intense physical pain going through this horrible procedure without any anaesthesia. I don't want any girl to go through this cutting but as a grown woman, I do not resent my parents for allowing me to be circumcised, as it was in "good" reason.

My parents openly communicated with me regarding the issue. As a little girl, I asked them why they decided that both girls (my sister and I) should go through this process. They told me that they tried to postpone and even to avoid this cultural ritual. However, the cultural pressure was immense and I later found out that they were afraid of future social exclusion-afraid that their girls would not be able to marry. They tried their best during that time and the cultural context of their environment by taking the precautions they could. My parents waited until our little bodies had grown to avoid infant circumcision which was the most common one, they ensured the woman used a disinfected and sterilized blade, and finally they used antibiotics and ointments to avoid infections and so that the wound would heal fast. Unfortunately for many young girls, these were privileges they did not have access to.

Later in life, my parents knew better and didn't allow my youngest female sibling to go through FGM although my brothers were circumcised by health professionals. Emotionally I am fine. However, I am a healthy mother who advocates stopping FGM practiced on girls anywhere in the world by educating the public, not by condemning them. My experience with FGM exemplifies that we are the fabric of our time and culture but we can always wash our cloth of its stains."

RECOMMENDATIONS: HEALTH CARE FOR AFRICAN WOMEN

The following recommendations were drawn from suggestions and views of participants:

- **More health information/ education for everybody**
  - There is an urgent need to stand up against FGM in all communities. Community leaders, service providers and policy makers need to advocate education in order to bring about positive change
  - More education on priority social determinants of health is needed in African communities
  - Agencies need to make services accessible to African and other vulnerable women by having information where women can find it
  - Educational workshops on physiology and anatomy of the reproductive system
  - There should be visual signage at agencies in support for Women's Rights on FGM

- **Training of service providers in cultural competence:**
  - Main stream service providers particularly those in Health care need to be culturally sensitive, respectful, nonjudgmental and inclusive when providing services to the populations they serve
  - Primary care physicians need to be:
    - More sensitive to the needs of African women living with FGM
    - Understanding of the psychological trauma of women living with FGM
    - Prepared to learn how to care for women with FGM to relate better with the women
  - All service providers need to be empathetic towards women living with FGM
  - There is a need for a presence of more African Doctors attending to African women for those living with FGM to be more comfortable as such Doctors will relate better with African culture

- **Anti-racism anti-discrimination and anti-oppression policies**
  - There is a need to address racism and other oppressive practices by service providers
  - Agencies must have anti-racism, anti-discrimination anti-oppression policies in place and practice them so that survivors of FGM and other vulnerable clients are not discriminated against so they can feel empowered
  - Agencies must be inclusive and treat all clients equally so that African women can feel welcome and comfortable while receiving services

- **Fighting Stigma**
  - Although some organizations have a policy of inclusion, they do not include FGM in subjects addressed openly.
  - Such organizations must include FGM in their programs with procedures to de stigmatize FGM
  - FGM should be discussed as part of other topics and not as a standalone topic.

- Cultural competency is key while providing seervices. Sometimes when issues that affect marginalized populations are discussed in public and through the media they are derogatory in nature fueling further stigmatization

- **Reinforcement of the law against FGM**
  - Proactive steps should be taken to enforce the law against FGM
  - Public education should be given to everybody on the law especially for families from countries where FGM is practiced.

- **Education on nutrition and other health needs**
  - African women information on healthy lifestyles: better nutrition, exercise as well as accessing health and social services
  - This will improve care for those living with other diseases such as diabetes and HIV/AIDS
  - There is a need for other service providers to work closely with African health care providers to reach vulnerable women through home visits (mobile clinics) for women who may not be accessing services due to stigma associate with FGM

- **Consistent and adequate funding for agencies serving African people**
  - Agencies need consistent funding to adequately address unique needs of African women
  - When funding is cut service users are forced to change providers and some may be discouraged to seek new providers
  - With limited funding only limited needs are met and many African women are left with same health issues for too long

- **Community support**
  - There is need for continued community support systems for African women that fosters opportunities to talk and socialize about cultural issues
  - Women need safe places to discuss family violence and abuse

DISCUSSION

The results of this study clearly indicated that there are African women in Toronto with Female Genital Mutilation (FGM) experience who have serious health concerns that need to be addressed by health care providers and other service providers. Women living with FGM experience need community support to help them cope with some of the physical and psychological trauma. The objectives of the study included a dissemination plan that will help increase public awareness and education on the subject of FGM. All participants stressed the need for education of women, community leaders and service providers, particularly primary health care providers to better understand the impact of FGM on women and how to better treat survivors of FGM.

This pilot study is the first in Canada to include women from more than ten African countries. Previous studies have reported experiences of women from the Somali community mostly (Einstein, 2012). This study has revealed that although the reasons for FGM which were reported as cultural and religious may be similar, the significance of the practice as well as the extent of FGM is different in different cultures hence different experiences among the women. Studies have revealed that women with FGM from sub-Saharan Africa have experienced various challenges including both physical and psychological trauma in the countries they migrated to due to the stigma associated with FGM (Perron, L., et al 2013). The women in this study confirmed the shame they experienced in their home countries and continue to experience in Canada when they feel different from other women who did not experience FGM. This is a manifestation of the stigma associated with FGM which prevents most women from seeking the health care they need especially reproductive health care. Other studies have shown similar trends where women have reported not seeking health care because FGM is a taboo subject and would not like to discuss it publicly (Huston, P. 2012, Berg et. al. 2010).

Women were concerned about the way they have been treated by some health care providers who were insensitive to their needs. Such women may shy away or opt not to be examined by Doctors. Some opt to have Caesarean operation instead of giving birth naturally (Perron, et al 2013). The issue of distrust of the health-care system has been reported in the USA among the Somali community (Johnson-Agbakwu et al, 2014). Lack of knowledge and understanding as well as incompetence on the part of service providers was a concern of many of the women participants. Other women preferred to be examined by female physicians instead of male physicians. Women would be most comfortable with African female doctors who may be familiar with most African cultures. Other concerns that are major social determinants of health (SDOH) women have to deal with included financial difficulties, language and cultural shock as immigrants in Canada.

On the legal front, all women were in favour of the law in Canada banning FGM. They all agreed there is a need for the public to understand the law and practice it. More importantly there is the need to understand the legal implications of the duty to report so that those who may still be ignorant of the harm associated with FGM may realize the legal consequences of supporting the practice. Some of the community leaders and service providers including some Doctors did not have the full knowledge and understanding of the law in Canada while some were not aware of

the law. Consequently, some community members and service providers may feel the law is interfering with cultural practices and find ways of circumventing the law thus putting more girls and women at risk of FGM and the harm associated with the practice. FGM practice is a violation of Human Rights and all women survivors of FGM have a right to reproductive care that would help them recover from some of the trauma the women experience (Abdulcadira, J. et al. (2011).

This research has therefore yielded recommendations that include public education and awareness on FGM for everybody in Canada, training in cultural competence for service providers and adequate and consistent funding for agencies serving African and other ethnic populations to be able to sustain programs on health promotion, education and awareness of SDOH as well as legislation on pertinent issues such as FGM in Canada. Education for families from countries where FGM is practiced has been suggested by other researchers ((Perron, et al 2013) especially for girls and women to know if they had FGM prior to immigrating to Canada (Jordan, L. 2012). This would enable service providers to refer women with FGM experience to other appropriate services. The results and outcomes of knowledge collected through this study will contribute to the growing literature that may, in time, benefit the African FGM women who shared their experiences. It is believed that recommendations from this study will inform policy on FGM in Canada.

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APPENDICES

APPENDIX I: LETTER OF INTRODUCTION

Uzima Women Relief Group International

Giving a new meaning of Life, hope and bright future to all women

Dear Community partners,

Re:Investigating Experiences And Health Concerns Of Female Genital Mutilation Among African Women In Toronto:Letter Of Information To Agencies

Uzima Women Relief Group International would like to request your participation as a community partner in a research project to investigate health concerns of African women in Toronto with or without lived experiences of Female Genital Mutilation (FGM) and how their health can be improved through education. The goal of the study is to explore FGM among African women in Toronto to understand the extend of the issue and what health concerns and issues the women may be experiencing such as barriers to accessing the reproductive health care they need.

The objectives include learning about the experiences and health concerns of these women and creating awareness about the health risks among cultural communities and through various media to the wider Canadian society. Understanding the sexual and reproductive needs of this population will lead to reduced stigma through sensitized culturally appropriate information sharing. It is anticipated that this project will generate recommendations that will help improve the health of women in the participating communities as well the wider Canadian society. The research is guided by this overall research question: ***What are the experiences and health concerns associated with female genital mutilation among African women in Toronto?***

Uzima aims to improve the health outcomes for this group of women through exploring the needs of the women using focus groups and key informant interviews as well as testimonials to understand the factors affecting this population of women. Participants will be women with/without lived experience, community leaders and service providers. By generating new knowledge, service providers, educators and the wider community will have an increased understanding of ways to more effectively support this group of women. Participants will be recruited from the following countries: Benin, Burkina Faso, Cameroon, Central African Republic, Chad, Côte d'Ivoire, Democratic Republic of Congo, Djibouti, Egypt, Ethiopia, Eritrea, Gambia, Ghana, Guinea, Guinea Bissau Kenya, Liberia, Mali, Mauritania, Niger, Nigeria, Senegal, Sierra Leon, Somalia, Sudan Tanzania, Togo, Uganda, Zambia A

A Community Advisory Committee (CAC) of 10 members will be formed to ensure a community based participation. As a service provider agency/community leader, we will request you to complete a survey about your organizational capacity to serve women from communities where FGM is practiced particularly those living with FGM experience as well as barriers you experience. Your clients will complete a client survey that will provide us with information about barriers that limit their access to services you provide. Additionally, focus group consultations will be conducted with your clients to gather information that may not be captured in the surveys. We therefore request you to help us in the recruitment of participants in this study using the attached flyer and information in this letter. Please do this during your routine service provision and ensure that clients do not in any way feel that they are being coerced into participation in the study. Participation in this study is voluntary and clients should be aware of that. This is further emphasized in the consent forms that participants will sign prior to participation. Consent forms contain substantive information on the risks and benefits of the study. Participants will read and understand the consent form before agreeing to participate in the study. With your support, it is believed that the information from this project will help guide organizational systems, processes and practices to serve people from communities where FGM is practiced. Attached, please find a flyer that you can use to inform your clients about this project. Below please also find a statement of ethics approval from the Community Research Ethic Board (CREO) as proof that this project has been cleared to conduct research on humans: For more information and to participate, please contact Jacobet Edith Wambayi, Principal Researcher by phone at 416 297 6826, or email at edithatieno5@yahoo.com

"This research project has been reviewed and approved by the Community Research Ethics Board. If you feel you have not been treated according to the descriptions in the information you received, or your rights as a participant in research have been violated during the course of this project, you may contact the Chair, Community Research Ethics Office (Canada) Corp. c/o Centre for Community Based Research, 190 Westmount Road North, Waterloo ON N2L 3G5. Email: creo@communitybasedresearch.ca

Yours sincerely,
Jacobet Edith Wambayi, PhD
Executive Director and Principal Researcher

WCHH
WOMEN'S COLLEGE HOSPITAL
Health care for women | REVOLUTIONIZED

APPENDIX II: FLYER

Uzima Women Relief Group International
Giving a new meaning of Life, hope and bright future to all women

UZIMA WOMEN RELIF GROUP INTERNATIONAL INVITES WOMEN FROM

Benin, Burkina Faso, Cameroon ,Central African Republic, Chad, Côte d'Ivoire, Democratic Republic of Congo, Djibouti, Egypt, Ethiopia, Eritrea, Gambia, Ghana, Guinea, Guinea Bissau Kenya, Liberia, Mali, Mauritania, Niger, Nigeria, Senegal, Sierra Leon, Somalia, Sudan Tanzania, Togo, Uganda, Zambia

TO PARTICIPATE IN A STUDY TO LOOK INTO THEIR HEALTH AND WELL BEING

Topics for discussion will include:
Health and social concerns for the female genital mutilation
(Commonly known as cutting or circumcision)
Barriers that limit access to health services
Suggestions about health care for African Women

Age: 16 Years and older

You can choose to participate in focus groups, key informant interviews or testimonials

The opportunity to participate is voluntary and the agency from which you receive services will not be told whether or not you decide to participate.

"This research project has been reviewed and approved by the Community Research Ethics Board. If you feel you have not been treated according to the descriptions in the information you received, or your rights as a participant in research have been violated during the course of this project, you may contact the Chair, Community Research Ethics Office (Canada) Corp. c/o Centre for Community Based Research, 190 Westmount Road North, Waterloo ON N2L 3G5. Email: creo@communitybasedresearch.ca."

All interviews will be conducted in the months of July and August. You will receive $20 for your participation as well as 2 TTC tokens. For more information and to participate, please contact Dr. Jacobet Edith Wambayi at 416 297 6826, info@uzimawomeninternational.org/

This study is Funded by:

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APPENDIX III: CONSENT FORM - WOMEN

Uzima Women Relief Group International

Giving a new meaning of Life, hope and bright future to all women

Title: Investigating Experiences and Health Concerns of Female Genital Mutilation among African Women in Toronto

Sponsor: Women's Xchange, Women's College Research Institute

Agency: *Uzima*Women Relief Group International

Research team:

Jacobet Edith Wambayi, PhD -Principal Investigator, Gillian Einstein, PhD, Ebby Madera, PhD Fatuma Swaleh, Falastin H. Yassin, Esther Simon, Jennifer Muyia

Community Advisory Committee (CAC): The CAC is comprised of members of the community, service providers and community leaders. The role of the CAC is to provide general advice and guidance to the research team as well as the overall research process. This includes reviewing of all research documents' content for ethics and cultural appropriateness. The CAC members will not have access to research data.

This consent form is designed to help you understand the research project so you can decide to participate in it voluntarily. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about anything mentioned here or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will keep the original copy of this form. The facilitator will keep a copy.

What Is The Purpose Of The Study? The aim of the study is to investigate health concerns of African women in Toronto with or without lived experiences of Female Genital Mutilation (FGM) and how their health can be improved through education. The goal of the study is to explore FGM among African women in Toronto to understand the extend of the issue and what health concerns and issues the women may be experiencing such as barriers to accessing the reproductive health care they need.

The objectives of the study include learning about the experiences and health concerns of these women and creating awareness about the health risks among cultural communities and through various media to the wider Canadian society. Understanding the sexual and reproductive needs of this population will lead to reduced stigma through sensitized

culturally appropriate information sharing. It is anticipated that this project will generate recommendations that will help improve the health of women in the participating communities as well as the wider Canadian society. The research is guided by this overall research question: ***What are the experiences and health concerns associated with female genital mutilation among African women in Toronto?***

What Would I Have To Do? Women who are immigrants from Africa are being requested to participate in focus group interview, an individual interview, or to provide a testimonial of their experiences with FGM. If you decide to participate in this study, the focus group conversations and testimonials will be audio recorded digitally as well as recorded by hand to ensure data accuracy. The focus groups recordings will be transcribed verbatim by a member of the research team. If the researcher is not available, a member from the research team will facilitate the session. All personal information will be removed.

What Are The Potential Risks? Participating in this study will require about 1- 2 hours of your time. It is up to you the participant to choose whether to participate in the focus group, interview or give a testimonial if you have FGM experience. The interviews will be conducted at a venue where you will be protected from family members, friends and agency staff who will not be part of the research project. You will be reimbursed two TTC tokens for your travel.Some questions may make you feel uncomfortable. If you are upset by the questions asked, you are free to stop. You can also skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be breached. Focus group facilitators will emphasize the request that participants not discuss information shared in the group outside of the group but that cannot be guaranteed.

In the event of your withdrawal from the study, the information obtained from you at that point will be used for the study as it is impossible to remove individual contributions from group data.To protect your confidentiality, the information gathered at the interview will be kept on a numbered form that does not have your name or other identifying information. The Researchers and Research Assistants who will transcribe the tapes from the focus groups will remove all identifying information from the transcriptions before the data is passed on to researchers for data analysis, and the tapes themselves will be destroyed after they have been transcribed. As well, all written notes, transcripts, testimonials will be will be kept in a secure research office, and only authorized research staff will have access to the information. All electronic information will be password protected while hard copies will be kept in locked cabinets. Confidentiality will be respected by the research team, and no information that discloses your identity will be released or published without consent, unless required by law. Direct quotes will not be tied to any other information (such as country of origin) that might lead to identification of an individual participant. All data will be destroyed after a period of 3 years.

Will I Benefit If I Take Part? You will be given an honorarium of $20 for your participation. You will also receive travel tokens for TTC to and from the focus group venue. It will be beneficial to participate as you will share your experiences with other participants and make

suggestions to improve your health and that of others. We will have other supports to which we will be able to refer participants if needed such as Counselors at community health centres. TAIBU CHC is one of the partners in this study who will also include FGM in their health promotion and support programs after the project ends. We have access to other agencies that can offer similar support.

Do I Have To Participate? Participation in this study is voluntary. It is your choice to take part in this research process. You can stop at any time and you may choose to withdraw from the focus group, individual interview or testimonial at any time. Any decision to not participate in this research project or to withdraw will have no effect on your privileges at your health and social services agencies. You are under no obligation to participate in this study. If you wish to stop participating please inform the facilitator immediately. Also, we would like to know if you will be comfortable for us to use direct quotation to qualify some of the responses. Again if you are not comfortable with this we will not use direct quotation from your responses. The research team led by Jacobet Edith Wambayi and *Uzima* is still responsible, legally and professionally, for what they do. Please sign below if you agree that we can use direct quotation.

Will The Results Be Published? In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or information that could identify you will be released. The results from this study may be used in future research, for training and health promotion purposes and will be published but your rights will be protected in the future as they are now.

I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study.

Contact Information: If you have further questions, concerning matters related to this research, please contact the Principal Researcher Jacobet Edith Wambayi at 416 297 6826

'I agree to the use of direct quotations that have had any identifying information of myself or others removed.'

Yes……..

No……

I will be given a signed copy of this consent form.

X_____ _____ _____

Signature of Participant/Parent/Guardian Name (printed) Date

_____ _____ _____

Signature of Interviewer/Principal explaining Research Name (printed) Investigator Date

"This research project has been reviewed and approved by the Community Research Ethics Board. If you feel you have not been treated according to the descriptions in the information you received, or your rights as a participant in research have been violated during the course of this project, you may contact the Chair, Community Research Ethics Office (Canada) Corp.

c/o Centre for Community Based Research, 190 Westmount Road North, Waterloo ON N2L 3G5. Email: creo@communitybasedresearch.ca."

This study was funded by:

APPENDIX IV: CONSENT FORM - COMMUNITY LEADERS AND SERVICE PROVIDERS

Uzima Women Relief Group International

Giving a new meaning of Life, hope and bright future to all women

Title: Investigating Experiences and Health Concerns of Female Genital Mutilation among African Women in Toronto

Sponsor: Women's Xchange, Women's College Research Institute

Agency: *Uzima* Women Relief Group International

Research team:

Jacobet Edith Wambayi, PhD -Principal Investigator, Gillian Einstein, PhD, Ebby Madera, PhD Fatuma Swaleh, Falastin H. Yassin, Esther Simon, Jennifer Muyia

Community Advisory Committee (CAC): The CAC is comprised of members of the community, service providers and community leaders. The role of the CAC is to provide general advice and guidance to the research team as well as the overall research process. This includes reviewing of all research documents' content for ethics and cultural appropriateness. The CAC members wil not have access to research data.

This consent form is designed to help you understand the research project so you can decide to participate in it voluntarily. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more details about anything mentioned here or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will keep the original copy of this form. The facilitator will keep a copy.

What Is The Purpose Of The Study? The aim of the study is to investigate health concerns of African women in Toronto with or without lived experiences of Female Genital Mutilation (FGM) and how their health can be improved through education. The goal of the study is to explore FGM among African women in Toronto to understand the extend of the issue and what health concerns and issues the women may be experiencing such as barriers to accessing the reproductive health care they need.

The objectives of the study include learning about the experiences and health concerns of these women and creating awareness about the health risks among cultural communities and through various media to the wider Canadian society. Understanding the sexual and reproductive needs of this population will lead to reduced stigma through sensitized

culturally appropriate information sharing. It is anticipated that this project will generate recommendations that will help improve the health of women in the participating communities as well as the wider Canadian society. The research is guided by this overall research question: ***What are the experiences and health concerns associated with female genital mutilation among African women in Toronto?***

What Would I Have To Do? As a community leader, we will request you to complete a survey about your organizational capacity to serve women from communities where FGM is practiced particularly those living with FGM experience as well as barriers they experience. If the researcher is not available, a member from the research team will facilitate the session. All personal information will be removed.

What Are The Potential Risks? Participating in this study will require about 1- 2 hours of your time. The interviews will be conducted at a venue where you will be protected from family members, friends and group/agency staff who will not be part of the research project. You will be reimbursed two TTC tokens for your travel if you are not a paid employee. Some questions may make you feel uncomfortable. If you are upset by the questions asked, you are free to stop. You can also skip any question you don't want to answer. There is potential risk to you if the confidentiality of the information you give us were to be breached.

In the event of your withdrawal from the study, the information obtained from you at that point will still be used for the study. To protect your confidentiality, the information gathered at the interview will be kept on a numbered form that does not have your name or other identifying information. The Researchers and Research Assistants will remove all identifying information from the data before it is passed on to researchers for data analysis. Only authorized research staff will have access to the information. All electronic information will be password protected while hard copies will be kept in locked cabinets. Confidentiality will be respected by the research team, and no information that discloses your identity will be released or published without consent, unless required by law. Direct quotes will not be tied to any other information (such as country of origin) that might lead to identification of an individual participant. All data will be destroyed after a period of 3 years.

Will I Benefit If I Take Part? You will be given an honorarium of $20 as well as TTC tokens for your participation if you are not a paid staff. It will be beneficial to participate as you will share your experiences and make suggestions to improve the health of members of your community. We will have other supports to which we will be able to refer participants if needed such as Counselors at community health centres. TAIBU CHC is one of the partners in this study who will also include FGM in their health promotion and support programs after the project ends. We have access to other agencies that can offer similar support.

Do I Have To Participate? Participation in this study is voluntary. It is your choice to take part in this research process. You can stop at any time and you may choose to withdraw from the interview at any time. Any decision to not participate in this research project or to withdraw will

have no effect on your privileges at your organization. You are under no obligation to participate in this study. If you wish to stop participating please inform the facilitator immediately. Also, we would like to know if you will be comfortable for us to use direct quotation to qualify some of the responses. Again if you are not comfortable with this we will not use direct quotation from your responses. The research team led by Jacobet Edith Wambayi and *Uzima* is still responsible, legally and professionally, for what they do. Please sign below if you agree that we can use direct quotation.

Will The Results Be Published? In the event that the results of this study are published or presented at conferences, seminars or other public forums, no individual information or information that could identify you will be released. The results from this study may be used in future research, for training and health promotion purposes and will be published but your rights will be protected in the future as they are now.

I acknowledge that the research study described above has been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of my right to choose to not participate in the study. As well, the potential risks, harms and discomforts have been explained to me and I also understand the benefits of participating in the research study. I understand that I have not waived my legal rights nor released the investigators, sponsors, or involved institutions from their legal and professional duties. I know that I may ask now or in the future any questions I have about the study or the research procedures. I have been assured that records relating to me will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission unless required by law. I have been given sufficient time to read and understand the above information.

By signing this consent, I agree to participate in this study.

Contact Information: If you have further questions, concerning matters related to this research, please contact the Principal Researcher Jacobet Edith Wambayi at 416 297 6826

'I agree to the use of direct quotations that have had any identifying information of myself or others removed.'

Yes……..

No……

I will be given a signed copy of this consent form.

X_____	_____	_____
Signature of Participant/Parent/Guardian	Name (printed)	Date
_____	_____	_____
Signature of Interviewer/Principal explaining Research	Name (printed) Investigator	Date

"This research project has been reviewed and approved by the Community Research Ethics Board. If you feel you have not been treated according to the descriptions in the information you received, or your rights as a participant in research have been violated during the course of this project, you may contact the Chair, Community Research Ethics Office (Canada) Corp.

c/o Centre for Community Based Research, 190 Westmount Road North, Waterloo ON N2L 3G5. Email: creo@communitybasedresearch.ca."

This study was funded by:

APPENDIX: V: KEY INFORMANT QUESTIONS – WOMEN

Investigating Experiences and Health Concerns of Female Genital Mutilation among African Women in Toronto

We appreciate your participation in this research. Please answer these demographic questions so that we can describe, as a group, the participants in this study

Interview Questions – Women participants

PART A: Demographics

Please circle the answer to the following questions. Do not put your name on this form

Q1. Age group: 15-20, 21-25, 26-30, 31-35, 36-40, 41-45, 46-50, 51-55, 56-60, 60+

Q2. Country of origin:

1) Benin

2) Burkina Faso

3) Cameroon

4) Central African Republic

5) Chad

6) Côte d'Ivoire

7) Democratic Republic of Congo

8) Djibouti

9) Egypt

10) Ethiopia

11) Eritrea

12) Gambia

13) Ghana

14) Guinea

15) Guinea Bisau

16) Kenya

17) Liberia

18) Mali

19) Mauritania

20) Niger

21) Nigeria

22) Senegal

23) Siera Leon

24) Somalia

25) Sudan

26) Tanzania

27) Togo

28) Uganda

29) Zambia

Q3. What year did you immigrate to Canada:

1990

Q4. What is your immigration status: Citizen, Permanent Resident, Refugee claimant, Refugee, Other (please explain)……..

Q5. What is your marital status: Single, Married, Common law

Q6. Number of children: How many children (biological) do you have?
5

What does Female Genital Mutilation/Cutting/Circumcision mean in your culture?
It means removing a part of the female sexual genital. Understood for men to have more power and control o women

Do you know if you had it done to you?

Yes I wasn't done to me

In hospital

No

Please explain why you had it or did not have it
Not spread in my country

What are your main health concerns whether you had FGM or not?

Mostly about diabetes and HB pressure

PART B

PARTICIPANT SURVEY QUESTIONS

1. **Since you arrived in Canada have you experienced or do you experience difficulties in finding health care and/or any other services? Yes No**
   If yes which difficulties?

2. **How do you determine when you need to go to the Doctor?**

3. When you have appointments b) When you are in pain c) When your children are sick d) Other reasons All of the Above

4. **Do you feel your health needs are met whether you had FGM or not?**

Yes
Why?
No
Why?

4**. What gender is your regular family doctor/Nurse practitioner?**
A Male
B Female
C I don't have one
Please tell us why…….

5. **When was your last pap test?**
A Less than 3 years ago
B More than 3 years ago
C I don't know
D I have never had it done
Please tell us why……

6. **Are you satisfied with the care you receive?**

   Yes
   Why?

   No
   Why?

7. **What type of social problems do you experience whether you had FGM or not?**

8. **According to you does FGM cause any harm?**

Yes
Why?

No
Why?

9. What does your community think about the harm associated with the practice?

a. Do you think women exposed to FGM are stigmatized?

Yes

Why?
No

Why?

b. Have you experienced spousal and/or other relationship stigmatization

Yes

How?
No

c. What other social problems do you and members of your community experience?

d. **If you are a parent can you tell us when FGM ceased in your community and with what generation?**

If you are not a parent go to the next question

10. Have you or anyone you know experienced stigma, denial and shame associated with FGM because you/they come from a country where FGM is practiced?

A Yes

B No

11. Do you think women exposed to FGM are stigmatized (Yes to #9)?

Yes
what can be done about it?

No

Do you think your local agencies are addressing FGM when providing services?

Yes

Why?

No
Why?

12. Is addressing FGM a way of providing services effectively to those with FGM?

Yes
Why?

No
Why?

13. **What bothers you about FGM whether you had it or not**
e.g about your country

14. Are social agencies addressing issues that women with FGM have?

Yes
Why?

No
Why?

16. In Canada FGM is recognized as a violation of Human Rights and is a criminal offence punishable by law. It is aggravated assault under the Criminal Code. – *(Interviewer to explain the law and consequences but also to state clearly that the information is for the study only and not to be used against them. Anyone having experienced FGM prior to coming to Canada is not subject to prosecution under Canadian law).*

a) Are you aware of this?

a. Yes

b. No

b) What do you think about the law in Canada?
Please explain

……

……

17. **What suggestions do you have about health care for African women**?

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Thank you for your participation

This study was funded by:

APPENDIX: VI: KEY INFORMANT QUESTIONS – COMMUNITY LEADERS AND SERVICE PROVIDERS

Investigating Experiences and Health Concerns of Female Genital Mutilation among African Women in Toronto

We appreciate your participation in this research. Please answer these demographic questions so that we can describe, as a group, the participants in this study

Interview Questions – Community Leaders

PART A: Demographics

Please circle the answer to the following questions. <u>Do not put your name on this form</u>

Q1. Age group

a) 15-19 b) 20-24 c) 25-29 d) 30-34 e) 35-39 f) 40-44 g) 45-49 h) 50-54 i) 55-59 j) 60+

Q2. Country of origin

1) Benin

2) Burkina Faso

3) Cameroon

4) Central African Republic

5) Chad

6) Côte d'Ivoire

7) Democratic Republic of Congo

8) Djibouti

9) Egypt

10) Ethiopia

11) Eritrea

12) Gambia

13) Ghana

14) Guinea

15) Guinea Bisau

16) Kenya

17) Liberia

18) Mali

19) Mauritania

20) Niger

21) Nigeria

22) Senegal

23) Siera Leon

24) Somalia

25) Sudan

26) Tanzania

27) Togo

28) Uganda

29) Zambia

Q3. What year did you immigrate to Canada

Q4. What is your immigration status?

a) Citizen

b) Permanent resident

c) Refugee claimant

d) Refugee

e) Other, (please explain)……..

Q5. What is your marital status

a) Single,

b) Married,

c) Common law

d) Divorced

e) Separated

f) Widowed

g) Other Please specify……..

Q6. Number of children: How many children of your own (biological) do you have?

Q7.What does Female Genital Mutilation/Cutting/Circumcision mean in your culture?

Female participants

Q8. Do you know if you had it done to you?

a) Yes:

b) No:

If no please go to question 11

Q9. **Where was it done to you?**

i) In hospital

ii) Other

Please specify

Q10. Please explain why it was done to you

Please go to Q12

Q11. Please explain why it was not done to you

YOUR GROUP/ORGANIZATION

Q12. Please tell us about your organization/group……
……..

Q13. What issues does your organization address?.....
.....**Q14**. What health needs do African women in your organization have?.....

Q15. What does your organization think about the harm associated with FGM?

----------a). Do you think women exposed to FGM in your organization/group are stigmatized?

……
……

b). Have women in your organization/group experienced spousal and/or other relationship stigmatization due to FGM?

.....

c). What other social problems have your members experienced?
.....

Q16. In Canada FGM is recognized as a violation of Human Rights and is a criminal offence punishable by law. It is aggravated assault under the Criminal Code. – *(Interviewer to explain the law and consequences but also to state clearly that the information is for the study only and not to be used against them. Anyone having experienced FGM prior to coming to Canada is not subject to prosecution under Canadian law)*

c) Are you aware of this?
   a. Yes
   b. No

d) What do you think about the law in Canada?
   Please explain……

Q17. What suggestions do you have about health care for African women?

"This research project has been reviewed and approved by the Community Research Ethics Board. If you feel you have not been treated according to the descriptions in the information you received, or your rights as a participant in research have been violated during the course of this project, you may contact the Chair, Community Research Ethics Office (Canada) Corp. c/o Centre for Community Based Research, 190 Westmount Road North, Waterloo ON N2L 3G5. Email: creo@communitybasedresearch.ca."

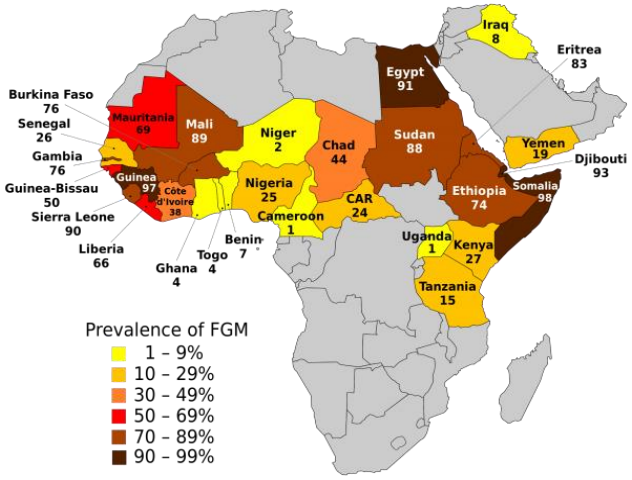
Thank you for your participation

This study was funded by:

WCHH
WOMEN'S COLLEGE HOSPITAL
Health care for women | REVOLUTIONIZED

APPENDIX: IX: FACT SHEET

THINGS YOU SHOULD KNOW ABOUT FEMALE GENITAL MUTILATION



http://fgm.co.nz/where-is-fgm-practiced/

Background

- Approximately 200 million women and girls around the world presently suffer the often awful consequences of FGM, which is also known as Female Genital Cutting or Female Circumcision with the practice most concentrated in Asia, The Middle East and Africa. (www.who.int/mediacentre/factsheets/fs241)
- Canada has banned FGM – It is Aggravated Assault punishable by law

Research Study

- ***Uzima*** **Women Relief Group International** conducted a study on health concerns of African women affected by the practice of FGM
- The study was conducted among African women in Toronto from African countries where FGM is practiced
- The aim of the research was to explore what health concerns and issues women with FGM are experiencing as well as determining their understanding of the Canadian law against it.
- As well as interviewing women, communities' perceptions and service providers' experiences were sought

Results of the study

- 21 women, 11 service providers and 8 community leaders were interviewed.

- 47% (10/21) women interviewed said that FGM is a stigmatized topic and some women may be afraid to disclose it to their service providers
- 95% (20/21) of the women interviewed have experienced a form of FGM which happened between infancy and adulthood
- This is an indication that many women from Africa are living with FGM experience
- All women expressed concern about the harm associated with the practice saying most of the injury is permanent and cannot be reversed
- Some community leaders said it is done for both cultural and religious reasons
- Some of the religious community leaders said that good morals and discipline can be instilled through education and mentoring without causing bodily harm
- All participants agreed there is serious harm associated with FGM and they expressed concerns on the health of women and entire communities
- In all the women interviewed, FGM was done at home rather than in a hospital.
- Reasons given for FGM included:
    - Transition to womanhood
    - Reducing sexual desire
    - Cultural/Religious norm to protect girls ensuring high moral standing necessary for marriage
    - Family's choice

Social Concerns:

- Talking about FGM outside of cultural group
- Shame
- Hard to date outside culture because of stigma from FGM in Canada
- Relationship stigmatization
- Infidelity by husbands
- Divorce

Health Concerns:

- All women have suffered the consequences of FGM including :
    - Severe psychological trauma resulting in mental health issues such as stress and depression
    - Reproductive and urinary system complications
    - Bleeding
    - Shock
    - Birth difficulties
    - Decreased sexual satisfaction
    - Painful menstruation

Health Services concerns:

- Hard to relate with Doctors
- Providers are not educated about FGM
- Lack of understanding of FGM to stand up against the practice
- Less satisfaction with providers due to:
    - Wait times
    - Doctors not paying enough attention

Recommendations

- Education and awareness on FGM is needed for communities and service providers
- Proactive steps should be taken to enforce the law against FGM
- Address anti-oppression in a direct way to empower women
- There should be some visual signage and campaign by Health care institutions to show support for women's rights surrounding FGM
- There should be community support systems for women of African descent to foster opportunity to socialize and talk about cultural issues

Read the full report at WCH and UZIMA websites

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