Measuring Female Genital Mutilation/Cutting in Switzerland: From Indirect Prevalence Estimates to Swiss University Hospital Data

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On application of:

Prof.em.Dr.med. Elisabeth Zemp Stutz
Prof. Nicole Probst-Hensch
Dr. Jasmine Abdulcadir
Prof.em.Dr.med. Johannes Bitzer
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Dean

Prof. Dr. Primo Leo Schär

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To Leila and Zoe <3

Summary

The term “female genital mutilation,” also referred to as “female genital cutting” and “female genital mutilation/cutting”, refers to all procedures involving the partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons. There are no known health benefits to FGM; in fact, it has been shown to be harmful to girls and women in numerous ways. Of critical importance, it causes acute and long-lasting pain and trauma. The removal of or damage to healthy, normal genital tissue interferes with the natural functioning of the body causing immediate and long-term health consequences. Moreover, FGM/C violates human rights conventions, including: The Universal Declaration of Human Rights, The Convention on the Elimination of All Forms of Discrimination against Women (1979), the Convention against Torture, and other Cruel, Inhuman or Degrading Treatment or Punishment, and the Convention on the Rights of the Child (1989). This harmful practice reflects deep-rooted inequality, embodying an extreme form of discrimination against women and girls.

FGM/C has been reported in around 30 countries, from Sub-Saharan Africa, to Asia, the Middle East and South America. UNICEF estimates that at least 200 million girls and women have undergone FGM/C. Due to migration, girls and women who were exposed to FGM/C in their home country or who are considered at risk of undergoing this procedure, also live in high-income countries. Many host countries are increasingly receiving migrant women and girls from these high-prevalence countries, who may require health interventions as a result of sequelae from having undergone FGM. In 2016, the Swiss Federal Office of Public Health estimated that approximately 14,700 girls and women were living with or at risk of FGM/C. In the past 5 years, there have been no updates on these estimates.

The aim of this PhD was to evaluate the available FGM/C data in Switzerland to help improve future FGM/C monitoring and routine data collection. It is based on five interrelated studies, employing indirect, direct and routine hospital data collection methods:

Firstly, an update of the national indirect estimates for women and girls living with FGM/C in Switzerland was conducted, with the use of annual estimates for 2010-2018. Secondly, based on systematic reviews and available literature on complications of FGM/C, we compiled a comprehensive list of diseases, disorders and health-related consequences of FGM/C in alignment with the International Classification of Diseases (ICD) ninth and tenth revisions. Thirdly, we gathered anonymized data from Swiss University hospitals about women and girls with a primary or secondary ICD diagnosis

of FGM/C and their co-morbidities. And finally, we conducted a national exploratory cross-sectional study, assisted by the Swiss HIV Cohort (SHCS). We administered two questions on history of FGM/C and previous discussion about it with a healthcare professional during routine visits between June and December 2019 to help validate our estimates for the number of women living with FGM/C in Switzerland.

Results from our Swiss national FGM/C indirect estimates show a significant increase in the absolute number of women and girls with FGM/C, mostly as a result of increased migratory flows: In 2010, out of 19,506 migrant women and girls living in Switzerland from one of 30 countries where FGM/C has been documented, 9,059 (46.4%) were estimated to have undergone some form of FGM/C. In 2018, the total number of migrant women and girls living in Switzerland estimated to have undergone some form of FGM/C was 21,706, out of 36,898 women and girls from FGM/C practicing countries (58.8%), corresponding to an increase of 26.7%. Our estimates also reported that in 2018, of the 11,022 girls living in Switzerland coming from one of the 30 high prevalence FGM/C countries, 3,512 are estimated to be at risk or have been subjected to the harmful practice (31.9%).

Our indirect estimate of the number of women and girls that have undergone FGM/C or could be at risk of undergoing FGM/C that were inpatients in the Swiss university hospitals from 2016 through 2018 was 4947 women and girls (1648 in 2016, 1671 in 2017, and 1628 in 2018). In the data of the Swiss University hospitals, we found exceptionally low reporting and recording of FGM/C among women and girls from high FGM/C prevalence countries in Swiss hospitals. We found that only 207 patients (2.29%, 95%CI: 1.98-2.62) out of the 4947 estimated women and girls with FGM/C had a recorded diagnosis of FGM/C. This very low number of ICD coded FGM/C cases suggests that FGM/C is not accurately diagnosed, recorded and/or coded in Switzerland.

Of these 207 women and girls, 199 were admitted either to gynaecology or obstetrics departments. The remaining women and girls were admitted to other specialty departments. The most frequently coded diagnoses were: perineal laceration during delivery (n=50), prolonged second stage of labour (n=21), postpartum haemorrhage (n=12), and vulvar cysts (n=5).

The cross-sectional survey of the number of women with FGM/C in the Swiss HIV Cohort Study showed that FGM/C is common (20.9%) among this population, despite a considerable number of non-

respondents (33.6%). A majority of the women (69.1%) who reported having undergone FGM/C, also reported that they had never discussed their cutting with a health professional before.

The PhD project points to the need of training. Healthcare professionals should be trained in screening, diagnosing, classifying and documenting FGM/C, as well as ensuring respectful communication using a culturally-sensitive approach.

This is the first study that has ever been done using the ICD diagnosis of FGM/C. It provides a detailed instrument for coding nearly all recognized conditions related to FGM/C, which will assist health care providers to find the correct category to diagnose FGM/C, and related diagnostic conditions, and provide greater diagnostic detail when recording diagnoses for statistical and reimbursement purposes. This dissertation is also helping to facilitate global communication about this condition using a unified concept. The public health relevance of such will be highly significant in the months and years ahead.

Abbreviations

AIDS	Acquired immunodeficiency syndrome
cART	Combination Antiretroviral Therapy
CHOP	Swiss Classification of Surgical Interventions and procedures
CHUV	Lausanne University Hospital
DHS	Demographic and Health Survey
EU	European Union
HIV	Human Immunodeficiency Virus
HUG	Geneva University Hospitals
Fedpol	Federal Office of Police
FGM/C	Female Genital Mutilation/Cutting
FOPH	Federal Office of Public Health
FSO	Federal Statistical Office
ICD	International Statistical Classification of Diseases and Related Health Problems
ICD-10-GM	International Statistical Classification of Diseases and Related Health Problems, 10th revision, German Modification
Inselspital	University Hospital of Bern
NGO	Non-Governmental Organization
NHS	National Health Service
MICS	Multiple Indicator Cluster Survey
SEM	State Secretariat for Migration
SHCS	Swiss HIV Cohort Study
STAT-TAB	FSO's Interactive Database
SwissEthics	Swiss Association of Research Ethics Committees
UK	United Kingdom
UN	United Nations
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
USD	United States Dollar
USZ	University Hospital of Zurich
WHO	World Health Organization
WHNS	Women's Health Needs Study

Introduction

Female genital mutilation, also referred to as “female genital cutting” and “female genital mutilation/cutting, includes “a range of practices involving the complete or partial removal or alteration of the external genitalia for nonmedical reasons”. (1) There are no known health benefits to FGM; in fact, it has been shown to be harmful to girls and women in numerous ways. Of critical importance, it causes acute and long-lasting pain and trauma. The removal of or damage to healthy, normal genital tissue interferes with the natural functioning of the body causing immediate and long-term health consequences. (2) Moreover, FGM/C violates human rights conventions, including: The Universal Declaration of Human Rights, The Convention on the Elimination of All Forms of Discrimination against Women (1979), the Convention against Torture, and other Cruel, Inhuman or Degrading Treatment or Punishment, and the Convention on the Rights of the Child (1989). (3) This harmful practice reflects “deep-rooted inequality, embodying an extreme form of discrimination against women and girls”. (4) FGM/C is performed at various ages depending on country and cultural practices, from 0-14 for numerous reasons, most of which relate to the preservation of premarital sex. (2,5) The term female genital mutilation (FGM) is used by the World Health Organization (WHO) and a majority of the United Nations (UN) community to emphasize the Human Rights violations that are committed through a practice that causes harm.

FGM/C has been reported in around 30 countries, from Sub-Saharan Africa, to Asia and South America. According to UNICEF, at least 200 million girls and women have undergone FGM/C. (6) Due to migration, girls and women who have undergone the practice in their home country or who are considered at risk of undergoing it, also live in high-income countries. (2,6,7) Many host countries are increasingly receiving migrant women and girls from these high-prevalence countries, who may require health interventions as a result of sequelae from having undergone FGM.

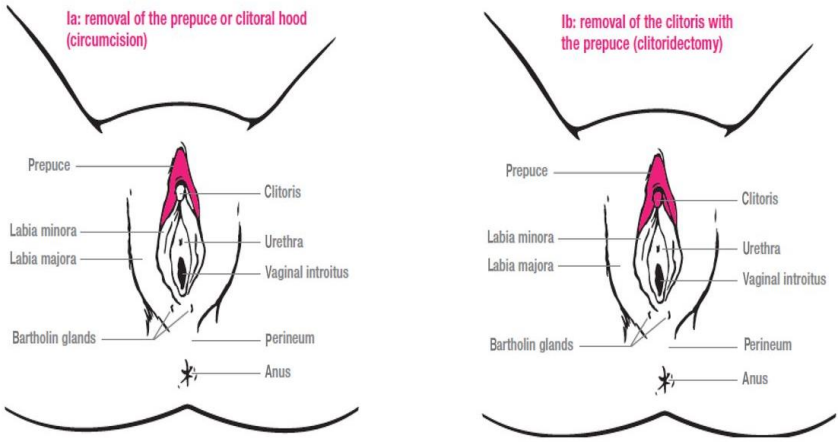
When the procedure first gained attention by NGOs and in the 1970s, it was known as “female circumcision”. (8) However, this term was directly compared to male circumcision—a very distinct and different practice. This led to providers using the term “female genital cutting”, as it was thought to be more effective for engaging people in dialogue around the topic. In this thesis, we use the term “female genital mutilation/cutting” (FGM/C) to incorporate the policy aspects of “mutilation” while simultaneously remaining sensitive to practicing communities and survivors, by including “cutting”.

Definition of FGM/C and Types of FGM/C

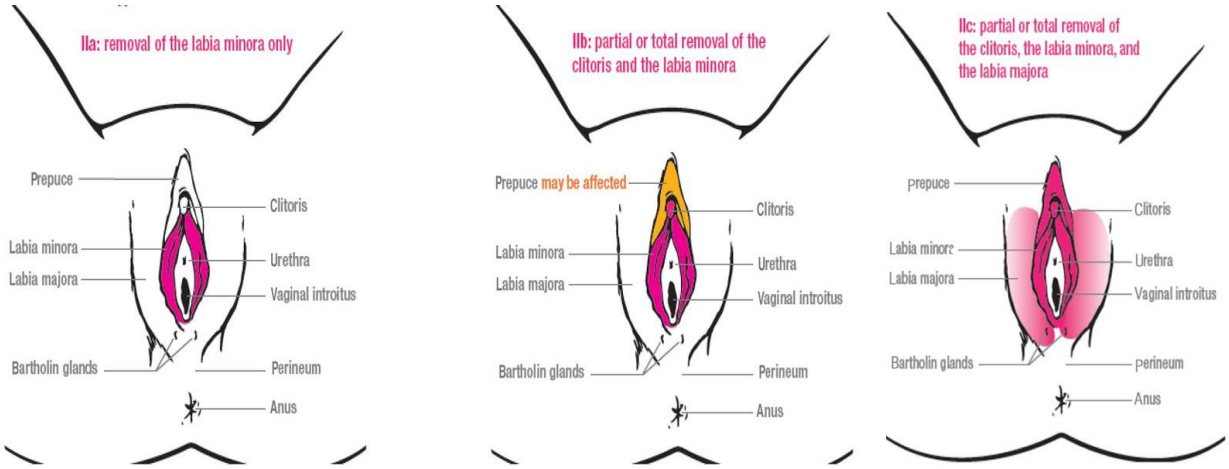
FGM/C refers to all procedures involving the partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons. (2) WHO classifies FGM/C into four main types, with severity of the FGM/C types increasing with the amount of tissue that is damaged or cut. Through experience with its use, experts have subdivided these categories further, capturing more detailed subtypes of FGM/C, as noted below.

Figure 1: The four major types of FGM, and their subtypes (1):

Type I Partial or total removal of the clitoral glans, and/or the prepuce/clitoral hood
Type Ia Removal of the prepuce/clitoral hood only
Type Ib Removal of the clitoral glans with the prepuce/clitoral hood



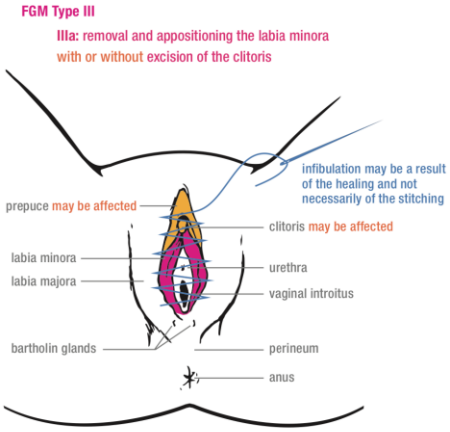
Type II Partial or total removal of the clitoral glans and the labia minora, with or without removal of the labia majora.
Type IIa Removal of the labia minora only
Type IIb Partial or total removal of the clitoral glans and the labia minora
Type IIc Partial or total removal of the clitoral glans, the labia minora and the labia majora

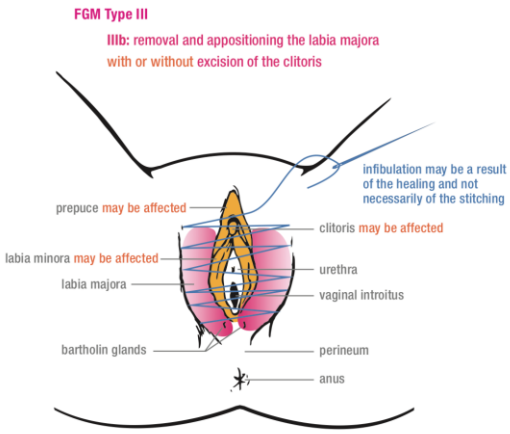


Type III (Infibulation) Narrowing of the vaginal opening with the creation of a covering seal. The seal is formed by cutting and repositioning the labia minora, or labia majora. The covering of the vaginal opening is done with or without removal of the clitoral prepuce/clitoral hood and glans (Type I FGM)

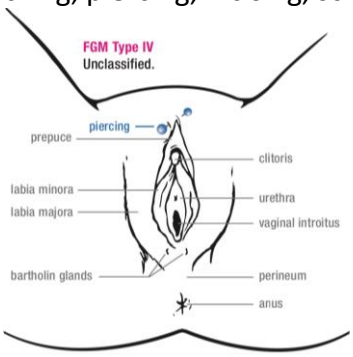
Type IIIa Removal and repositioning of the labia minora

Type IIIb Removal and repositioning of the labia majora





Type IV All other harmful procedures to the female genitalia for non-medical purposes, for example pricking, piercing, incising, scraping and cauterization.



Health Consequences

There are no known health benefits associated with FGM/C. The health consequences associated with FGM/C are generally categorized into acute, and long-term or chronic and range from genito-urinary, gynecological, obstetric, sexual and mental health complications.

Knowledge of the health consequences of this procedure have come from several systematic reviews of complications associated with FGM/C. These have been conducted and are periodically updated with new research as it becomes available. Various “reviews of reviews” exist that synthesize the findings from these systematic reviews for clinical and professional audiences. Systematic reviews of complications associated with FGM often report bias in the evidence including a lack of rigorous research methodologies and heterogeneity of the studies makes meta-analyses challenging. (9)

Regarding complications, FGM/C is typically carried out by traditional practitioners who have little knowledge of the female anatomy. Reports suggest that they use rudimentary “surgical” instruments that have not undergone proper cleaning or sterilization, resulting in immediate/acute injury. The most commonly reported acute complications from FGM are hemorrhage, urinary tract infections and urinary retention and genital swelling. Additionally, infection, fever, and in rare instances, death have also been recorded. (10–13) A “Dose-response” consequence has indicated that women and girls often experience multiple morbidities, based on the type of FGM/C; with the severity of consequences increasing by type, from Type I to Type III. (10,14)

Health care providers in other migrant host countries, including Switzerland, are unlikely to see girls or women with acute health complications, with the exception of newly arrived immigrants who underwent FGM/C right before leaving their country. (15) Young girls who may have been traveling to visit their family or relatives overseas and have recently returned after undergoing FGM/C may also have presented with acute complications from FGM/C. (15) Therefore, it is likely that the potential burden of disease from FGM/C seen by Swiss providers is mostly related to longer term health problems, some of which may be chronic health issues that would require lifelong treatment.

Women and girls living with Type III FGM/C are also at higher risk of long-term health complications than those with type I, II, or IV. Genito-urinary complications associated with FGM/C include vaginal discharge, itching, urological complications, menstrual pain and infections. (10,11,16) Women with type III FGM/C may suffer from chronic urinary tract infections due to poor urinary flow and bacterial growth below the infibulation scar. (17) All types of FGM/C may cause damage to the urethra, resulting in urinary stricture and stenosis, or fistulae.(18) Other complications such as scarring and cysts have been reported, although are thought to be more rare. (19) This could be a reporting bias on the part of the provider, however.

The obstetric complications most commonly reported to be associated with FGM/C are prolonged labour, increased caesarean section rate, episiotomy, instrumented delivery, perineal tears and lacerations, as well as postpartum hemorrhage. (10,16,20–22) However, data is limited, possibly due to both detection bias, selection bias and/or information bias—the result of providers’ lack of familiarity with the management of care for patients who present with a history of FGM/C. (23)

FGM/C is also associated with female sexual dysfunction, as the removal of sexual tissue (glans of clitoris and labia minora) may reduce sensitivity, in addition to pain caused by scarring near and around the clitoris. Women who have undergone FGM/C may report sexual pain, reduced sexual desire or arousal, orgasm dysfunction and a reduction of overall sexual satisfaction. (24–28)

Because FGM/C is practiced in many countries that have a high prevalence of HIV and hepatitis B, where non-sterile instruments are often used, women and girls may be at a higher risk for HIV and hepatitis B and C, although there is little evidence supporting this. (29,30)

It is obvious and not surprising that when a girl/woman discovers the consequences of such FGM/C procedures, that she may feel anxious, depressed or even have symptoms of post-traumatic stress disorder. Until the scientific field includes more investigators and person-centered efforts, there will be a lack of specificity surrounding these consequences. (10,31)

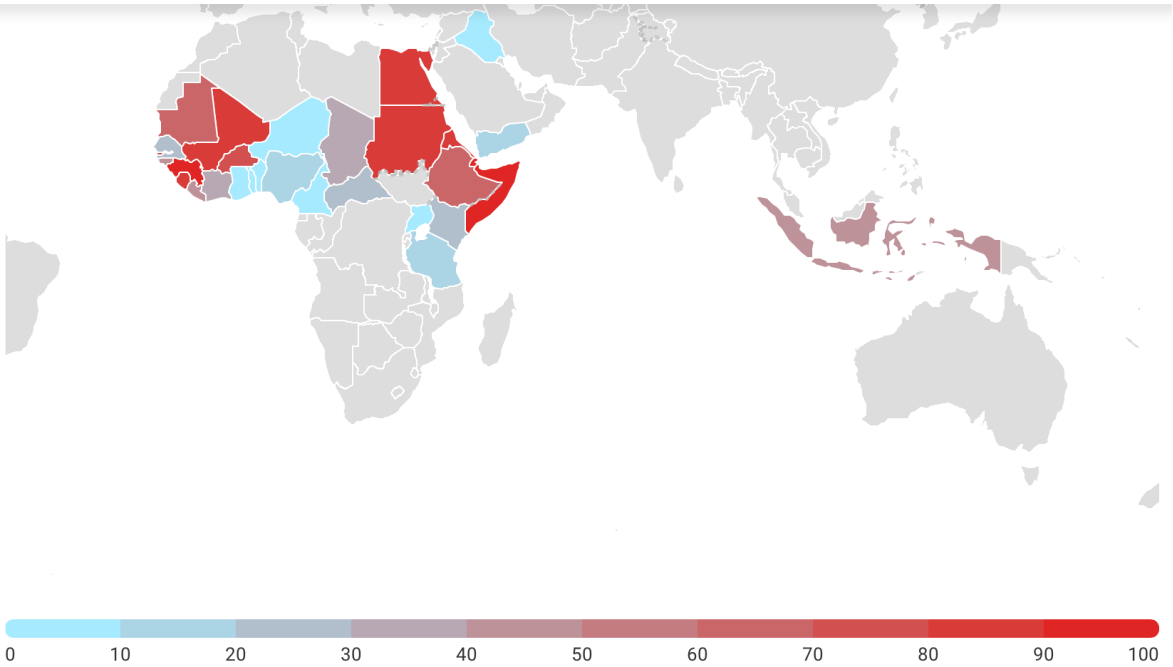
In addition to all of the health risks previously mentioned, there are various gynecologic procedures and routine activities that may become difficult due to the alterations of the genitals such as difficulties in performing gynecological examinations, IUD insertion and removal, and using tampons.(2) Again, until the field of investigators in these areas grow, we are reliant on the few small studies done to date.

Global Prevalence

UNICEF estimates that there are more than 200 million girls and women who have had a FGM/C procedure globally. (6) As noted in the illustration below (32), countries where FGM/C is widely practiced include: East and West Africa, the Middle East and South East Asia. The countries with the highest prevalence of FGM/C are Somalia (98%, 2006), Guinea (95%, 2018), Djibouti (94%, 2003), Mali (89%, 2018), Egypt (87%, 2015), Sudan (87%, 2014), Sierra Leone (86%, 2017), Eritrea (83%, 2010), Burkina Faso (76%, 2010), Gambia (76%, 2018), Mauritania (67%, 2015), and Ethiopia (65%, 2016). (33,34) There have been reports of FGM/C in the Maldives due to nationally representative surveys being recently conducted Indonesia is also a country with FGM/C; however, the data for this country only includes girls from newborn to 11 years of age. (35) Some data additionally indicates

that FGM/C exists in Colombia, India, Malaysia, Oman, Saudi Arabia, and the United Arab Emirates, although there are no population-level estimates available for these countries. (27,36–40)

Figure 2: UNICEF FGM/C Global Estimates Map, 2020 (32)



Notes: In Liberia, girls and women who have heard of the Sande society were asked whether they were members; this provides indirect information on FGM since it is performed during initiation into the society. Data for Indonesia refer to girls aged 0 to 11 years since prevalence data on FGM among girls and women aged 15 to 49 years is not available. The boundaries and names shown and the designations used on this map do not imply official endorsement or acceptance by the United Nations.

Source: UNICEF global databases, 2020, based on DHS, MICS and other national surveys, 2004-2018.

Measurement/Diagnosis

Demographic and Health Surveys & Multiple Indicator Cluster Surveys

Global estimates for FGM/C, used internationally, and within this thesis, were generated through large-scale population-based surveys including: Demographic and Health Surveys (DHS) conducted by the United States Agency for International Development (USAID) and Multiple Indicator Cluster Surveys (MICS), supported by the UNICEF initiative. The most recent estimates for all 31 of the countries where FGM/C has been recorded, with the exception of Eritrea, Indonesia, and Djibouti's most recent estimates from 2016, rely on DHS and MICS household survey data. (33,34) Since 1984 when the DHS was developed and 1995 when MICS was first conducted, these household surveys

have facilitated many countries to collect nationally representative data on numerous indicators such as child and maternal health, nutrition, education, and HIV/AIDS.

Though FGM/C was first introduced by DHS in their 1989-1990 survey in Sudan, MICS first included the FGM/C questions in their 2000 survey in the Central African Republic, Chad and Sudan. Since then, DHS and MICS have included the FGM/C module in 29 countries at varying intervals. For example, Somalia's most recent FGM/C prevalence dates back to 2006, while most countries conduct the DHS or MICS surveys every 4 or 5 years. The two organizations have been working to harmonize the questionnaires to ensure comparability between both the DHS and MICS survey data. The following table, shows recent FGM/C prevalence estimates available for women ages 15-49 until May 2015. (41) The year that the nationally representative survey was conducted is listed next to the FGM/prevalence (%) either with an underline (MICS surveys) or without an underline (DHS). The difference between the minimum and maximum prevalence between all years is listed in the final column. For every recent prevalence estimate, additional columns are used (t-1, t-2, t-3, t-4).

The indicator for FGM/C was first introduced by DHS in their 1989-1990 survey in Sudan. MICS first included the FGM/C questions in their 2000 survey in the Central African Republic, Chad and Sudan. Since then, they have included the FGM/C module in 29 countries at varying intervals, and have worked to harmonize the questionnaires to ensure comparability between both the DHS and MICS surveys.

Table 1: FGM/C Prevalence Estimates, women ages 15-49, until May 2015

Country	Most recent (t)	% FGM	t-1	% FGM	t-2	% FGM	t-3	% FGM	t-4	% FGM	Max-Min
Benin	2011/12	7,3%	2006	12,9%	2001	16,8%					9,5%
Burkina Faso	2010	75,8%	2006	72,5%	2003	76,6%	1998/99	71,6%			5,0%
Cameroon	2004	1,4%									0,0%
Central African Republic	2010	24,2%	2006	25,7%	1994/95	43,4%					19,2%
Chad	2010	44,2%	2004	44,9%							0,7%
Côte d'Ivoire	2011/12	38,2%	2006	36,4%	2005	41,7%	1998/99	44,5%	1994	42,7%	8,1%
Djibouti	2006	93,1%									0,0%
Egypt	2008	91,1%	2005	95,8%	2003	97,0%	2000	97,3%	1995	97,0%	6,2%
Eritrea	2010[a]	83,0%	2002	88,7%	1995	94,5%					11,5%
Ethiopia	2005	74,3%	2000	79,9%							5,6%
Gambia, The	2010	76,3%	2005/06	78,3%							2,0%
Ghana	2011	3,8%	2006	3,8%							0,0%
Guinea	2012	96,9%	2005	95,6%	1999	98,6%					3,0%
Guinea-Bissau	2010	49,8%	2006	44,5%							5,5%
Iraq	2011	8,1%									0,0%
Kenya	2008/09	27,1%	2003	32,2%	1998	37,6%					10,5%
Liberia	2013	55,5%	2007	58,2%							8,4%
Mali	2012/13	91,4%	2006	85,2%	2001	91,6%	1995/96	93,7%			8,5%
Mauritania	2011	69,4%	2007	72,2%	2000/01	71,3%					2,8%
Niger	2012	2,0%	2006	2,2%	1998	4,5%					2,5%
Nigeria	2013	24,8%	2008	29,6%	2007	26,0%	2003	19,0%	1999	25,1%	10,6%
Senegal	2014	24,7%	2010/11	25,7%	2005	28,2%					3,5%
Sierra Leone	2013	89,6%	2010	88,3%	2008	91,3%	2005	94,0%			4,4%
Somalia	2006	97,9%									0,0%
Sudan[b]	2010	87,6%	2000	Unspecified	1989/90	89,2%					1,2%
Tanzania	2010	14,6%	2004/05	14,6%	1996	17,9%					3,3%
Togo	2013/14	4,7%	2010	3,9%	2006	5,8%					1,9%
Uganda	2011	1,4%	2006	0,6%							0,8%
Yemen[c]	2012/13	18,5%	2003	38,2%	1997	22,6%					19,7%

[a]Eritrean Population and Health Survey (2010)

[b]Sudan Household Health Survey SHHSII (2010); report of 2000 did not give a total FGM prevalence

[c]National Health and Demographic Survey (2003; 2012–13)

Source: De Schrijver, L., Van Baelen, L., Van Eekert, N. et al. Towards a better estimation of prevalence of female genital mutilation in the European Union: a situation analysis. Reprod Health 17, 105 (2020). https://doi.org/10.1186/s12978-020-00947-2

FGM/C Questionnaire and Prevalence Indicators

DHS and MICS surveys that include the FGM/C module ask women of reproductive age (15-49) the following questions, “Have you ever heard of female circumcision? Have you yourself ever been circumcised? Was any flesh removed from the genital area? Was the genital area just nicked without removing and flesh? Was the genital area sewn closed, or sealed? Who circumcised you?” (33,42)

If the woman has daughters that are alive, they are asked the following questions, “Have any of your daughters been circumcised? If yes, how many? To which of your daughters did this happen most recently (Give name)? Was any flesh removed from the genital area? Was the genital area just nicked without removing and flesh? Was the genital area sewn closed, or sealed? Who circumcised her?”(42)

Some countries have added questions about women’s attitudes towards the practice and whether or not it should continue in their communities. The 2004 DHS survey in Chad and Cameroon was the first to implement the indicator on boys and men’s attitudes towards FGM/C, asking boys and men aged 15 to 49 years, “have you heard about FGM and if yes, do you think this practice should be continued or should it be discontinued? (32)

The proportion of girls aged 15-19 self-reporting any form of FGM/C is one of the indicators used to measure FGM/C. This can be used as a proxy for incidence, as it focuses on girls who may recently have undergone the procedure. The FGM/C indicator for girls younger than 15 may not accurately reflect their final FGM/C status, and may underreport the number of girls who have undergone the procedure. (43) This is because most girls are cut before the age of 15. (44) There is a diverse age range for women girls to undergo FGM/C, ranging from 90% of girls between ages 5-14 in Egypt to 60% before age 5 in Ethiopia. (45)

The most widely used indicator for FGM/C is the self-reported prevalence of FGM/C for women and girls. This question, asked to women and girls of reproductive age (15-49), paints an overall picture of FGM/C. However, any recent changes to the country prevalence, from the abandonment of the harmful practice, may not be evident from this indicator. For example, a decline in country prevalence for women and girls ages 15-49 from prevention programmes conducted starting in 2020 may only be visible as late as 2034 in countries where the practice is carried out on a 1 year-old. (43)

More and more countries are implementing the DHS and MICS surveys that include the module on FGM/C. Trend analyses can be conducted to compare the prevalence of FGM/C over time within age groups, either for the full 15-49 cohort, or across five-year age cohorts. Trends can also be compared between five-year age cohorts from the same country. Corrections need to be made when comparing the prevalence of FGM/C among girls under 15, as prevalence is likely to be underestimated depending on the age of cutting.

Prevalence in Europe

There is a real need for data from European countries. Global FGM/C estimates lack data about migrant women who have undergone FGM/C. The prevalence and incidence of FGM/C is unknown in many parts of Europe, including Switzerland, as there are no nationally representative surveys comparable to the DHS or MICS. (46) Demographers predict that migrants coming from FGM/C-practicing countries towards high income and European countries such as Switzerland have been on the rise and will continue to increase. (47) A study published in 2016 using data from the 2011 European census estimated that, of the nearly 1.4 million women and girls in Europe aged 10 years and above coming from one of the 30 highest-prevalence FGM/C countries, nearly 600,000 women and girls had already undergone one type of FGM/C. (46) The surge of migrants from these countries has increased the number of women and girls living with FGM/C in Europe and this is placing a high burden for care and support on the European health care system. In 2016, estimates in Switzerland showed that approximately 14,700 women and girls had a history of FGM/C. (48) No further estimates have been reported. This number was published on the Swiss Federal Office of Public Health website, where FGM/C is discussed, without any mention of methodologies. (48) The most recent documentation available for recent estimates of FGM/C comes from the UNICEF Switzerland FGM/C report, published in 2012. (49)

Extrapolation of data method

Estimates of prevalence of FGM/C in Europe are calculated using an “extrapolation method” to produce an indirect estimate of FGM/C prevalence. This method uses data from various sources such as population registers or census data to identify female migrants coming from countries with a high prevalence of FGM/C. The FGM/C prevalence rate in the countries of origin (DHS/MICS) is multiplied

by the total number of girls and women in the country of destination who have migrated from an FGM/C country of origin.

The indirect estimation is a straightforward systematic and affordable method for estimating the number of women with FGM/C in high-income countries. (41,50,51) While indirect estimations allow governments, policy makers and public health officials to look for trends as well as evaluate the impact of prevention programs based on reliable approximations, they are limited by their methodological biases as they may not reflect the actual FGM/C prevalence among migrants in Switzerland or any community for that matter. (52)

To mitigate these limitations, the "extrapolation methods" can be enriched by making a wide assortment of corrections to account for various factors that can influence a woman or girl's likelihood of having undergone FGM/C, as ethnicity or socio-economic status. A more in-depth description is provided in the following chapters and discussion. (41,53) Another bias may be attributed to selection bias in the population in that migrant populations may or may not be representative of the population in their country of origin. This is specifically due to socio-economic status, regional origin, religion or ethnicity; therefore they may not accurately estimate the prevalence of FGM/C in their home country.

Direct Estimates

Some of the weaknesses of indirect methods could be improved through direct estimates, for example, ethnicity, level of education, change in beliefs after length of time spent in host country, and other such risk factors/predictors. However, direct estimations also have their own limitations. One of the main challenges of sampling communities in migrant host countries is that FGM/C is a sensitive topic to discuss and women may not want to disclose whether they have undergone FGM/C. This reporting bias may be directly associated with who is asking the questions, how old the woman/girl is and such like. There may also be memory bias in that women/girls may not remember if they were cut, or what type of FGM/C they had undergone, especially if it was performed at an early age. Likewise, they may not be familiar with the terminology used by healthcare professionals to describe FGM/C. Additionally, they may not have even been told they were cut.

Administrative data

Without national FGM/C prevalence rates, the field must look to other methods for estimates of the prevalence of FGM/C in migrant communities. Administrative data is one potential means for gathering FGM/C data that may be routinely collected and readily available such as hospital or medical records and asylum requests that could be used as proxy indicators for prevalence and incidence of FGM/C. Routine hospital data collection and patient medical records may be an underutilized resource for data on women and girls living with FGM/C, containing information on maternal and neonatal morbidity and mortality, de-infibulation, surgical repair/reconstruction and other chronic and long-term complications from FGM/C.

ICD

The International Classification of Diseases (ICD) is an international health information nosological standard currently used in more than 150 countries, for coding mortality and morbidity, signs, symptoms, reasons for encounter, and external causes of injury and disease that allows measurements and comparisons at national and international level of medical, epidemiologic and economic information.(54) The ICD-10 is translated into more than 40 languages and is used to help record information on primary diagnosis and any additional (secondary) diagnoses. (54) The ICD classification has its roots in the London Bills of Mortality from the 1530's, as well as the Parisian Bertillon Classification from the 1800's and was adopted by the WHO in 1948. (55) The ICD is now going on its 11th version, which was just adopted by the 77th World Health Assembly and will be coming into effect in January, 2022. (54) Until recently, it was not possible to record history of FGM/C in a patient's hospital records using the ICD. Germany introduced the FGM/C code in their 2014 version (ICD-10-GM 2014), as well as a code for all four subtypes. In 2016, the German modification updated their classification, but maintained FGM/C diagnoses for all subtypes. Switzerland uses the German modification of the ICD, and translates it into French and Italian to support the diverse language requirements of the country. Several other countries have introduced a code for FGM/C to their national modification, but few have listed their subtypes. In 2016, WHO formally introduced the code Z91.7 "Personal history of female genital mutilation" to the International version of the ICD-10 (2016).

ICD-10 German Modification (Switzerland) FGM/C Codes

Table 2: ICD-10-GM FGM/C Codes

ICD Code	Code Description	Year Implemented
N90.80	Female genital mutilation, type unspecified	2014
N90.81	Female genital mutilation, type 1	2014
N90.82	Female genital mutilation, type 2	2014
N90.83	Female genital mutilation, type 3	2014
N90.84	Female genital mutilation, type 4	2014
N90.88	Other specified non-inflammatory diseases of the vulva and perineum	2014
N90.9	Non-inflammatory disease of vulva and perineum, unspecified	2014
Z91.7	Personal history of female genital mutilation	2016
Z91.70	Personal history of female genital mutilation, type unspecified	2016
Z91.71	Personal history of female genital mutilation, type 1	2016
Z91.72	Personal history of female genital mutilation, type 2	2016
Z91.73	Personal history of female genital mutilation, type 3	2016
Z91.74	Personal history of female genital mutilation, type 4	2016

Source: ICD-10-GM

In summary, data on FGM/C in high-income diaspora countries, are almost exclusively obtained through indirect estimates. (56)(58) Indirect estimates almost all exclusively use the “extrapolation method”, which uses age-specific FGM/C prevalence rates from immigrants' home countries which are multiplied by the number of women and girls from those same countries in diaspora countries. (46) Estimates for Switzerland were provided in 2016, without any published methods or sources of data. The last published estimates for Switzerland that provide a full methodology date back to 2011. Although Switzerland releases data from their population register annually, the indirect estimates for women and girls living with FGM/C in Switzerland must be updated. In addition to indirect estimates, hospital data in Switzerland has information on FGM/C related to primary or secondary diagnoses for inpatients using the ICD-10-GM since 2016, making it one of only a small handful of countries to implement FGM/C in its national modification of the ICD. No studies have ever reported FGM/C diagnoses using the ICD.

Project Aims, Research Questions and Methods

The fluctuating migration flows from certain high-prevalence countries, in addition to changes in the prevalence rates of FGM/C in the migrant's country of origin, necessitates an immediate update of the national indirect estimates in diaspora countries to help inform policy and public health programmes. Switzerland is also in a unique position to test the feasibility of using hospital data to inform FGM/C prevalence among migrant women, as it is one of a handful of countries that codes FGM/C among inpatients as well as FGM/C Type. Improved monitoring of the prevalence and incidence of FGM/C and its complications is imperative for both epidemiological reasons and for assessing prevention campaigns, laws, and care because is it a public health crisis. Accurate information about the health and wellbeing of the Swiss migrant population is valuable for improving clinical care, provision of services, and designing and implementing public health prevention strategies to reduce FGM/C health-related complications. Relatively little is known about the health-care needs of women and girls with FGM/C in Switzerland. A better understanding of the consequences for the girls and women who have undergone FGM/C living in Switzerland is important, predominantly because of the high prevalence rates in some communities coupled with the likely increasing rate due to migration trends.

The overarching aim of this thesis:
The purpose of this research was to evaluate the existing FGM/C data in Switzerland, and the concomitant available hospital data that could potentially capture and improve routine data collection. Improving the quality and availability of FGM/C data would facilitate more accurate data on prevalence and improve healthcare services. Data obtained from our research will give fundamental information for future policies, training strategies and surveillance in the Swiss health care system with respect to FGM/C. We expect to find weak capacities in diagnosing, recording, and coding of FGM/C and its clinical and surgical management, which will represent a possible target to implement an important and needed public health surveillance system in Switzerland.

This study had the following specific aims:

1) To update the Swiss Indirect Estimates for the number of women and girls living with FGM/C in Switzerland.

2) To create a coding guide for using the International Classification of Diseases to document FGM/C and its complications based on systematic reviews and clinical expertise.
3) To obtain indirect estimates for the number of women and girls living with FGM/C hospitalized in the 5 Swiss University hospitals “Niveau 1”.
4) To describe the inpatients with an FGM/C diagnosis in the 5 Swiss University hospitals, their co-morbidities and their procedures
5) To compare indirect estimates between 5 Swiss University hospitals “Niveau 1” and FGM/C diagnoses.
6) To generate descriptive statistics on FGM/C among HIV-infected women included in the Swiss HIV cohort.

Hypotheses include:

1) ^{H1} There are an increasing number of women and girls living with FGM/C in Switzerland—with a significant increase in the past 5 years.
2) ^{H2} The number of women and girls with FGM/C in Swiss University Hospitals is underreported and not often recorded on the patient’s medical record.
3) ^{H3} Among HIV-infected women, the number of women and girls living with FGM/C in the Swiss HIV Cohort is not recorded but is high.

Outline of Thesis

Following the introduction, background (Chapter 1), and aims of the thesis (Chapter 2), the methods are briefly described (Chapter 3).

Chapter 4 presents the proposed method of documenting and coding health conditions and procedures related to FGM/C using the International Classification of Diseases, ninth (ICD-9) and tenth revision (ICD-10) (Aim 2).

Chapter 5 presents the findings of the updated indirect estimates for 2010 through 2018, for women and girls living with FGM/C in Switzerland (Aim 1), using data from the Swiss Federal Statistical Office of migrant women and girls, born in one of the 30 high-prevalence FGM/C countries, who are currently living in Switzerland,

Chapter 6 presents the findings of the study assessing the indirect estimates of women and girls with FGM/C admitted to Swiss university hospitals between 2016 and 2018 from 30 FGM/C high prevalence

countries, as well as descriptive statistics of inpatients with a coded diagnosis of FGM/C using anonymized data (Aims 3 & 4 & 5).

Chapter 7 presents the results of primary and secondary FGM/C diagnoses, their comorbidities and their procedures recorded among inpatient women in Swiss University hospitals (Aim 4).

Chapter 8 presents the results from our cross-sectional study of women with FGM/C in the Swiss HIV Cohort study (Aim 6).

In Chapter 9, the main findings included in Chapters 4-8 are summarized, including the strengths and limitations of the research as well as the public health implications of the study findings for research, and policy practice.

Methods

This dissertation involved a series of papers contributing to the science of estimating FGM/C in Switzerland. We began by updating the indirect estimates for women and girls living with FGM/C in Switzerland, with annual estimates for 2010 through 2018. We applied the DHS and MICS total country prevalence estimates for FGM/C (for girls and women age 15-49) from high-prevalence countries to the number of migrant women and girls living in Switzerland. We also conducted a separate analysis for girls aged 0-14, applying the prevalence estimates of girls 0-14 to all migrant girls of the same age living in Switzerland with the same country of origin. When prevalence estimates for girls 0-14 were not available, we applied the prevalence estimates for their older counterparts (15-19 years of age). We used the most recent MICS or DHS estimates available for each year.

To investigate other methods besides indirect estimates to determine prevalence of women and girls with FGM/C in Switzerland, as well as gain a further understanding of the health complications facing women living with FGM/C, we turned to anonymized hospital data from Swiss university hospitals and to the Swiss HIV Cohort Study.

Based on available literature from systematic reviews and peer-reviewed publications about complications of FGM/C, we composed a comprehensive list of diseases, disorders and health-related consequences of FGM/C in alignment with the International Classification of Diseases (ICD). Four people, two of whom are clinicians/researchers working in specialized FGM/C clinics and two experts in ICD, reviewed both the ICD-9 and 10 to identify all conditions and medical procedures relevant to FGM/C. All known national modifications of the ICD were reviewed to identify all country-specific codes used to record FGM/C, as part of our proposed method of documenting and coding FGM/C.

Anonymized data were collected for all inpatient women and girls with a nationality from any of the 30 FGM/C practicing countries and all inpatients with a diagnosis of FGM/C between 2016 and 2018. Next, we calculated indirect estimates of FGM/C in Swiss hospitals as the proportion of the total number of FGM/C cases recorded on the total number of women and girls from the same countries in four Swiss university hospitals between 2016 and 2018. Using the country prevalence estimates of

FGM/C among women and girls with a nationality from high prevalence countries in 2016, 2017, and 2018, we then multiplied this to the total number of inpatient women and girls registered with the same nationality in the hospital data. We provided descriptive statistics with mean, ±standard deviation (SD), and median for continuous variables; number and proportions for categorical variables.

Then, we compared all categorical variables by year and FGM/C Type by region (West Africa vs. East Africa) using Chi-square or Fischer's exact tests. We compared mean ages by year using the non-parametric Kruskal-Wallis test and estimated FGM/C prevalence within the Swiss university hospital population between 2016 and 2018 and their 95% confidence intervals (95%CIs) using the binomial exact method (Clopper-Pearson method).

We analyzed all ICD diagnoses of FGM/C and interventions coded in the medical record from patients with a coded primary or secondary diagnosis of FGM/C. We provided descriptive statistics with mean, ±standard deviation, and median for continuous variables; numbers and proportions for categorical variables.

And finally, we conducted a national exploratory cross-sectional study with the help of the Swiss HIV Cohort Study (SHCS), administering two questions about history of FGM/C. We asked women if they had experienced FGM/C, and if so, whether they have ever discussed it with a healthcare provider. This was carried out during routine medical exams between June and December 2019 to help improve and inform our estimates for the number of women living with FGM/C in Switzerland.

Relevance of Research

The number of women and girls living with FGM/C continues to grow, not only in Switzerland but globally. Being able to stay abreast of fluctuating trends in both FGM/C prevalence and migration flows in diaspora countries is required to help inform policy and public health programmes.
Our indirect estimates will use the most recent prevalence figures available for each year in our analysis. To the best of our knowledge, no scientific publications on indirect estimates have been published at this time that present the updated list of DHS and MICS FGM/C prevalence rates past 2015-2016.

Our study is the first ever study of the use of ICD to identify health complications of FGM/C (to the best of our knowledge). We believe that FGM/C can be coded using the ICD, and will allow for comparisons over time and between countries/hospitals. ICD coding also permits the evaluation of the financial costs of FGM/C, as most countries use diagnostic related groupings (DRGs) for reimbursement that are linked to the classification. The ICD is a well-established tool that is used by many countries around the world to collect and record health data. Our recommended FGM/C coding method uses the ICD to document FGM/C and any related health conditions and/or procedures which we believe would be feasible for many countries.

We propose the use of indirect, direct and routine hospital data collection methods to help evaluate the available FGM/C data in Switzerland to improve future FGM/C monitoring and routine data collection.

Chapter 4: Coding Female Genital Mutilation/Cutting and its complications using the International Classification of Diseases: a commentary

Authors:

Sara Cottler-Casanova[1], Mathilde Horowicz[2], Sarah Gieszl[3], Crista Johnson-Agbakwu[4], Jasmine Abdulcadir[1]

1. Department of Paediatrics, Obstetrics and Gynaecology. Geneva University Hospitals. 30 Bld de la Cluse, 1211 Geneva, Switzerland
2. Faculty of Medicine. University of Geneva. Rue Michel-Servet 1, 1206 Geneva, Switzerland
3. Bureau of Public Health Statistics, Arizona Department of Health Services. 150 N 18th avenue, Phoenix, AZ 85007, USA
4. Refugee Women's Health Clinic. Obstetrics & Gynecology, Maricopa Integrated Health System. 2601 East Roosevelt Street, Phoenix, AZ 85008, USA
5. Office of Refugee Health, Southwest Interdisciplinary Research Center (SIRC). Watts College of Public Service & Community Solutions, Arizona State University. MC 5120, 201 North Central Avenue, 33rd Floor, Phoenix, AZ 85004, USA

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Commentary

Coding female genital mutilation/cutting and its complications using the International Classification of Diseases: a commentary

S Cottler-Casanova,[a] M Horowicz,[b] S Gieszl,[c] C Johnson-Agbakwu,[d,e] J Abdulcadir[a]

[a] Department of Woman, Child and Adolescent, Geneva University Hospitals, Geneva, Switzerland [b] Faculty of Medicine, University of Geneva, Geneva, Switzerland [c] Arizona Department of Health Services, Bureau of Public Health Statistics, Phoenix, AZ, USA [d] Refugee Women's Health Clinic, Obstetrics & Gynecology, Maricopa Integrated Health System, Phoenix, AZ, USA [e] Office of Refugee Health, Southwest Interdisciplinary Research Center (SIRC), Watts College of Public Service and Community Solutions, Arizona State University, Phoenix, AZ, USA

Correspondence: J Abdulcadir, Division of Gynaecology, Department of Woman, Child and Adolescent, Geneva University Hospitals, 30 Bld de la Cluse, 1211 Geneva, Switzerland. Email: jasmine.abdulcadir@hcuge.ch

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Female genital mutilation/cutting (FGM/C) is a procedure involving the partial or total removal of the external female genitalia for non-therapeutic reasons which can result in genitourinary, obstetric, and psychosexual complications.[1] According to UNICEF, at least 200 million girls and women have undergone FGM/C.[2] The available estimates are based on nationally representative data on FGM/C collected through survey programmes known as the Multiple Indicator Cluster Service (MICS), developed by UNICEF[2] or the Demographic and Health Surveys (DHS), carried out by ICF International. FGM/C has been reported in around 30 countries, in sub-Saharan Africa, Asia, and South America. Due to migration, girls and women who have undergone the practice in their home country or who are considered at risk of undergoing it, also live in high-income countries.[1–3]

Current data on FGM/C

Data on FGM/C in high-income diaspora countries, including the USA, Canada, Australia, New Zealand, Japan, and Europe, were mostly obtained using indirect estimates.[4] In the European Union (EU), 500 000 women and girls were estimated to be living with FGM/C, based on a secondary analysis of data from the 2011 EU census, using the extrapolation method, which uses age-specific FGM/C prevalence rates in immigrants' home countries.[5] In the USA, 513 000 women and girls with FGM/C were estimated to be living with FGM/C by applying country-specific prevalence of FGM/C to the estimated number of women and girls living in the USA or with a parent born in that country.[6]

The available estimates have several limitations. In high-income countries, there is the assumption that immigrants behave the same as they would in their home countries. However, recent studies suggest that education, acculturation, migration, length of stay in a country where FGM/C is illegal and not valued or normative, and being part of a new generation or community of immigrants seems to reduce support for the traditional practice.[7,8] In both high- and low-prevalence FGM/C countries, the reliability of self-reported FGM/C and FGM/C type through community or population-based surveys is low.[9] Women might not know whether they have experienced FGM/C, or which type they have undergone. Furthermore, the Demographic and Health Surveys and the MICS ask whether cutting was performed, and whether tissue was removed or sewn closed,[3] thus not differentiating the FGM/C types described by the World Health Organization (WHO) (Table 1).

An improved monitoring of the prevalence and incidence of FGM/C and its complications is important for both epidemiological reasons and for assessing prevention campaigns, laws, and care.

Monitoring FGM/C and its complications with the ICD

This paper suggests a method of documenting and coding health conditions and procedures related to FGM/C using the International Classification of Diseases, ninth (ICD-9) and tenth revisions (ICD-10).

The ICD is an international health information standard currently utilised in more than 100 countries, for coding

Table 1. Classification of FGM/C according to WHO[1]

Type I: Partial or total removal of the clitoris and/or the prepuce (clitoridectomy)
Type Ia: removal of the clitoral hood or prepuce only
Type Ib: removal of the clitoris with the prepuce
Type II: Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision)
Type IIa: removal of the labia minora only
Type IIb: partial or total removal of the clitoris and the labia minora
Type IIc: partial or total removal of the clitoris, the labia minora and the labia majora
Type III: Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation)
Type IIIa: removal and apposition of the labia minora
Type IIIb: removal and apposition of the labia majora
Type IV: Unclassified
All other harmful procedures to the female genitalia for non-medical purposes, for example, pricking, piercing, incising, scraping and cauterisation

The classification about FGM from WHO was proposed in 2007 and still refers to 'total removal of the clitoris' but the clitoris is not totally removed. It is the glans more or less the body of the clitoris that are removed.

mortality and morbidity, signs, symptoms, reasons for encounter, and external causes of injury and disease that allows measurements and comparisons at national and international level of medical, epidemiologic and economic information.[10] It can also inform decisions, interventions and policies and on disease incidence and outcomes.[10] In order to define health conditions, the ICD uses alphanumeric codes consisting of three characters: one letter and at least two digits.[11] Supplementary characters add more specificity. It has been revised several times. The ICD-9 codes expanded to the fifth character level and the ICD-10 codes to the sixth and seventh character level.[10,12]

The ICD could constitute a basis for monitoring the incidence and prevalence of FGM/C and its complications among women and girls across countries.[13] Our paper suggests a method of documenting and coding health conditions and procedures related to FGM/C using the ICD-9 and 10.

Four of the authors, two clinicians and researchers caring for women and girls with FGM/C in specialised clinics in Europe (J.A.) and USA (C.J.A.) and two epidemiologists with expertise in ICD (S.C., S.G.), reviewed the ICD-10 and ICD-9 manuals and identified conditions and medical procedures related to FGM/C and its complications according to available systematic reviews[1,14] and their clinical experience. We identified 166 codes of health conditions and medical procedures related to FGM/C in the ICD-10 and 148 codes in the ICD-9, and classified them into four groups: physical, psychological, sexual health, and obstetrical, perinatal, and fetal complications and procedures (Appendices S1 and S2). We also summarised country-specific codes used to describe FGM/C, depending on the ICD version used (Table 2). Indeed, some countries have made further specifications to the original WHO codes in order to describe FGM/C.[12] For instance, the original ICD-10 code 'Z91.7' indicates any type of FGM/C. The ICD-10 USA version uses the code 'N90.81' with several FGM/C type-specific five-character codes.

For our suggested method to be used, accurate documentation and coding of FGM/C by trained healthcare professionals and coders is needed. Depending on the countries, either caregivers may be responsible for coding or it may be performed by medical coders with specialised training. Our list could help caregivers and coders in the process of coding FGM/C complications, and may facilitate identification of certain clinical situations as complications of FGM/C. Such data would be useful to assess and inform prevention and care programmes at inter-regional, country-specific or transcontinental levels. For example, the appropriate mode of delivery in women with FGM/C type III could represent one area of study, as infibulated women are reported to be at higher risk of delivering by caesarean section in areas where defibulation is not routinely offered.[1] Furthermore, in the absence of a clear indication for a caesarean, women with FGM/C often undergo the procedure for maternal, rather than fetal indications, unlike women without FGM/C,[17] because of a lack of training on defibulation procedures and treatment plans among medical students and practitioners. This could be rectified with adapted training programmes. By monitoring caesarean section rates and their indications among women with and without FGM/C type III across different hospitals, insights may be gleaned on quality of care and needs for professional training.

FGM/C can inflict substantial medical and socio-economic costs, which could be reduced by eliminating the practice[18] and/or managing the increased risks, such as facilitating timely defibulation in cases of FGM/C type III. Systematic documentation and coding of FGM/C is essential to evaluate the economic costs of FGM/C itself, its complications, and related procedures. In addition, it would allow measurement of the cost effectiveness of specialised care, policies, prevention, and training campaigns, as precise analysis is still lacking.[18]

The UK presents national prevalence data on FGM/C through *The Female Genital Mutilation (FGM) Enhanced Dataset* (SCCI 2026).[19] The protocol requires that all acute, general, and mental health practices document demographic, clinical, and family information for all women with FGM/C and that they submit these data, without anonymisation, to the Health and Social Information

Table 2. Examples of FGM/C codes according to ICD national modifications

ICD version	Countries	Code	Diagnosis
ICD-10 2016 (International Version)	For example: UK[15]	Z91.7	Personal History of Female Genital Mutilation
ICD-10-AM (Australia)	Australia, Ireland, Slovenia[16]		
ICD-10-FR (France)	France[16]		
ICD-10-GM (Germany)	Germany, Switzerland, Austria[16]	Z91.7	Personal History of Female Genital Mutilation
		Z91.70	Personal History of Female Genital Mutilation, Type unspecified
		Z91.71	Personal History of Female Genital Mutilation, Type 1
		Z91.72	Personal History of Female Genital Mutilation, Type 2
		Z91.73	Personal History of Female Genital Mutilation, Type 3
		Z91.74	Personal History of Female Genital Mutilation, Type 4
ICD-10-CM (USA)	USA, Belgium, Luxembourg, Portugal, Spain[16]	N90.81	Female Genital Mutilation status
		N90.810	Female Genital Mutilation status, unspecified
		N90.811	Female Genital Mutilation Type I status
		N90.812	Female Genital Mutilation Type II status
		N90.813	Female Genital Mutilation Type III status
		N90.818	Other Female Genital Mutilation Status
ICD-9-CM (USA	Italy[16]	629.2	Female Genital Mutilation status
		629.20	Female Genital Mutilation status, unspecified
		629.21	Female Genital Mutilation Type I status
		629.22	Female Genital Mutilation Type II status
		629.23	Female Genital Mutilation Type III status
		629.29	Other Female Genital Mutilation Status

Centre for prevalence monitoring.[19] Documenting the FGM/C status is to be performed even if FGM/C is not the reason of consultation, and a clinical examination may be indicated to determine the FGM/C type.[20] Women and girls might find such an approach invasive or stigmatising, leading to disengagement from health services.[13,21] Furthermore, this method would be time- and resource-consuming, expensive, and hardly suitable for other countries with both high and low FGM/C prevalence.

Implementing ICD monitoring of FGM/C

The main current limitation of collecting data on FGM/C through ICD-coding is the lack of accurate documentation, which is mainly a consequence of insufficient training.[13] Education on FGM/C is rarely or poorly included in medical curricula in most countries. Healthcare professionals find it difficult to screen, ask about, diagnose, classify, and document FGM/C correctly.[22] According to the 2019 NHS report, only 59% of 6415 previously and newly documented women and girls had a known type of FGM/C documented.[19] If FGM/C is not documented and/or misreported by most caregivers, we can hypothesise that the ICD coding of FGM/C and its link to relevant comorbidities, complications, and procedures is underreported. First, healthcare professionals should be trained on the diagnosis of FGM/C and its related conditions, and should ensure a tactful approach to establish a therapeutic alliance and minimise risk of re-traumatisation. Learning tools that include drawings, pictures, and videos[17,23] are already being used for training in low- and high-prevalence countries. A WHO handbook is also available.[1] Continuous education programmes on FGM/C can be organised in various hospital departments and medical associations. Secondly, caregivers should be sensitised to accurate documentation of FGM/C. Thirdly, medical coders (and caregivers for countries where they also code) should receive appropriate training on the use of ICD codes for FGM/C. A study conducted in Belgium between 2012 and 2015 showed that coding of FGM/C cases significantly increased after training sessions on accurate registration of FGM/C.[24] We recommend the sensitisation and training of obstetricians and gynaecologists, paediatricians, infectious disease and travel medicine specialists, urologists, emergency medicine, forensics, and primary care providers, as well as nurses and midwives in these departments/services, as they often carry out genital examinations.

The tables presented in our paper will need to be updated, as different countries will begin documenting with ICD-11 codes, already available online, from January 2022 onwards.[10] The latest version, ICD-11, includes codes for the subtypes of FGM/C which are lacking in both ICD-9 and ICD-10.

The number of girls at risk of FGM/C in several EU countries has been estimated through indirect prevalence

estimates combined with the impact of migration, acculturation, and length of stay in destination countries.[8] An integrative method could include specific codes for girls at risk of FGM/C to enable the implementation of surveillance and monitoring of the incidence of the practice among uncut girls who have been identified as 'at risk'. The non-specific code Z60.8 'other problems related to social environment' was proposed as a code for 'risk of FGM/C' at an expert meeting in Barcelona in 2018.[25]

Currently, the absence of a harmonised database for destination countries for migration (EU versus non-EU countries) prevents the comparability of available indirect FGM/C prevalence estimates.[4] Given the longstanding and widespread use of the ICD around the world, our suggested ICD coding method of FGM/C related conditions and procedures is easily achievable for several countries. ICD is an existing and unique, reproducible tool that could enable standardised international comparisons. Additionally, we can hypothesise that accurate documentation and coding of FGM/C by caregivers will give more reliable data than those obtained through self-reports.[9] Traditional studies conducted to assess directly the prevalence and consequences of FGM/C incur substantial human and financial resources and must be repeated over time. If healthcare professionals invest time and monetary resources in maintaining this standardised ICD method, we believe this will result in a reproducible, sustainable, and comparable data source without incurring significant additional costs.

We recommend healthcare professionals and medical coders start using this proposed list of ICD codes to document and code FGM/C, its associated procedures, and complications, as well as girls 'at risk'. The introduction of the ICD-11 may serve as the springboard to initiate longitudinal prospective studies on FGM/C and its relevant complications in order to capture accurate prevalence and incidence data and build case finding algorithms. Pilot sites could be designated whereby medical coders and healthcare professionals could be trained on how to document and code FGM/C, its associated procedures and complications, as in Belgium.[24] The impact of FGM/C and its complications could be studied through its economic burden, cost effectiveness of care (e.g. specialised clinics, certified interpreters in migration countries), enacted policies, prevention campaigns, and changes in medical education.

Disclosure of interests

None declared. Completed disclosure of interests forms are available to view online as supporting information.

Contribution to authorship

JA designed and directed the project. SC, SG, CJA, and JA reviewed and extracted the codes of FGM/C, its complications, and related procedures in the ICD-9 and ICD-10 manuals. MH and JA wrote the manuscript in collaboration with SC, CJA, and SG. All the authors reviewed and approved the manuscript.

Details of ethics approval

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1. FGM/C complications and ICD-9 corresponding codes.

Appendix S2. FGM/C complications and ICD-10 corresponding codes. ■

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Chapter 5: Estimating the indirect prevalence of Female Genital Mutilation/Cutting in Switzerland

Authors:

Sara Cottler-Casanova[1,2,3], Jasmine Abdulcadir[3,4]

1. Department of Epidemiology and Public Health, Swiss Tropical and Public Health Institute, Basel, Switzerland
2. University of Basel, Basel, Switzerland
3. Department of Paediatrics, Obstetrics and Gynaecology. Geneva University Hospitals. 30 Bld de la Cluse, 1211 Geneva, Switzerland
4. Faculty of Medicine. University of Geneva. Rue Michel-Servet 1, 1206 Geneva, Switzerland

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Estimating the indirect prevalence of female genital mutilation/cutting in Switzerland

S. Cottler-Casanova[1,2,3*] and J. Abdulcadir[1]

Abstract

Background: We updated the indirect estimates for women and girls living with Female Genital Mutilation Cutting (FGM/C) in Switzerland, using data from the Swiss Federal Statistical Office of migrant women and girls born in one of the 30 high-prevalence FGM/C countries that are currently living in Switzerland.

Methods: We used Yoder and Van Baelen's "Extrapolation of FGM/C Countries' Prevalence Data" method, where we applied DHS and MICS prevalence figures from the 30 countries where FGM/C is practiced, and applied them to the immigrant women and girls living in Switzerland from the same 30 countries.

Results: In 2010, the estimated number of women and girls living with or at risk of FGM/C in Switzerland was 9059, whereas in 2018, we estimated that 21,706 women and girls were living with or at risk of FGM/C.

Conclusion: Over the past decade, there have been significant increases in the number of estimated women and girls living with or at risk of FGM/C in Switzerland due to the increase in the total number of women and girls originally coming form the countries where the practice of FGM/C is traditional.

Keywords: Female genital mutilation, Female genital cutting, Female genital mutilation/cutting, Indirect estimates, Prevalence, Switzerland

Background

The practice of Female Genital Mutilation/Cutting (FGM/C) has been recorded in more than 31 countries around the world. The prevalence of the traditional practice has been widely documented, with standardized survey methodologies developed and refined over the past decades. The main surveys used to estimate prevalence of FGM/C are the Demographic Health Survey (DHS) developed by ICF International [1] and the Multiple Indicator Cluster Surveys (MICS) led by UNICEF [2]. These surveys provide national FGM/C estimates by sampling households that are representative of the national population and asking them a series of questions about FGM/C, such as whether and how the procedure was conducted, at what age, and by type of practitioner.

UNICEF's most recent estimates report that the number of women and girls that have undergone FGM/C globally have reached 200 million [3]. However, their estimates lack data from countries where the traditional practice is carried out but no data exists (e.g. Saudi Arabia, India, etc.). Additionally, this estimate does not include data from high-income countries where first or following generations of women and girls with FGM/C live [4]. The real prevalence and incidence of FGM/C is unknown in Switzerland and many parts of Europe, as there are no representative surveys similar to DHS or

* Correspondence: sara.cottler@me.com
[1]Division of Gynaecology, Department of Paediatrics, Gynaecology and Obstetrics, Geneva University Hospitals, Boulevard de la Cluse 30, Geneva 1211, Switzerland
[2]Department of Epidemiology and Public Health, Swiss Tropical and Public Health Institute, Basel, Switzerland
Full list of author information is available at the end of the article

MICS for European countries. Demographers predict that migrants coming from FGM/C-practicing countries towards high income and European countries such as Switzerland will continue to increase [5]. A study published in 2016 analyzing data from the 2011 European census, estimated that, of the 1,353,970 women and girls in Europe aged 10 years and above coming from 1 of the 30 high-prevalence FGM/C countries, an estimated 578,068 women and girls have undergone some type of FGM/C [4]. As of February 2020, there are now 31 FGM/C high-prevalence countries with MICS/DHS estimates, with the addition of the Maldives. The surge of migrants from these countries thus affects the number of women and girls living with FGM/C in Europe. In 2016, estimates in Switzerland showed that around 14,700 women and girls were respectively living with FGM/C or were considered to be theoretically at risk of having undergone or undergoing FGM/C in the future due to their geographical origin only [6]. Since then, estimates have not been updated.

Maria Roth Bernasconi's parliament initiative to introduce a specific Swiss penal code article against female genital mutilation was the catalyst for the Swiss government's involvement in the issue of FGM/C [7]. The Federal Office of Public Health (FOPH) has been funding awareness-raising and prevention measures aimed at preventing FGM/C through the national program Migration and Health since 2003. The State Secretariat for Migration, SEM, has been involved in these activities since 2010 as well. In 2015, the National Council decided to support a network to tackle female genital mutilation for the 2016–2019 period. This period has been prolonged until 2021 [8].

More recent and regular estimates on women and girls affected by FGM/C need to be carried out in Switzerland to guide policies. One of the biggest challenges to getting up-to-date estimates is to determine a reliable number of migrant women and girls by country of origin, which usually requires access to census data of the country—limiting estimates to ten-year periods for many European countries. Switzerland is in a unique position because since 2010, the Swiss census is carried out annually, providing a modern statistical database for researchers, policy makers, etc. to observe various data points on a continuous basis [9].

The aim of this study is to update the indirect prevalence estimates for women and girls living with FGM/C in Switzerland, using data from the Swiss Federal Statistical Office of migrant women and girls, born in one of the 30 high-prevalence FGM/C countries that are currently living in Switzerland, i.e. first-generation migrants. Such an update is the first step of a wider research project conducted in Switzerland in 2018 entitled "Female Genital Mutilation/Cutting with a focus on prevalence, risk factors and Swiss health care professionals' capacities".

Methods

We used a similar methodology to Yoder and Van Baelen [4, 10], applying FGM/C DHS and MICS prevalence figures (for girls and women age 15–49) from high-prevalence countries to the number of migrant women and girls living in Switzerland.

We applied the total country prevalence estimates of women aged 15–49 to all migrant women and girls living in Switzerland from the same countries. We also conducted a separate analysis for girls aged 0–14, where we applied the prevalence estimates of girls 0–14 to all migrant girls 0–14 living in Switzerland from the same countries. Where no prevalence estimates for girls 0–14 were available, we applied the prevalence estimates for girls 15–19.

We used the most recent MICS or DHS estimates available for each year (Table 1) and multiplied them to the number of immigrant women and girls from each FGM/C high-prevalence country from 2010 to 2018 based on the Swiss Federal Statistical Office (FSO)'s Interactive Database. USAID's Demographic and Health Surveys (DHS) and UNICEF's Multiple Indicator Cluster Surveys (MICS) are large-scale population-based surveys that produce estimates of socioeconomic and health indicators in low- and middle-income countries [1, 2]. The DHS and MICS surveys have played an important role in the reporting of FGM/C prevalence data in low- and middle- income countries over the past 30 years. Table 1 shows the prevalence estimates from women and girls aged 15–49 that are available for 30 countries where FGM/C is practiced that we used in our study.

We used the Swiss Federal Statistical Office's (FSO) publicly available interactive database STAT-TAB to obtain the number of female permanent and non-permanent residents living in Switzerland from 2010 to 2018 from high FGM/C prevalence countries [11].

We included women and girls of all ages, who have a residence permit labeled "Swiss", Residence permit (permit B), a settlement permit (permit C), a residence permit with gainful employment (permit Ci), a status of provisionally admitted person (permit F), or of asylum seeker (permit N), or who were diplomats, international civil servants with diplomatic immunity and international civil servants without diplomatic immunity. The citizenship countries that we included were the ones for which FGM/C estimates were available and is known to be practiced: Benin, Burkina Faso, Cameroon, Central African Republic, Chad, Ivory Coast, Djibouti, Egypt, Eritrea, Ethiopia, Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Liberia, Mali, Mauritania, Niger, Nigeria, Senegal, Sierra Leone, Somalia, Sudan and South Sudan, Tanzania, Togo, Uganda, Iraq, Yemen (Table 2) [3]. Table 2 shows the number of migrant women and girls of all ages living in Switzerland from high FGM/C

Table 1 FGM/C Country Prevalence Estimates

Country	Prevalence Estimate (Women ages 15–49), Source, Year of Publication
Benin	(.129 DHS 2006) (.073 DHS 2011–2012) (.092 MICS 2014)
Burkina Faso	(.758 DHS 2010)
Cameroon	(.014 DHS 2004)
Central African Republic	(.242 MICS 2010)
Chad	(.442 MICS 2010) (.384 DHS 2014–2015)
Djibouti	(.931 MICS 2006)
Egypt	(.911 DHS 2008) (.923 DHS 2014) (.872 DHS 2015)
Eritrea	(.83 PHS 2010)
Ethiopia	(.743 DHS 2005) (.652 DHS 2016)
Gambia	(.763 MICS 2010) (.749 DHS 2013) (.757 MICS 2018)
Ghana	(.038 MICS 2006) (.038 MICS 2011)
Guinea	(.956 DHS 2005) (.969 DHS/MICS 2012) (.968 MICS 2016) (.945 DHS 2018)
Guinea-Bissau	(.498 MICS 2010) (.449 MICS 2014)
Iraq	(.081 MICS 2011) (.074 MICS 2018)
Ivory Coast	(.364 MICS 2006) (.382 DHS 2011–2012) (.367 MICS 2016)
Kenya	(.271 DHS 2008–2009) (.21 DHS 2014)
Liberia	(.582 DHS 2007) (.498 DHS 2013)
Mali	(.885 MICS 2010) (.914 DHS 2013) (.827 MICS 2015) (.886 DHS 2018)
Mauritania	(.722 MICS 2007) (.694 MICS 2011) (.666 MICS 2015)
Niger	(.022 DHS/MICS 2006) (.02 DHS/MICS 2012)
Nigeria	(.296 DHS 2008) (.27 MICS 2011) (.248 DHS 2013) (.184 MICS 2016–2017) (.195 DHS 2018)
Senegal	(.257 DHS/MICS 2010–2011) (.247 DHS 2014) (.242 DHS 2015) (.227 DHS 2016) (.24 DHS 2017)
Sierra Leone	(.88 MICS 2010) (.896 DHS 2013) (.861 MICS 2017)
Somalia	(.979 MICS 2006)
Sudan & South Sudan	(.876 SHHS 2010) (.866 MICS 2014)
Tanzania	(.146 DHS 2010) (.1 DHS 2015–2016)
Togo	(.039 MICS 2010) (.047 DHS 2013–2014)
Uganda	(.006 DHS 2006) (.014 DHS 2011) (.03 DHS 2016)
Yemen	(.215 FHS 2003) (.185 DHS 2013)

prevalence countries between 2010-2018. This differs slightly from the UNICEF Switzerland estimates from 2012, as Zambia has since been excluded, and Iraq has been included [12].

Table 3 shows the number of migrant girls aged 0–14 living in Switzerland from 2010 to 2018 from high FGM/C prevalence countries. We used the STAT-TAB database to obtain the information.

Results

Table 4 describes the estimated total number of women and girls in Switzerland that are living with FGM/C. Indonesia was excluded because there are no DHS and MICS prevalence estimates for the country. In 2010, there were 914 women and girls from Indonesia living in Switzerland, and in 2018, there were 1229.

The evolution of migratory flows throughout the past years has had an effect on the total number of female migrants from these high-prevalence FGM/C countries (Table 2). Between 2010 and 2018, the total number of female migrants has increased, particularly from Eritrea (5-fold increase), with smaller increases from Ethiopia, Egypt, Gambia, Iraq, Kenya, Nigeria, Senegal, Somalia, and Sudan & South Sudan. The number of women from Chad, Sierra Leone and Liberia has slightly declined, while others have stayed stable. Thus, the number of girls and women affected by FGM/C has changed as well.

Over the past decade, there have been significant increases in the number of estimated women and girls living with FGM/C in Switzerland. Our estimates show that in 2010, of the 19,506 women and girls living in Switzerland coming from 1 of the 30 countries where FGM/C is traditional, an estimated 9059 were subjected

Table 2 Migrant Women and Girls in Switzerland 2010–2018

Country	Swiss 2010 Migrants Living in Switzerland [WOMEN & GIRLS]	Swiss 2011 Migrants Living in Switzerland [WOMEN & GIRLS]	Swiss 2012 Migrants Living in Switzerland [WOMEN & GIRLS]	Swiss 2013 Migrants Living in Switzerland [WOMEN & GIRLS]	Swiss 2014 Migrants Living in Switzerland [WOMEN & GIRLS]	Swiss 2015 Migrants Living in Switzerland [WOMEN & GIRLS]	Swiss 2016 Migrants Living in Switzerland [WOMEN & GIRLS]	Swiss 2017 Migrants Living in Switzerland [WOMEN & GIRLS]	Swiss 2018 Migrants Living in Switzerland [WOMEN & GIRLS]
Benin	116	124	147	156	145	150	146	143	127
Burkina Faso	168	180	181	180	187	189	189	199	192
Cameroon	2694	2724	2721	2728	2724	2741	2760	2737	2705
Central African Republic	28	27	31	24	25	24	29	33	33
Chad	59	57	62	73	71	70	68	64	64
Djibouti	11	13	14	14	15	18	19	16	16
Egypt	668	736	761	813	826	827	834	865	864
Eritrea	3558	5017	7321	8388	10,300	12,859	14,339	15,600	16,543
Ethiopia	1495	1535	1668	1772	1847	1946	2050	2076	2095
Gambia	64	68	86	98	106	123	121	130	141
Ghana	693	688	701	707	715	708	714	715	723
Guinea	215	229	260	269	287	299	319	335	362
Guinea-Bissau	19	34	45	49	47	54	53	54	61
Iraq	2768	2821	2794	2809	2901	3490	3719	3725	3804
Ivory Coast	885	921	958	976	984	978	971	1006	1008
Kenya	867	907	922	934	972	999	1023	1028	1072
Liberia	64	66	69	69	63	62	60	59	56
Mali	106	103	115	117	121	104	108	108	115
Mauritania	30	35	35	31	31	28	27	33	32
Niger	41	39	40	42	44	48	42	41	49
Nigeria	695	795	880	857	889	900	909	967	987
Senegal	498	522	547	567	591	632	656	675	672
Sierra Leone	79	71	75	68	64	76	71	74	72
Somalia	2266	2396	2648	2705	2819	3031	3243	3275	3290
Sudanb	256	274	289	286	312	324	373	373	409
Tanzania	163	165	162	170	174	177	184	183	188
Togo	568	599	628	649	680	697	699	688	687
Uganda	222	214	219	222	214	204	210	235	253
Yemen	210	225	239	250	271	277	266	270	278
Total	19,506	21,585	24,618	26,023	28,425	32,035	34,202	35,707	36,898

to the harmful practice. In 2018, of the 36,898 women and girls living in Switzerland coming from 1 of the 30 high prevalence FGM/C countries, an estimated 21,706 have been subjected to the harmful practice.

More than 16,000 of the 36,898 migrant women from the FGM/C high prevalence countries in 2018 come from Eritrea. The indirect estimation of Eritrean women living in Switzerland, where FGM/C estimated prevalence is among the highest in the world, is 13, 730. The second highest migrant group of this population comes from Somalia, where the FGM/C estimated prevalence is almost 98%. Out of 3290 women

Table 3 Migrant Girls in Switzerland 2010–2018

Country	Swiss 2010 Migrants Living in Switzerland [GIRLS 0–14]	Swiss 2011 Migrants Living in Switzerland [GIRLS 0–14]	Swiss 2012 Migrants Living in Switzerland [GIRLS 0–14]	Swiss 2013 Migrants Living in Switzerland [GIRLS 0–14]	Swiss 2014 Migrants Living in Switzerland [GIRLS 0–14]	Swiss 2015 Migrants Living in Switzerland [GIRLS 0–14]	Swiss 2016 Migrants Living in Switzerland [GIRLS 0–14]	Swiss 2017 Migrants Living in Switzerland [GIRLS 0–14]	Swiss 2018 Migrants Living in Switzerland [GIRLS 0–14]
Benin	29	32	41	46	36	41	40	41	31
Burkina Faso	27	24	27	20	23	21	24	26	28
Cameroon	409	407	410	413	407	419	425	406	392
Central African Republic	3	3	4	0	0	0	3	4	4
Chad	15	16	20	22	26	29	27	25	24
Djibouti	3	4	5	5	6	7	5	2	2
Egypt	166	178	184	212	216	213	202	207	194
Eritrea	1084	1556	2214	2685	3235	3923	4632	5355	5970
Ethiopia	367	360	412	417	418	435	465	496	497
Gambia	10	12	20	26	27	34	31	33	39
Ghana	150	144	150	156	154	150	142	138	133
Guinea	48	49	63	62	64	80	87	89	102
Guinea-Bissau	4	7	11	11	11	12	13	13	16
Iraq	934	918	885	895	930	1152	1233	1211	1253
Ivory Coast	120	135	147	160	159	158	157	167	163
Kenya	94	115	118	117	139	134	143	136	141
Liberia	15	16	19	18	15	15	12	12	13
Mali	22	20	23	22	20	15	20	19	16
Mauritania	5	10	9	6	5	3	4	8	6
Niger	8	10	10	11	12	13	10	9	11
Nigeria	172	210	225	227	228	242	240	251	260
Senegal	75	78	85	97	107	116	121	123	119
Sierra Leone	18	19	20	19	19	22	20	21	17
Somalia	754	817	925	973	1005	1038	1092	1151	1172
Sudanb	77	87	92	83	89	84	100	93	103
Tanzania	22	23	22	23	21	22	27	26	30
Togo	158	175	187	187	201	205	198	185	180
Uganda	36	28	31	34	31	24	25	31	41
Yemen	75	77	77	84	89	85	70	67	65
Total	4900	5530	6436	7031	7693	8692	9568	10,345	11,022

and girls living in Switzerland from Somalia, the applied indirect estimate is 3220 women.

Some countries have made improvements to their prevalence rates over the past years, for example Ethiopia, whose prevalence was .742 in 2010 and has decreased to .650 in 2016, which has an impact on the number of women and girls originating from these countries estimated to be living with FGM/C in Switzerland. In 2010, out of 1495 women and girls from Ethiopia, 1110 were estimated to be living with FGM/C. Fast forward to 2018, 1365 women and girls are estimated to be living with FGM/C out of 2095 total migrant women from Ethiopia.

Table 4 Applied Indirect Estimates for Women and Girls (Age 15+) 2010–2018

Country	Swiss 2010 Applied Indirect Estimate [WOMEN & GIRLS]	Swiss 2011 Applied Indirect Estimate [WOMEN & GIRLS]	Swiss 2012 Applied Indirect Estimate [WOMEN & GIRLS]	Swiss 2013 Applied Indirect Estimate [WOMEN & GIRLS]	Swiss 2014 Applied Indirect Estimate [WOMEN & GIRLS]	Swiss 2015 Applied Indirect Estimate [WOMEN & GIRLS]	Swiss 2016 Applied Indirect Estimate [WOMEN & GIRLS]	Swiss 2017 Applied Indirect Estimate [WOMEN & GIRLS]	Swiss 2018 Applied Indirect Estimate [WOMEN & GIRLS]
Benin	14.964	9.052	10.731	11.388	13.340	13.800	13.432	13.156	11.684
Burkina Faso	127.344	136.440	137.198	136.440	141.746	143.262	143.262	150.842	145.536
Cameroon	37.716	38.136	38.094	38.192	38.136	38.374	38.640	38.318	37.870
Central African Republic	6.776	6.534	7.502	5.808	6.050	5.808	7.018	7.986	7.986
Chad	26.078	25.194	27.404	32.266	27.264	26.880	26.112	24.576	24.576
Djibouti	10.241	12.103	13.034	13.034	13.965	16.758	17.689	14.896	14.896
Egypt	608.548	670.496	693.271	740.643	762.398	721.144	727.248	754.280	753.408
Eritrea	2953.140	4164.110	6076.430	6962.040	8549.000	10,672.970	11,901.370	12,948.000	13,730.690
Ethiopia	1110.785	1140.505	1239.324	1316.596	1372.321	1445.878	1336.600	1353.552	1365.940
Gambia	48.832	51.884	65.618	73.402	79.394	92.127	90.629	97.370	106.737
Ghana	26.334	26.144	26.638	26.866	27.170	26.904	27.132	27.170	27.474
Guinea	205.540	218.924	251.940	260.661	278.103	289.731	308.792	324.280	342.090
Guinea-Bissau	9.462	16.932	22.410	24.402	21.103	24.246	23.797	24.246	27.389
Iraq	224.210	228.501	226.314	227.529	234.981	282.690	301.239	301.725	281.496
Ivory Coast	322.140	351.822	365.956	372.832	375.888	373.596	356.357	369.202	369.936
Kenya	234.957	245.797	249.862	253.114	204.120	209.790	214.830	215.880	225.120
Liberia	37.248	38.412	40.158	34.362	31.374	30.876	29.880	29.382	27.888
Mali	93.810	91.155	101.775	106.938	110.594	86.008	89.316	89.316	101.890
Mauritania	21.660	24.290	24.290	21.514	21.514	18.648	17.982	21.978	8.986
Niger	0.902	0.858	0.800	0.840	0.880	0.960	0.840	0.820	0.980
Nigeria	205.720	214.650	237.600	212.536	220.472	223.200	167.256	177.928	192.465
Senegal	127.986	134.154	140.579	145.719	145.977	152.944	148.912	162.000	161.280
Sierra Leone	69.520	62.480	66.000	60.928	57.344	68.096	63.616	63.714	61.992
Somalia	2218.414	2345.684	2592.392	2648.195	2759.801	2967.349	3174.897	3206.225	3220.910
Sudanb	224.256	240.024	253.164	250.536	270.192	280.584	323.018	323.018	354.194
Tanzania	23.798	24.090	23.652	24.820	25.404	17.700	18.400	18.300	18.800
Togo	22.152	23.361	24.492	30.503	31.960	32.759	32.853	32.336	32.289
Uganda	1.332	2.996	3.066	3.108	2.996	2.856	0.630	0.705	0.759
Yemen	45.150	48.375	51.385	46.250	50.135	51.245	49.210	49.950	51.430
Total	9059.01	10,593.10	13,011.079	14,081.462	15,873.622	18,317.183	19,650.957	20,841.151	21,706.691

Table 5 describes the estimated total number of girls ages 0–14 in Switzerland that are at risk of or have undergone FGM/C. This number is based on the indirect prevalence calculation, using data from the Swiss Federal Statistical Office of migrant girls born in one of the 30 high-prevalence FGM/C countries that are currently living in Switzerland (Tables 3 and 4), and multiplied by each country's most recent DHS and MICS prevalence estimates for ages 0–14. Where estimates for this age group were not available, estimates for the 15–19 age group were used. In 2018, of the 11,022 girls living in Switzerland coming from 1 of the 30 high prevalence FGM/C countries, 3512 are estimated to be at risk or have been subjected to the harmful practice. Migrant girls from countries such as Eritrea, Gambia, Guinea, Senegal and Somalia all saw increases in the number of

Table 5 Applied Indirect Estimates for Girls at risk or having undergone FGM/C (Ages 0–14) 2010–2018

Country	Swiss 2010 Applied Indirect Estimate [GIRLS 0–14]	Swiss 2011 Applied Indirect Estimate [GIRLS 0–14]	Swiss 2012 Applied Indirect Estimate [GIRLS 0–14]	Swiss 2013 Applied Indirect Estimate [GIRLS 0–14]	Swiss 2014 Applied Indirect Estimate [GIRLS 0–14]	Swiss 2015 Applied Indirect Estimate [GIRLS 0–14]	Swiss 2016 Applied Indirect Estimate [GIRLS 0–14]	Swiss 2017 Applied Indirect Estimate [GIRLS 0–14]	Swiss 2018 Applied Indirect Estimate [GIRLS 0–14]
Benin	0.06	0.10	0.12	0.14	0.07	0.08	0.08	0.08	0.062
Burkina Faso	3.59	3.19	3.59	2.66	3.06	2.79	3.19	3.46	3.724
Cameroon	2.86	2.85	2.87	2.89	2.85	2.93	2.98	2.84	2.744
Central African Republic	0.02	0.02	0.03	0.00	0.00	0.00	0.02	0.03	0.032
Chad	1.83	1.95	2.44	2.68	2.57	2.87	2.67	2.48	2.376
Djibouti	1.46	1.94	2.43	2.43	2.91	3.40	2.43	0.97	0.97
Egypt	40.01[d]	42.90[d]	44.34[d]	51.09[d]	46.22[d]	30.03	28.48	29.19	27.354
Eritrea	478.04	686.20	976.37	1184.09	1426.64	1730.04	2042.71	2361.56	2632.77
Ethiopia	138.36	135.72	155.32	157.21	157.59	164.00	73.01	77.87	78.029
Gambia	4.24	5.09	8.48	19.84[a]	20.60[a]	25.94[a]	23.65[a]	25.18[a]	19.734
Ghana	2.10[a]	0.58	0.60	0.62	0.62	0.60	0.57	0.55	0.532
Guinea	27.26	27.83	28.67	28.21	29.12	36.40	39.41	40.32	39.882
Guinea-Bissau	1.55	2.71	4.26	4.26	3.26	3.55	3.85	3.85	4.736
Iraq	192.40[b]	189.11	182.31	184.37	191.58	237.31	254.00	249.47	6.265
Ivory Coast	11.40	14.18	15.44	16.80	16.70	16.59	17.11	18.20	17.767
Kenya	13.72[a]	16.79[a]	17.23[a]	17.08[a]	3.89	3.75	4.00	3.81	3.948
Liberia	5.37[a]	5.73[a]	6.80[a]	5.60	4.67	4.67	3.73	3.73	4.043
Mali	16.41	14.92	17.16	15.22	13.84	11.46	15.28	14.52	11.632
Mauritania	3.29	5.48	4.93	3.29	2.74	1.60	2.13	4.26	3.192
Niger	0.07[a]	0.09[a]	0.14[a]	0.15[a]	0.17[a]	0.18[a]	0.14[a]	0.13[a]	0.154[a]
Nigeria	51.43	40.32	43.20	38.36	38.53	40.90	60.72	63.50	49.92
Senegal	9.68[c]	10.06[c]	10.97	12.51	13.80	16.94	16.46	17.22	16.66
Sierra Leone	1.80	1.90	2.00	14.12[a]	14.12[a]	16.35[a]	14.86[a]	1.76	1.428
Somalia	346.84	375.82	425.50	447.58	462.30	477.48	502.32	529.46	539.12
Sudanb	28.49	32.19	34.04	30.71	28.04	26.46	31.50	29.30	32.445
Tanzania	0.75	0.78	0.75	0.78	0.71	1.03	1.27	1.22	1.41
Togo	0.63	0.70	0.75	0.56	0.60	0.62	0.59	0.56	0.54
Uganda	0.18	0.03	0.03	0.03	0.03	0.02	0.03	0.03	0.041
Yemen	16.13	16.555	16.56	13.78[a]	14.60[a]	13.94[a]	11.48[a]	10.99[a]	10.66[a]
Total	1399.97	1635.72	2007.32	2257.07	2501.81	2871.93	3158.67	3496.51	3512.17

[a]Estimates for ages 15–19 were used when estimates for 0–14 were unavailable
[b]In Iraq, estimates for 2011 were used when estimates for 2010 were unavailable
[c]Estimates for Senegal for 2010–2011 are for girls ages 0–10, not 0–15
[d] Estimates for Egypt from 2010 to 2014 include ages 0–19

girls aged 0–14 that are estimated to be living with or at risk of FGM/C in Switzerland between 2010 and 2018. Over the past 10 years, some countries saw a decrease in the number of girls aged 0–14 that are estimated to be living with FGM/C in Switzerland, such as Egypt, Ethiopia, Kenya, Liberia, and Yemen,

The applied indirect estimates for 2018 show a significant decrease for the number of migrant girls with

FGM/C from Iraq. New prevalence estimates reported that .005% of girls in Iraq are reported to be at risk or have undergone any form of FGM/C. Out of 1253 girls from Iraq, only 6 girls are estimated to be at risk or have undergone FGM/C. All tables and estimations are available in Additional file 1.

Discussion

The increase in overall migration from the 30 high-prevalence FGM/C countries should not be overlooked. This increased migrant population leads to an increased estimated FGM/C indirect prevalence [11]. Take for example, the large number of Eritreans present in Switzerland. In 2017, 18,088 people sought asylum in Switzerland [13]. The main country of origin of asylum seekers was Eritrea, with 3375 applications, accounting for over 10% of all applications [13]. Eritreans have been fleeing compulsory military service and dictatorship in their country [14]. However, these asylum applications have continued to fall the past couple of years both in Europe and Switzerland [13]. In 2017, asylum applications were down 33% from 2016—one of the main reasons being that Eritrean arrivals had significantly fallen and that had a direct impact on the number of asylum applications.

Indirect estimation is a systematic and affordable method for estimating the number of women with FGM/C in high-income countries [15–17]. Leye et al. outline that these estimations allow policy makers to look for trends as well as evaluate the impact of prevention programs based on reliable approximations [18]. However, it has methodological limitations and may not reflect the actual FGM/C prevalence among migrants in Switzerland or any community.

There are several demographic characteristics that can influence a woman or girl's likelihood of having undergone FGM/C that are not taken into account when making indirect estimates. The migrant population in Switzerland may or may not be representative of the population in their country of origin due to socio-economic status, regional origin, religion or ethnicity and therefore may not accurately emulate the prevalence of FGM/C in their home country [19]. For example, we cannot accurately rely on indirect measures for migrants from countries where FGM/C prevalence differs greatly according to ethnicity, without taking into account the migrant's ethnicity, which is often not included in demographic or census data [20, 21].

Indirect estimates do not account for factors that may influence migrant's change of behavior, attitudes and beliefs towards FGM/C such as laws prohibiting the practice of FGM/C as well as social pressure not to carry out the traditional practice. However, laws do not always explain the diminishing trend of FGM/C, as similar trends are observed in countries with and without legislation forbidding the practice [22]. The longer migrants stay in Switzerland, the more acculturation is likely to occur, which could lead either to the abandonment of the practice, or to the preservation of the tradition [23].

Prevalence estimations do not account for the many women and girls that are unaware if they underwent the cutting or of the type of FGM/C they may be living with because there is no physical examination of the genitalia, and therefore the estimations of the prevalence in their country of origin may be underreported [24]. Because of that, surveying samples of migrants might inform future estimates and inform interventions, but would also have limitations.

The real prevalence and incidence of FGM/C and the number of minors at risk remain unknown in many countries, including Switzerland. Our estimates look at major age groupings of girls 0–14 and women over 15. We did not take into account age-adjusted groupings by 5-year groups. Additionally, prevalence estimates that would look at both the Swiss region and canton would allow us to implement more targeted interventions. To obtain more accurate indirect estimates, more detailed information on migrant's ethnicity as well as their region of origin would need to be recorded upon entry into Switzerland, as FGM/C prevalence often varies significantly in certain ethnic groups and regions.

Despite the various limitations to using indirect measures, we can nevertheless show that there has been a significant increase in the number of women and girls living with or at risk of FGM/C in Switzerland since the previous estimates were conducted. Although we must improve our future estimates, our data show that we must also improve the Swiss capacity for FGM/C monitoring, prevention, treatment and training on this population across diverse settings (medical, social, school, asylum, police).

Conclusion

Our indirect estimates can only partially inform future policy and public health programs. We believe that indirect estimates should be conducted alongside direct estimates. Direct measures may provide more accurate estimates that could guide policy- and clinical decision-making. Surveying samples of migrants to estimate FGM/C prevalence also has limitations, as they might not know whether they experienced FGM/C or be unaware of the type. However, the implementation of questions about history and type of FGM/C could be integrated into routine health examinations for women and girls coming from countries at risk upon entry into Switzerland, as long as the necessary training is provided. We recommend healthcare professionals and medical coders to use our proposed list of codes from

the International Classification of Diseases (ICD) to document and code FGM/C, its associated procedures, and complications, as well as girls "at risk" [25]. Because the ICD is already used by countries around the world, our proposed methods would be feasible in many countries with the proper training on how to diagnose, classify and document FGM/C correctly. ICD is an existing tool that allows for standardized international comparisons [25]. Additionally, we hypothesize that accurate documentation and coding of FGM/C by care-givers will provide more reliable data than those obtained through self-reporting. Furthermore, hospital data represents an opportunity to study access and quality of care for patients who underwent FGM/C, providing guidance for health interventions.

These estimates are meant to be compared with direct data obtained from Swiss University Hospitals in the next steps of a wider research project conducted in Switzerland in 2018 entitled "Female Genital Mutilation/Cutting with a focus on prevalence, risk factors and Swiss health care professionals' capacities. As a follow-up to these estimates, we conducted a study to assess the coded diagnoses of FGM/C in the five Swiss University Hospitals (paper under review).

Abbreviations

DHS: Demographic and Health Survey; FGM/C: Female Genital Mutilation/Cutting; MICS: Multiple Indicator Cluster Survey

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12889-021-10875-w.

Additional file 1. This is the full excel file of all FGM/C indirect estimates from 2010 to 2018 for women and girls living in Switzerland.

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Authors' contributions

SCC- Conceptualization, Data collection, Data Analyses, Interpretation, Discussion of Findings, Review of Literature. JA-Conceptualization, Interpretation, Discussion of Findings, Review of Literature. All authors read and approved the final manuscript.

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Availability of data and materials

The datasets generated and/or analysed during the current study are available in the Swiss Statistical Office' interactive database, STAT-TAB available at: https://www.bfs.admin.ch/bfs/en/home/services/recherche/stat-tab-online-data-search.html
The DHS and MICS data used in this paper are publicly available on the respective websites (www.dhsprogram.com; www.mics.unicef.org/surveys). The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

No ethics approval and consent to participate was required to access the relevant data.

Consent for publication

Not Applicable. Data was fully anonymized.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]Division of Gynaecology, Department of Paediatrics, Gynaecology and Obstetrics, Geneva University Hospitals, Boulevard de la Cluse 30, Geneva 1211, Switzerland. [2]Department of Epidemiology and Public Health, Swiss Tropical and Public Health Institute, Basel, Switzerland. [3]University of Basel, Basel, Switzerland.

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Publisher's Note

Chapter 6: Female Genital Mutilation/Cutting (FGM/C) coding capacities in Swiss University Hospitals using the International Classification of Diseases (ICD)

Authors:

Sara Cottler-Casanova[1,2,3*], Mathilde Horowicz[4*], Angèle Gayet-Ageron[5], Jasmine Abdulcadir[1CA]

[*]First co-authorship

1. Department of Paediatrics, Obstetrics and Gynaecology. Geneva University Hospitals. 30 Bld de la Cluse, 1211 Geneva, Switzerland
2. Department of Epidemiology and Public Health, Swiss Tropical and Public Health Institute, Basel, Switzerland
3. University of Basel, Basel, Switzerland
4. Faculty of Medicine. University of Geneva
5. CRC & Division of clinical-epidemiology, Department of health and community medicine, University of Geneva & University Hospitals of Geneva

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RESEARCH Open Access

Female genital mutilation/cutting (FGM/C) coding capacities in Swiss university hospitals using the International Classification of Diseases (ICD)

S. Cottler-Casanova[1,2,3†], M. Horowicz[4†], A. Gayet-Ageron[5] and J. Abdulcadir[1*]

Abstract

Background: The real prevalence and incidence of women living with or at risk of female genital mutilation/cutting (FGM/C) is unknown in Switzerland and many parts of Europe, as there are no representative surveys similar to DHS or MICS for European countries. Indirect estimates are commonly used to estimate the number of women with FGM/C in high-income countries, but may not reflect the actual FGM/C prevalence among migrants. Direct measures may provide more accurate estimates that could guide policy- and clinical decision-making. Swiss hospital data may provide a sample of patients that can be used to describe the prevalence of FGM/C in Swiss hospitals. Our study assesses the number of inpatient women and girls in Swiss university hospitals from countries with high FGM/C prevalence, and of inpatients with a coded diagnosis of FGM/C.

Methods: We conducted an exploratory descriptive study in Switzerland to assess the number of women and girls admitted to Swiss university hospitals between 2016 and 2018 from 30 FGM/C practicing countries, as well as inpatients with a coded diagnosis of FGM/C using anonymized data. We calculated indirect estimates for inpatient women and girls living with or at risk of FGM/C and compared them with the number of inpatients with a coded diagnosis of FGM/C.

Results: 8720 women and girls from FGM/C practicing countries were admitted. 207 patients had a coded diagnosis of FGM/C, including 7 with a nationality outside the 30 targeted countries, corresponding to an overall prevalence of 2.3% (95%CI, 2.0–2.6). The number of FGM/C cases by hospital was significantly different across years ($P < 0.001$), with a higher proportion of cases collected in Geneva, Switzerland.

Conclusions: The comparison between indirect estimates of inpatients with or at risk of FGM/C and the low number of FGM/C cases coded, suggests low recording and coding capacities of FGM/C.

Tweetable abstract: The capacity of coding primary and secondary diagnosis of FGM/C in Swiss university hospitals seems low.
Protocol number: 2018–01851: SwissEthics Committee, Canton of Geneva, Switzerland.

* Correspondence: jasmine.abdulcadir@hcuge.ch
†S. Cottler-Casanova and M. Horowicz contributed equally to this work.
[1]Division of Gynaecology, Department of the Woman, the Child and the Adolescent, Geneva University Hospitals, 30 Bld de la Cluse, 1211 Geneva, Switzerland
Full list of author information is available at the end of the article

Keywords: Female genital mutilation, Female genital cutting, Female genital mutilation/cutting, Indirect estimates, Prevalence, Coding, International classification of diseases, ICD, Switzerland

Introduction

Female genital mutilation/cutting (FGM/C) is the partial or total removal of the external female genitalia for non-medical reasons [1]. The World Health Organization describes four FGM/C types [Table 1]. Approximately 200 million women and girls have undergone the practice according to UNICEF [2]. The Demographic Health Survey (DHS) developed by ICF International or the Multiple Indicator Cluster Surveys (MICS) directed by UNICEF, conducted in 27 African and three Asian countries practicing FGM/C provide FGM/C prevalence estimates based on nationally representative data [4]. These estimates do not include women and girls living with FGM/C who emigrated from FGM/C practicing countries [4]. In the European Union (EU), there were an estimated 578,068 women and girls living with FGM/C in 2011 [5], and 21,706 in Switzerland in 2018 [6] based on indirect measures, where the number of migrant women from a FGM/C practicing country is multiplied by the FGM/C prevalence rate from the same country. The European Institute for Gender Equality estimated the number of migrant girls (0–18) from FGM/C practicing countries at risk of FGM/C as 44,106 in France (2014); 18,339 in Italy (2016); 6122 in Belgium (2016), and a few hundred in Greece, Cyprus, Malta, Ireland, Portugal and Sweden [7, 8].

Indirect estimation is a systematic and affordable method for estimating the number of women with FGM/C in high-income countries, in the assumption that the prevalence of FGM/C among migrants does not significantly differ from prevalence among non-migrants [9–11]. However, due to several reasons, including cultural change and varying socioeconomic, and ethnic origins of migrants, it may not reflect the actual FGM/C prevalence in migrants' country of residence or community [12, 13]. The real prevalence and incidence of FGM/C and the number of minors at risk remains unknown in many countries.

Direct measures may provide more accurate estimates that could guide policy- and clinical decision-making. Surveying samples of migrants to estimate FGM/C prevalence also has limitations, as they might not know whether they experienced FGM/C or be unaware of the type [14]. Swiss hospital data may provide a sample of patients that can be used to describe the prevalence of FGM/C in Swiss hospitals. Furthermore, hospital data represents an opportunity to study access and quality of care for patients who underwent FGM/C, providing guidance for health interventions [15–17].

No data are available on the number of women and girls with FGM/C in Swiss hospitals. No accurate information is available on Swiss healthcare professionals' capacities to record FGM/C and deal with its complications and prevention. Weak capacities in diagnosis, recording and coding represent the major obstacle to studying hospital data on FGM/C. Studies from Switzerland and other high- and low-income countries, among midwives, gynecologists and obstetricians,

Table 1 Classification of FGM/C according to WHO [3]. When WHO refers to "glans of the clitoris", part of the body of the clitoris can also be affected

Type I	Partial or total removal of the clitoral glans (the external and visible part of the clitoris, which is a sensitive part of the female genitals, with the function of providing sexual pleasure to the woman), and/or the prepuce/clitoral hood (the fold of skin surrounding the clitoral glans).
Type Ia	Removal of the prepuce/clitoral hood only
Type Ib	Removal of the clitoral glans with the prepuce/clitoral hood
Type II	Partial or total removal of the clitoral glans and the labia minora, with or without removal of the labia majora.
Type IIa	Removal of the labia minora only
Type IIb	Partial or total removal of the glans of the clitoris and the labia minora
Type IIc	Partial or total removal of the glans of the clitoris, the labia minora and the labia majora
Type III (Infibulation)	Narrowing of the vaginal opening with the creation of a covering seal. The seal is formed by cutting and repositioning the labia minora, or labia majora. The covering of the vaginal opening is done with or without removal of the clitoral prepuce/clitoral hood and glans.
Type IIIa	Removal and apposition of the labia minora
Type IIIb	Removal and apposition of the labia majora
Type IV	All other harmful procedures to the female genitalia for non-medical purposes, for example, pricking, piercing, incising, scraping and cauterization.

general and travel medicine practitioners have shown difficulties in screening, diagnosing, classifying and recording FGM/C [18–23]. Pediatricians also lack training on FGM/C and rarely perform external genital examinations [24, 25].

In this manuscript, we aim to:

(1) Assess the number of women and girls from FGM/C practicing countries admitted to Swiss university hospitals.
(2) Estimate, using indirect measures, the potential number of inpatients who are possibly living with FGM/C.
(3) Measure the number of inpatients with a coded primary or secondary diagnosis of FGM/C. The comparison between indirect estimates of inpatients with FGM/C and the number of FGM/C cases coded in the same hospitals, can inform the diagnostic, recording and coding capacities of FGM/C in Swiss university hospitals.

Methods

This cross-sectional study was part of a larger research study approved in December, 2018: protocol number 2018–01851 by the Swiss Ethics Committees (SwissEthics) and conducted according to the protocol, the Swiss legal requirements, and the World Medical Association Declaration of Helsinki. An exemption of informed consent was granted by the state of Geneva Swiss Ethics committee for the use of anonymized data extracted from the university hospitals databases. We first calculated the indirect estimates of women and girls living with FGM/C in Switzerland between 2010 and 2018 [6]. We used a similar methodology to Yoder and Van Baelen [5, 26], applying the most recent FGM/C DHS and MICS prevalence figures for each year (for girls and women aged 15–49) from FGM/C practicing countries to the number of migrant women and girls living in Switzerland. We applied the total country prevalence estimates of women aged 15–49 to all migrant women and girls living in Switzerland from the same countries. We also conducted a separate analysis for girls aged 0–14, where we applied the prevalence estimates of girls 0–14 to all migrant girls 0–14 living in Switzerland from the same countries. Where no prevalence estimates for girls 0–14 were available, we applied the prevalence estimates for girls 15–19. Full details are available in another paper [6] [Tables S1 & S2].

Secondly, in February 2019, we asked the five Swiss university hospitals to provide anonymized data for all inpatient women and girls with a nationality from the 30 FGM/C practicing countries [Table 2], and for all inpatients with a diagnosis of FGM/C between 2016 and 2018 [Table 3]. Swiss hospital data only provided information on patient's nationality, and we therefore used this as a proxy for country of origin, discussed in limitations. In Swiss hospitals, healthcare professionals record diagnosis in patients' electronic medical charts, and professional coders code this information with the tenth edition of the International Classification of Diseases (ICD) [27]. We received data from the University Hospitals of Geneva (HUG), Lausanne (CHUV), Bern (Inselspital) and Zurich (USZ). The University Hospital of Basel did not participate due to logistical difficulties in data provision. The implication is discussed in the conclusion. Analyses were carried out using STATA version 15.

The participating hospitals provided data on all inpatient women and girls from the 30 targeted countries and all primary and secondary diagnoses of FGM/C coded between January 1, 2016 and December 31, 2018. Therefore, we estimate indirect prevalence of FGM/C in Swiss hospitals as the proportion of the total number of FGM/C cases recorded on the total number of women and girls from the targeted countries in four Swiss university hospitals between 2016 and 2018. Using the country prevalence estimates of FGM/C among women and girls with a nationality from FGM/C practicing countries in 2016, 2017, and 2018, we then multiplied this prevalence estimates to the total number of inpatient women and girls registered with the same nationality in the hospital database during the same period and obtained an indirect estimation of the number of inpatients with FGM/C in our Swiss hospitals [Table 5]. Inpatients with an FGM/C diagnosis that had a nationality from other countries than the ones targeted were not considered in this estimation.

We provided descriptive statistics with mean, ±standard deviation (SD), and median for continuous variables; number and proportions by categories for qualitative variables. We compared all categorical variables by year and FGM/C type by region (West Africa vs. East Africa) using Chi-2 or Fischer's exact tests. We compared mean ages by year using non-parametric Kruskal-Wallis test. We estimated FGM/C prevalence within the Swiss university hospital population between 2016 and 2018 and their 95% confidence intervals (95%CIs) using the binomial exact method (Clopper-Pearson method).

Results

8720 women and girls from countries with high FGM/C prevalence were admitted between 2016 and 2018: 4388 in Bern, 2372 in Geneva, 1218 in Lausanne and 742 in Zurich [Table 2]. Most of them came from Eritrea (31.0%), followed by Somalia in Geneva, Zurich and Bern (11.6%), and Cameroon in Lausanne (9.7%).

207 inpatient women and girls had a coded diagnosis of FGM/C [Table 3]. The number of FGM/C cases by

Table 2 Total number of women and girls in Swiss university hospitals between 2016 and 2018 from 30 FGM/C practicing countries

Country of origin	ZürichTotal	Lausanne Total	Geneva Total	Bern Total	Total
Benin	2	12	18	5	37
Burkina Faso	3	12	54	21	90
Cameroon	52	256	261	274	843
Central African Republic	1	1	3	3	8
Chad	2	1	2	13	18
Djibouti	0	4	3	0	7
Egypt	20	15	107	101	243
Eritrea	167	295	362	1881	2705
Ethiopia	59	100	123	287	579
Gambia	7	3	8	16	34
Ghana	42	6	53	79	180
Guinea	8	41	101	31	181
Guinea-Bissau	0	14	9	2	25
Indonesia	20	12	33	64	129
Iraq	66	74	164	481	785
Ivory Coast	41	47	146	72	306
Kenya	41	6	63	125	235
Liberia	2	3	5	5	15
Mali	2	1	32	6	41
Mauritania	0	1	27	1	29
Niger	0	4	23	11	38
Nigeria	42	36	88	169	335
Senegal	5	42	195	29	271
Sierra Leone	4	3	20	23	50
Somalia	101	157	233	523	1014
Sudan and South Sudan	30	2	79	63	174
Tanzania	7	1	33	13	54
Togo	3	61	78	36	178
Uganda	3	1	28	24	56
Yemen	12	7	21	20	60
Grand Total	**742**	**1218**	**2372**	**4388**	**8720**

center significantly changed over the years ($P < 0.001$) with more cases in Geneva overall, and it was significantly different by department ($P < 0.001$) with most cases coded in obstetrics. Patients with an FGM/C diagnosis mostly originated from Eritrea ($n = 85$) and Somalia ($n = 54$).

The FGM/C type differed significantly depending on the region of origin ($P = 0.004$): types II and III were significantly more frequent among patients from West Africa and from East Africa, respectively [Table S3].

For all years combined, the calculated FGM/C prevalence was 2.29% (95%CI: 1.98–2.62). We excluded seven patients from CHUV who had a coded diagnosis of FGM/C and were registered as Swiss (n = 4), Ecuadorian ($n = 1$), Turkish (n = 1) and French (n = 1). Thus, outside the 30 targeted countries. FGM/C prevalence significantly increased over time in participating centers: 1.24% in 2016, 2.32% in 2017, and 3.32% in 2018 ($P < 0.001$).

FGM/C prevalence in Swiss hospitals was 3.53% among inpatients from countries with the highest FGM/C prevalence (≥81%), and thus higher than among inpatients from countries with lower FGM/C prevalence ($P < 0.001$). [Table S3]. FGM/C prevalence was significantly higher in women from East Africa ($P < 0.001$).

Table 3 Description of patients with a FGM/C ($n = 207$) as main or secondary diagnosis between 2016 and 2018 in one of four Swiss university hospitals (Geneva, Lausanne, Bern and Zurich)

Variables	2016 ($n = 42$)	2017 ($n = 69$)	2018 ($n = 96$)	*P* value
Center, n (%)				< 0.001[a]
Geneva	20 (47.6)	24 (34.8)	67 (69.8)	
Lausanne	13 (31.0)	10 (14.5)	19 (19.8)	
Bern	3 (7.1)	23 (33.3)	6 (6.3)	
Zurich	6 (14.3)	12 (17.4)	4 (4.2)	
Country of origin, n (%)				0.097[a]
Benin	0 (0)	0 (0)	1 (1.0)	
Burkina Faso	1 (2.4)	2 (2.9)	0 (0)	
Cameroon	1 (2.4)	0 (0)	0 (0)	
Egypt	0 (0)	0 (0)	5 (5.2)	
Eritrea	12 (28.6)	37 (53.6)	36 (37.5)	
Ethiopia	2 (4.8)	3 (4.4)	2 (2.1)	
Guinea	0 (0)	0 (0)	6 (6.2)	
Guinea-Bissau	0 (0)	0 (0)	2 (2.1)	
Ivory Coast	1 (2.4)	1 (1.5)	1 (1.0)	
Mali	0 (0)	0 (0)	1 (1.0)	
Mauritania	0 (0)	0 (0)	1 (1.0)	
Nigeria	1 (2.4)	1 (1.5)	3 (3.1)	
Senegal	0 (0)	0 (0)	3 (3.1)	
Somalia	14 (33.3)	18 (26.1)	22 (22.9)	
Sudan and South Sudan	1 (2.4)	1 (1.5)	3 (3.1)	
Unknown or other	9 (21.4)	6 (8.7)	10 (10.4)	
Service, n (%)				< 0.001[a]
Gynecology	13 (31.0)	12 (17.4)	9 (9.4)	
Gynecology or Obstetrics*	1 (2.4)	23 (33.3)	6 (6.3)	
Obstetrics	23 (54.8)	33 (47.8)	79 (82.3)	
Others	5 (11.9)	1 (1.5)	2 (2.1)	
Mean age at first visit (±SD, median)	30.7 (±12.0, 27)	27.7 (±6.1, 27.4)	29.8 (±6.7, 30)	0.162[b]
FGM/C type, n (%)				0.116[b]
Type I	3 (7.1)	13 (18.8)	10 (10.4)	
Type II	8 (19.1)	16 (23.2)	33 (34.4)	
Type III	21 (50.0)	33 (47.8)	39 (40.6)	
Type IV	0 (0)	1 (1.5)	2 (2.1)	
Unspecified or other	10 (23.8)	6 (8.7)	12 (12.5)	
FGM/C type, n (%)				
N90.80 (Female genital mutilation, type unspecified)	3 (7.1)	0 (0)	0 (0)	
N90.81 (FGM, Type I)	3 (7.1)	0 (0)	0 (0)	
N90.82 (FGM, Type II)	8 (19.1)	0 (0)	0 (0)	
N90.83 (FGM, Type III)	21 (50.0)	0 (0)	0 (0)	
N90.88 Other specified non-inflammatory diseases of the vulva and perineum	7 (16.7)	0 (0)	0 (0)	
Z91.70 Personal history of female genital mutilation, type unspecified	0 (0)	6 (8.7)	12 (12.5)	
Z91.71 (FGM, Type I)	0 (0)	13 (18.8)	10 (10.4)	
Z91.72 (FGM, Type II)	0 (0)	16 (23.2)	33 (34.4)	

Table 3 Description of patients with a FGM/C ($n = 207$) as main or secondary diagnosis between 2016 and 2018 in one of four Swiss university hospitals (Geneva, Lausanne, Bern and Zurich) *(Continued)*

Variables	2016 ($n = 42$)	2017 ($n = 69$)	2018 ($n = 96$)	*P* value
Z91.73 (FGM, Type III)	0 (0)	33 (47.8	39 (40.6)	
Z91.74 (FGM, Type IV)	0 (0)	1 (1.5)	2 (2.1)	

[a]Fischer's exact test; [b]Kruskal-Wallis nonparametric test
* Bern's datasets did not differentiate gynecological from obstetrical units

We applied the FGM/C prevalence among inpatients from each at-risk country separately [Table 5] and indirectly estimated the number of inpatients who could have undergone or be at risk of undergoing FGM/C: 1648 in 2016, 1671 in 2017, and 1628 in 2018 ($n = 4947$).

FGM/C prevalence was lower among minors (0.66%), compared to women above 18 years old (2.46%) ($P < 0.001$) [Tables 4 and 5]. FGM/C prevalence also varied by hospital department, with higher prevalence among inpatients in gynecology and obstetrics ($P < 0.001$). It also varied among women and girls from at-risk countries. It was higher in Geneva, similar in Lausanne and Zürich, and lower in Bern ($P < 0.001$). Prevalence was higher in institutions featuring regular educational programmes about FGM/C and/or a clinic or referral physician for FGM/C.

Discussion

Main findings

Our findings show that only 207 patients (2.29%) have a coded FGM/C diagnosis, with an increase between 2016 and 2018. There is a drastic difference between FGM/C cases coded in Swiss university hospitals (n = 207) and the possible number of women and girls with FGM/C in these hospitals based on our indirect estimates ($n = 4947$). Our results suggest that FGM/C is not accurately diagnosed, recorded and/or coded in Swiss university hospitals. Moreover, most women and girls came from Eritrea and Somalia, where FGM/C prevalence exceeds 80%, and where type III is frequent, the latter type being easier to identify, and associated with more long-term complications [1]. Infibulation was indeed the most frequent type among inpatients from East Africa.

Seven inpatients with an FGM/C code did not have the nationality of a country where the practice is usually performed. The nationality recorded or FGM/C coding might be incorrect. Alternatively, these women come from FGM/C practicing countries but possess another nationality, and underwent FGM/C before migrating, or afterwards while visiting their country of origin. In such case, and if coding is accurate, monitoring FGM/C

Table 4 Prevalence of FGM/C by age, hospital department, center, and educational programme attendance ($n = 200$ FGM/C)

Variables	Number of cases, n	N	Prevalence, % (95%CI)	*P* value
Category of age, n (%)				0.001[a]
< 18 years	5	757	0.66 (0.21–1.53)	
> =18 years	195	7936	2.46 (2.13–2.82)	
Hospital department, n (%)				< 0.001[a]
Gynecology & obstetrics	195	4163	4.68 (4.06–5.37)	
Surgery	2	1266	0.16 (0.019–0.57)	
Medical department	1	2362	0.042 (0.0011–0.24)	
Emergency	0	573	0 (0–0.64)	
Pediatrics	2	374	0.53 (0.065–1.92)	
Center, n (%)				< 0.001[b]
Geneva	111	2390	4.64 (3.84–5.57)	< 0.001[b]
Lausanne	35	1218	2.87 (2.01–3.97)	
Bern	32	4388	0.73 (0.50–1.03)	
Zürich	22	742	2.96 (1.87–4.45)	
Educational programme organised, n (%)				
Yes (Geneva, Lausanne)	146	3608	4.05 (3.43–4.74)	
No or unknown (Bern, Zürich)	54	5130	1.05 (0.79–1.37)	

[a]Fischer's exact test, [b]Chi-2 test

Table 5 Estimated prevalence of FGM/C among inpatients by country and year ($n = 182$ FGM/C, as no nationality was recorded for 18 patients with an FGM/C diagnosis)

Variables		2016					2017					2018			
Country of origin	2016 FGM/C country prevalence (DHS/MICS)	Inpatients, N	FGM/C codes expected among inpatients, n[a]	FGM/C codes among inpatients, n	FGM/C prevalence calculated among inpatients, % (95%CI)	2017 FGM/C country prevalence (DHS/MICS)	Inpatients, N	FGM/C codes expected among inpatients, n[a]	FGM/C codes among inpatients, n	FGM/C prevalence calculated among inpatients, % (95%CI)	2018 FGM/C country prevalence (DHS/MICS)	Inpatients, N	FGM/C codes expected among inpatients, n[a]	FGM/C codes among inpatients, n	FGM/C prevalence calculated among inpatients, % (95%CI)
Benin	0.092	10	1	0	0 (0–30.85)	0.092	13	1	0	0 (0–24.71)	0.092	14	1	1	7.14 (0.18–33.87)
Burkina Faso	0.758	35	27	1	2.86 (0.072–14.92)	0.758	24	18	2	8.33 (1.03–26.99)	0.758	31	23	0	0 (0–11.22)
Cameroon	0.014	268	4	1	0.37 (0.009–2.06)	0.014	311	4	0	0 (0–1.18)	0.014	264	4	0	0 (0–1.39)
Central African Republic	0.242	1	0	0	0 (NA)	0.242	3	1	0	0 (0–70.76)	0.242	4	1	0	0 (0–60.24)
Chad	0.384	7	3	0	0 (0–40.96)	0.384	7	3	0	0 (0–40.96)	0.384	4	2	0	0 (0–60.24)
Djibouti	0.931	3	3	0	0 (0–70.76)	0.931	2	2	0	0 (0–84.19)	0.931	2	2	0	0 (0–84.19)
Egypt	0.872	81	71	0	0 (0–4.45)	0.872	79	69	0	0 (0–4.56)	0.872	83	72	5	6.02 (1.98–13.50)
Eritrea	0.83	878	729	12	1.37 (0.71–2.38)	0.83	910	755	37	4.07 (2.88–5.56)	0.83	917	761	36	3.93 (2.76–5.39)
Ethiopia	0.652	210	137	2	0.95 (0.12–3.40)	0.652	188	123	3	1.60 (0.33–4.59)	0.652	181	118	2	1.10 (0.13–3.93)
Gambia	0.749	14	10	0	0 (0–23.16)	0.749	15	11	0	0 (0–21.80)	0.757	5	4	0	0 (0–52.18)
Ghana	0.038	59	2	0	0 (0–6.06)	0.038	69	3	0	0 (0–5.21)	0.038	52	2	0	0 (0–6.85)
Guinea	0.968	43	42	0	0 (0–8.22)	0.968	63	61	0	0 (0–5.69)	0.945	75	71	6	8.00 (2.99–16.60)
Guinea-Bissau	0.449	5	2	0	0 (0–52.18)	0.449	5	2	0	0 (0–52.18)	0.449	15	7	2	13.33 (1.66–40.46)
Iraq	0.367	265	97	0	0 (0–1.38)	0.367	263	97	0	0 (0–1.39)	0.367	257	94	0	0 (0–1.43)
Ivory Coast	0.21	88	18	1	1.14 (0.029–6.17)	0.21	101	21	1	0.99 (0.025–5.39)	0.21	117	25	1	0.85 (0.022–4.67)
Kenya	0.498	81	40	0	0 0–4.45)	0.498	77	38	0	0 (0–4.68)	0.498	77	38	0	0 (0–4.68)
Liberia	0.827	4	3	0	0 (0–60.24)	0.827	4	3	0	0 (0–60.24)	0.886	7	6	0	0 (0–40.96)
Mali	0.666	20	13	0	0 (0–16.84)	0.666	11	7	0	0 (0–28.49)	0.666	10	7	1	10.00 (0.25–44.50)
Mauritania	0.02	11	0	0	0 (0–28.49)	0.02	10	0	0	0 (0–30.85)	0.02	8	0	1	12.50 (0.32–52.65)
Niger	0.184	19	3	0	0 (0–17.65)	0.184	7	1	0	0 (0–40.96)	0.195	12	2	0	0 (0–26.46)
Nigeria	0.227	100	23	1	1.00 (0.025–5.45)	0.24	124	30	1	0.81 (0.020–4.41)	0.24	111	27	3	2.70 (0.56–7.70)
Senegal	0.896	96	86	0	0 (0–3.77)	0.861	91	78	0	0 (0–3.97)	0.861	84	72	3	3.57 (0.74–10.08)
Sierra Leone	0.979	17	17	0	0 (0–19.51)	0.979	19	19	0	0 (0–17.65)	0.979	14	14	0	0 (0–23.16)
Somalia	0.866	352	305	14	3.98 (2.19–6.58)	0.866	358	310	18	5.03 (3.01–7.83)	0.866	304	263	22	7.24 (4.59–10.75)
Sudan and South Sudan	0.1	58	6	1	1.72 (0.044–9.24)	0.1	65	7	1	1.54 (0.039–8.28)	0.1	51	5	3	5.88 (1.23–16.24)
Tanzania	0.047	19	1	0	0 (0–17.65)	0.047	18	1	0	0 (0–18.53)	0.047	17	1	0	0 (0–19.51)
Togo	0.003	69	0	0	0 (0–5.21)	0.003	53	0	0	0 (0–84.19)	0.003	56	0	0	0 (0–6.38)
Uganda	0.185	15	3	0	0 (0–21.80)	0.185	21	4	0	0 (0–16.11)	0.185	20	4	0	0 (0–16.11)
Yemen	0.092	24	2	0	0 (0–14.25)	0.092	15	1	0	0 (0–21.80)	0.092	21	2	0	0 (0–16.11)
Total	**NA**	**2892**	**1648**	**33**	**NA**	**NA**	**2973**	**1671**	**63**	**NA**	**NA**	**2855**	**1628**	86	NA

n[a]= rounded to the unit

prevalence with ICD codes might give more reliable results than indirect estimates and overcome the issue of nationality and ethnicity.

Coding was significantly higher in gynecology and obstetrics compared to other departments. Obstetricians and gynecologists routinely examine the external genitalia and might be more trained to recognize FGM/C. Furthermore, our results suggest that pregnancy and delivery are critical times for diagnosing FGM/C, because it was significantly more coded in obstetrics than in gynecology. Only two girls in pediatrics and two women in urology were coded with FGM/C.

The prevalence of FGM/C codes in minors (0.66%) was significantly lower than in adult women (2.46%). Belonging to a new generation of immigrants, length of stay, and migration in a country where FGM/C is illegal could explain why it is less frequent among minors [7, 8, 12]. However, insufficient screening and routine genital examinations among pediatricians, or absent documentation can also explain the low numbers [23]. A specific code for "risk of FGM/C" might facilitate screening and prevention [17].

Longstanding training and protocols about FGM/C in Geneva and Lausanne could explain why FGM/C prevalence in these hospitals was higher than in Bern, even though Bern numbered more patients from FGM/C practicing countries. At HUG for instance, a retrospective review of the medical files of patients who attended the FGM/C outpatient clinic between 2010 and 2012 revealed missed and misclassification of FGM/C in more than one-third of cases [18]. Therefore, the obstetric and gynecologic divisions implemented several interventions: updating the protocols for the care of women and girls with FGM/C, learning tools with drawings, pictures and videos [28], workshops for midwives, and simulation programmes on defibulation. Since 2010, workshops were also organized in pediatrics, travel medicine, HIV clinic, infectious disease, and primary care. In 2017, the HUG hosted an International expert symposium on the care of women and girls with FGM/C and on prevention [29]. In 2012, the HUG's division of gynecology introduced an FGM/C checkbox in electronic medical forms to record FGM/C and its type. An update in February 2018 [Figs. 1 & 2] added the description of FGM/C types and subtypes in gynecology and obstetrics. This may have facilitated screening and recording, explaining why FGM/C codes almost tripled between 2017 and 2018.

According to a survey run by the Swiss Network against Female Circumcision in 2017 (unpublished, data obtained from the authors), FGM/C was taught at the medical faculties of the Universities of Geneva, Lausanne and Fribourg but not in Bern, whose university hospital admitted 4388 women and girls from FGM/C practicing countries between 2016 and 2018. This might partially explain the higher FGM/C prevalence in Geneva and Lausanne. Zürich's medical faculty did not reply to this survey.

Strengths and limitations

One strength of the study was the use of ICD-10 codes for estimating FGM/C prevalence, making it easily reproducible to allow comparison of data over time, and after specific interventions [17].

The main weakness is that we could only collect data of patients, for whom FGM/C had been coded, and undercoding is evident. FGM/C is probably not recorded/coded when the reason for hospitalization and FGM/C are not related. However, even when they are related, FGM/C recording/coding is probably missing:

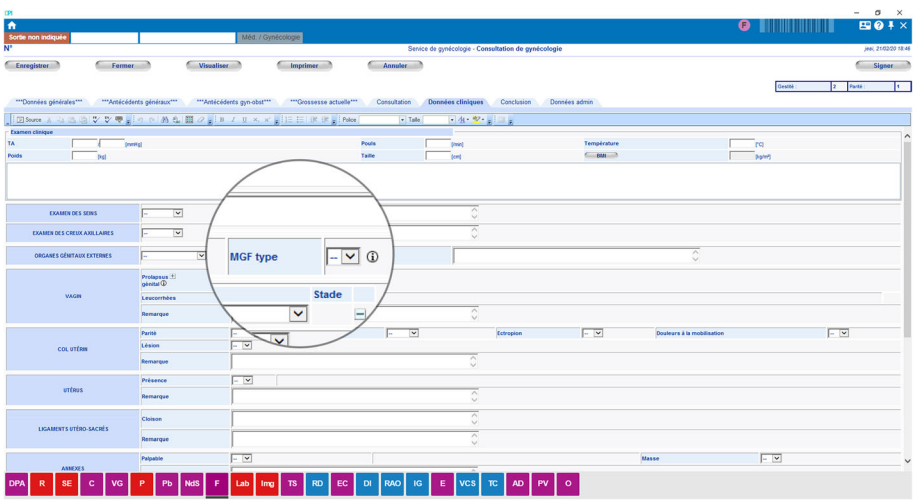

Fig. 1 FGM/C checkbox in the gynecological electronic medical chart

Fig. 2 FGM/C type and description in the gynecological electronic medical chart

the calculated prevalence of FGM/C among 4163 inpatient women in obstetrics and gynecology is only 4.68%.

We included inpatients registered with the nationality from one of 30 FGM/C practicing countries, irrespective of whether they were first- or second- (or third-) generation migrants. This may exclude women who might originally come from one of these countries but have now a different nationality.

We did not have the information regarding the age of all inpatient women in the anonymized data. However, the aim of our study was not to assess the prevalence by 5-year age groupings as is often done in high FGM/C prevalence countries to assess the evolution of the practice. Even though FGM/C is age-dependent, it is generally performed before menarche [30] and before migrating [31, 32]. Furthermore, in Swiss university hospitals, inpatients that are less than 16 years old are generally hospitalized in the pediatric division. We can hypothesize that all inpatients except for those from pediatric departments are more than 16 years old, and are therefore likely over the age of cutting. Future research reproducing our methodology might analyze the age of the women and girls included. We can hypothesize that a considerable number of inpatient women in Swiss university hospitals are mainly women of childbearing age as they were mostly attended in gynecology or obstetrics units.

We limited our study to four Swiss university hospitals. Basel's University Hospital could not provide the data requested, but we hypothesize that we would have found equally low FGM/C prevalence. We did not study regions without university hospitals, such as Tessin, on the Italian border, where hospitals could admit migrant women and girls with or at risk of FGM/C [9].

We included hospitalized patients only. It would be interesting to analyze data of outpatient women and girls in pediatrics, travel medicine, infectious disease, primary care services, and migrants' physical and mental health programmes.

Interpretation

The number of inpatients with an FGM/C diagnosis out of all women and girls potentially living with FGM/C is low in all hospitals and specialties, including gynecology and obstetrics. We believe that FGM/C coding indirectly reflects awareness of the phenomenon. If FGM/C is not recognized or discussed, women and girls living with FGM/C cannot access specific care, health and legal information and prevention.

Our study suggests that training healthcare professionals and medical students increases the number of patients coded with FGM/C. A study conducted in Belgium showed that more patients were coded with FGM/C after delivering information on FGM/C and its management [33]. The introduction of an FGM/C checkbox in electronic medical charts also seems to facilitate the diagnosis. Similar use of electronic tools facilitated identification of intimate partner violence, together with routine protocols on appropriate screening and counseling [34]. Since November 2019, at HUG, the FGM/C checkbox is linked to a standardized form where physicians, nurses and midwives can record the type, subtype and complications identified, and access an illustrated description from a learning tool for each item [28].

Conclusion

The present study shows that assessing FGM/C coding through ICD-10 is feasible but FGM/C coding capacities among inpatients in Swiss university hospitals are low.

Future policies should include training on appropriate screening, diagnosis, management and referral in case of FGM/C. Training should be organized in different specialties such as urology, obstetrics and gynecology, infectious diseases, general practice, pediatrics and psychiatry [35], and stress the importance of recording and coding. Certified interpreters and coders should also receive training. Finally, professionals in obstetrics, pediatrics, primary care, and travel medicine should be able to identify children at risk and discuss prevention, national laws on FGM/C and child's rights [22–25, 36]. Sensitizing and teaching about FGM/C in existing pre-graduate classes, such as anatomy, gynecology and obstetrics, urology, infectious disease, pediatrics, psychiatry and primary care could improve standard training.

Our next step is to assess knowledge, attitudes and practice of healthcare professionals in the same hospitals to tailor training programmes and tools that can improve screening, prevention, diagnosis and management of FGM/C. We will also analyze our data according to the belonging of the included institutions to *Swiss Hospitals for equity*, a network aiming at improving healthcare access for underprivileged groups, regardless of their origin, language and socioeconomic situation. Routine availability of certified interpreters, like in Geneva and Lausanne, might facilitate diagnosis, recording and coding of FGM/C.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12889-021-11160-6.

Additional file 1.

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Authors' contributions

JA designed and directed the project. SCC collected the data, together with JA and MH. SCC and AGA did the data analysis. MH, SCC and JA wrote the manuscript in collaboration with AGA. All the authors reviewed and approved the manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Declarations

Details of ethics approval

This cross-sectional study was part of a larger research study approved in December, 2018: protocol number 2018–01851 by the Swiss Ethics Committee (SwissEthics) and conducted according to the protocol, the Swiss legal requirements, the World Medical Association Declaration of Helsinki. An exemption of informed consent was granted by the state of Geneva Swiss Ethics committee for the use of anonymized data extracted from the university hospitals databases.

Consent for publication

All authors have approved the manuscript for submission.

Competing interests

No competing interests to declare.

Author details

[1]Division of Gynaecology, Department of the Woman, the Child and the Adolescent, Geneva University Hospitals, 30 Bld de la Cluse, 1211 Geneva, Switzerland. [2]Department of Epidemiology and Public Health, Swiss Tropical and Public Health Institute, Basel, Switzerland. [3]University of Basel, Basel, Switzerland. [4]Faculty of Medicine, University of Geneva, Geneva, Switzerland. [5]CRC & Division of clinical-epidemiology, Department of health and community medicine, University of Geneva & University Hospitals of Geneva, Geneva, Switzerland.

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Publisher's Note

Chapter 7: Diagnoses and procedures of inpatients with female genital mutilation/cutting in Swiss University Hospitals: a cross-sectional study

Mathilde Horowicz[1], Sara Cottler-Casanova[2,3,4*], Jasmine Abdulcadir[1CA]

1. Faculty of Medicine. University of Geneva
2. Department of Paediatrics, Obstetrics and Gynaecology. Geneva University Hospitals. 30 Bld de la Cluse, 1211 Geneva, Switzerland
3. Department of Epidemiology and Public Health, Swiss Tropical and Public Health Institute, Basel, Switzerland
4. University of Basel, Basel, Switzerland

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RESEARCH

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Diagnoses and procedures of inpatients with female genital mutilation/cutting in Swiss University Hospitals: a cross-sectional study

Mathilde Horowicz[1], Sara Cottler-Casanova[2,3] and Jasmine Abdulcadir[2*]

Abstract

Background: Female genital mutilation/cutting (FGM/C) can result in short and long-term complications, which can impact physical, psychological and sexual health. Our objective was to obtain descriptive data about the most frequent health conditions and procedures associated with FGM/C in Swiss university hospitals inpatient women and girls with a condition/diagnosis of FGM/C. Our research focused on the gynaecology and obstetrics departments.

Methods: We conducted an exploratory descriptive study to identify the health outcomes of women and girls with a coded FGM/C diagnose who had been admitted to Swiss university hospitals between 2016 and 2018. Four of the five Swiss university hospitals provided anonymized data on primary and secondary diagnoses coded with the International Classification of Diseases (ICD) and interventions coded in their medical files.

Results: Between 2016 and 2018, 207 inpatients had a condition/diagnosis of FGM/C. The majority (96%) were admitted either to gynaecology or obstetrics divisions with few genito-urinary and psychosexual conditions coded.

Conclusions: FGM/C coding capacities in Swiss university hospitals are low, and some complications of FGM/C are probably not diagnosed. Pregnancy and delivery represent key moments to identify and offer medical care to women and girls who live with FGM/C.

Trial registration: This cross-sectional study (protocol number 2018-01851) was conducted in 2019, and approved by the Swiss ethics committee.

Plain English Summary

Female genital mutilation/cutting (FGM/C) can result in short and long-term complications, which can impact physical, psychological and sexual health. Our objective was to obtain descriptive data about the most frequent health conditions and procedures associated with FGM/C among inpatients with a condition/diagnosis of FGM/C in Swiss university hospitals. We asked the Swiss university hospitals anonymized data of women and girls with a coded FGM/C diagnose who had been admitted between 2016 and 2018. Four of the five Swiss university hospitals provided the primary and secondary diagnoses coded with the International Classification of Diseases (ICD) and the interventions coded in their medical files. Only 207 inpatients had a condition/diagnosis of FGM/C. The majority was admitted either to gynaecology or obstetrics divisions. Some complications of FGM/C are probably not diagnosed. Pregnancy

*Correspondence: jasmine.abdulcadir@hcuge.ch
[2] Division of Gynaecology, Department of the Woman, The Child and the Adolescent, Geneva University Hospitals, 30 Bld de la Cluse, 1211 Geneva, Switzerland
Full list of author information is available at the end of the article

and childbirth represent key moments to care for and counsel a population that might not consult or be identified otherwise.

Keywords: Female genital mutilation, Female genital cutting, Female genital mutilation/cutting, International classification of diseases, ICD, Coding, Switzerland

Introduction

Female Genital Mutilation/Cutting (FGM/C) comprises all procedures involving partial or total removal of the external female genitalia without medical indication [1]. The World Health Organization (WHO) defines four main types of FGM/C (Table 1) [2]. 200 million women and girls have undergone the practice in 31 countries according to nationally representative household surveys, without counting female migrants with FGM/C who live high-income countries [3, 4]. According to estimates, almost 600,000 individuals living in the European Union are believed to have been exposed to ritual genital cutting (2016) [5], and in Switzerland, approximately 21,706 women and girls are estimated to have been exposed to this practice (2018) [6]. These estimates were obtained by indirect measures: multiplying the number of female migrants from an FGM/C practicing country with the FGM/C prevalence rate from the same country. This method does not account for regional and ethnic variations of the practice within countries, and does not include corrections for any changes in attitudes towards FGM/C, which have been described among migrants [7–11], nor include other female genital modifications such as female genital cosmetic surgeries. The actual prevalence of FGM/C among communities of migrants remains unknown [12, 13]. Recent studies conducted in the United Kingdom (UK) showed significantly fewer cases of FGM/C than expected among minors according to prevalence estimates [14, 15]. Nevertheless, the total number of women and girls who have undergone FGM/C is expected to grow in high-income countries because of increasing migration from countries where FGM/C prevalence remains high [16]. Although several interventions effectively promote the abandonment of FGM/C, many countries are simultaneously facing population growth, with consequent increase in the absolute number of girls exposed to FGM/C [17].

It has been widely studied that FGM/C, particularly type III, can result in short and long-term complications, which can impact physical, psychological and sexual health [1]. Systematic reviews and meta-analyses show that female individuals with FGM/C are at higher risk of dyspareunia, genito-urinary complications, prolonged labour, episiotomies, and birth complications [18–21]. Frequently cited as a limitation, the lack of high-quality studies makes it difficult to reach consensus surrounding the association between FGM/C and caesarean section, infertility and HIV [18–20]. Depending on the study design, some of the available data about FGM/C complications and their clinical management may be subject to self-report and recall bias [22]. Inappropriate health management due to the lacking training surrounding FGM/C may further bias the existing data. To our knowledge, no study has yet described FGM/C complications

Table 1 Classification of FGM/C types and subtypes according to WHO [2]

Type I	Partial or total removal of the clitoral glans (the external and visible part of the clitoris, which is a sensitive part of the female genitals, with the function of providing sexual pleasure to the woman), and/or the prepuce/clitoral hood (the fold of skin surrounding the clitoral glans)
Type Ia	Removal of the prepuce/clitoral hood only
Type Ib	Removal of the clitoral glans with the prepuce/clitoral hood
Type II	Partial or total removal of the clitoral glans and the labia minora, with or without removal of the labia majora
Type IIa	Removal of the labia minora only
Type IIb	Partial or total removal of the clitoris and the labia minora
Type IIc	Partial or total removal of the clitoris, the labia minora and the labia majora
Type III (Infibulation)	Narrowing of the vaginal opening with the creation of a covering seal. The seal is formed by cutting and repositioning the labia minora, or labia majora. The covering of the vaginal opening is done with or without removal of the clitoral prepuce/clitoral hood and glans
Type IIIa	Removal and apposition of the labia minora
Type IIIb	Removal and apposition of the labia majora
Type IV	All other harmful procedures to the female genitalia for non-medical purposes, for example, pricking, piercing, incising, scraping and cauterization

and associated procedures using hospital inpatient data coded with the International Classification of Diseases (ICD).

We sought to describe the most frequent health conditions and procedures associated with FGM/C in inpatient women and girls identified from ICD diagnoses of FGM/C from five Swiss university hospitals.

Materials and methods

This cross-sectional study (protocol number 2018-01851) was conducted in 2019, and approved by the Swiss ethics committee. We invited all five Swiss university hospitals (Geneva, Lausanne, Bern, Basel and Zürich) to provide anonymized data for all inpatient adult women and girls (< 18 years) with a nationality from any of the 30 FGM/C practicing countries [3] in addition to all inpatients who had a coded condition/diagnosis of FGM/C between January 1, 2016 and December 31, 2018. We did not include inpatients from the Maldives, where FGM/C has been recently reported [23], because no nationally representative survey was available when the study began. Please note that we talk about a "condition/diagnosis" of FGM/C as the ICD contains specific codes for FGM/C, which are also used to justify reimbursement of healthcare provided in case of need by health insurances. We also use the term condition, to acknowledge the fact that not all women and girls with FGM/C are sick.

In Swiss university hospitals, healthcare professionals record the diagnosis responsible for the hospitalization (primary diagnosis); eventual complications that arise during the patient's hospital stay, as well as any additional diseases treated (secondary diagnoses) in the patients' electronic medical charts. Professional coders in Switzerland code this information with the German Modification of the tenth edition of the ICD (ICD-10-GM), and interventions are coded with the Swiss Classification of Surgical Interventions (CHOP) [24].

We received the requested data from four university hospitals: Geneva (HUG), Lausanne (CHUV), Bern (Inselspital), and Zürich (USZ). The university hospital of Basel (USB) did not participate due to logistical difficulties in data provision. All data were then merged in a single database using STATA version 15.

The data for all inpatient women and girls from the 30 targeted FGM/C countries and all primary and secondary diagnoses of FGM/C coded between January 1, 2016 and December 31, 2018 was anonymized. The university hospital of Bern did not provide data on the interventions performed. Lausanne and Zürich provided CHOP codes of the interventions performed, and Geneva provided the name of the CHOP interventions. We analyzed all diagnoses and interventions in patients' records with a coded primary or secondary diagnosis of FGM/C. We provided descriptive statistics with mean, ± standard deviation, and median for continuous variables, numbers by categorical variables. We compared all diagnoses from our sample with the FGM/C ICD "tip-sheet" for FGM/C associated health conditions (full methods available in another manuscript) [25]. We focused our analysis on the gynaecology and obstetrics divisions, where most of the inpatients with an FGM/C code were admitted.

The Swiss Federal Office of Public Health, the Swiss Network against Female Circumcision, and Caritas Switzerland funded the study. They had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Results

In four of the five Swiss university hospitals, 207 inpatients received a primary (n = 22, 10.6%) or a secondary (n = 185) diagnosis of FGM/C during the study period (Table 2). Of these 207 women and girls, 199 (96%, 89.4%) were admitted either to gynaecology or obstetrics divisions. The remaining women and girls were admitted to other departments (surgery, internal medicine, emergency, and paediatrics).

The primary diagnoses of women with a secondary diagnosis of FGM/C (n = 185) spanned 11 chapters of the ICD-10 (Table 3). 156 inpatients had a primary diagnosis related to pregnancy and childbirth. The most frequent diagnoses were perineal laceration during delivery (n = 29, 18.6%), labour and delivery complicated by fetal heart rate anomaly (n = 16, 10.3%), prolonged second stage of labour (n = 13, 8.3%) and premature rupture of membranes (n = 13, 8.3%). Nine patients were admitted for some type of anaemia: anaemia complicating pregnancy, childbirth and the puerperium (n = 5), iron deficiency anaemia (n = 3), and post-haemorrhagic anaemia (n = 1). Primary diagnoses of genitourinary diseases included vulvar cysts (n = 4), and infectious diseases such as abscess of vulva (n = 2), chronic salpingitis and oophoritis (n = 1) and pyonephrosis (n = 1).

The mean number of secondary diagnoses coded among women with a primary or secondary diagnosis of FGM/C was 2.59 (median 2, range 0–15), spanning 16 chapters of the ICD-10 (Table 4). There were 281 secondary diagnoses related to pregnancy and childbirth, including 114 codes describing duration of pregnancy (O09.1-O09.7, O48). Other frequent codes were perineal laceration during delivery (n = 21), prolonged second stage of labour (n = 8), and anaemia complicating pregnancy, childbirth and the puerperium (n = 24).

Among diseases of the genitourinary system, coded diagnoses featured vulvar cyst (n = 1), urinary tract infection (n = 1) and mild cervical dysplasia (n = 1). Other secondary diagnoses related to infections were

Table 2 Description of inpatients with a FGM/C (n = 207) as primary or secondary diagnosis between 2016 and 2018 followed in one of four Swiss university hospitals (Geneva, Lausanne, Bern and Zürich)

Variables	2016 (n = 42)	2017 (n = 69)	2018 (n = 96)
Center, n (%)			
Geneva	20 (47.6)	24 (34.8)	67 (69.8)
Lausanne	13 (31.0)	10 (14.5)	19 (19.8)
Bern	3 (7.1)	23 (33.3)	6 (6.3)
Zürich	6 (14.3)	12 (17.4)	4 (4.2)
Country of origin, n (%)			
Benin	0 (0)	0 (0)	1 (1.0)
Burkina Faso	1 (2.4)	2 (2.9)	0 (0)
Cameroon	1 (2.4)	0 (0)	0 (0)
Côte d'Ivoire	1 (2.4)	1 (1.5)	1 (1.0)
Egypt	0 (0)	0 (0)	5 (5.2)
Eritrea	12 (28.6)	37 (53.6)	36 (37.5)
Ethiopia	2 (4.8)	3 (4.4)	2 (2.1)
Guinea	0 (0)	0 (0)	6 (6.2)
Guinea-Bissau	0 (0)	0 (0)	2 (2.1)
Mali	0 (0)	0 (0)	1 (1.0)
Mauritania	0 (0)	0 (0)	1 (1.0)
Nigeria	1 (2.4)	1 (1.5)	3 (3.1)
Senegal	0 (0)	0 (0)	3 (3.1)
Somalia	14 (33.3)	18 (26.1)	22 (22.9)
Sudan and South Sudan	1 (2.4)	1 (1.5)	3 (3.1)
Unknown or other	9 (21.4)	6 (8.7)	10 (10.4)
Service, n (%)			
Gynaecology	13 (31.0)	12 (17.4)	9 (9.4)
Gynaecology or obstetrics[a]	1 (2.4)	23 (33.3)	6 (6.3)
Obstetrics	23 (54.8)	33 (47.8)	79 (82.3)
Others	5 (11.9)	1 (1.5)	2 (2.1)
Mean age at first visit (± SD, median)	30.7 (± 12.0, 27)	27.7 (± 6.1, 27.4)	29.8 (± 6.7, 30)
FGM/C type, n (%)			
Type I	3 (7.1)	13 (18.8)	10 (10.4)
Type II	8 (19.1)	16 (23.2)	33 (34.4)
Type III	21 (50.0)	33 (47.8)	39 (40.6)
Type IV	0 (0)	1 (1.5)	2 (2.1)
Unspecified or other	10 (23.8)	6 (8.7)	12 (12.5)

[a] Data obtained from Bern did not specify whether patients were admitted in gynecology or obstetrics

Streptococcus group B (n = 17), possibly describing a carrier-state in pregnant women, and carrier of other specified bacterial or infectious diseases (n = 17), and asymptomatic HIV status (n = 1). Eight women required immunization against viral diseases such as measles, diphtheria, and other viral diseases.

Mental disorders and sexual health conditions were rarely coded as either primary or secondary conditions. "Problems related to psychosocial and/or economic circumstances" appeared five times as secondary diagnosis, and once as a primary diagnosis for a minor inpatient that was admitted in paediatrics. Out of the other four minors with a code of FGM/C (n = 5), another was admitted in paediatrics to undergo surgery for mitral valve stenosis, and the remaining two were admitted in gynaecology for surgical treatment of a vulvar cyst. The only minor inpatient with a primary diagnosis of FGM/C underwent defibulation and had secondary codes related to pregnancy.

In total, there were 62 primary and secondary diagnoses of anaemia in 36 patients admitted in gynaecology or obstetrics. Among them, six had third-stage haemorrhage, six a first- or second-degree perineal tear, and nine underwent caesarean section 27 of 135 patients admitted

Table 3 Primary diagnoses of inpatients with a secondary diagnosis of FGM/C (n=185) presented by chapter of the ICD-10

Variables		N
ICD-10 chapter and codes	ICD-10 diagnoses	
Neoplasms		3
C77.4, C90.00	Malignant neoplasms	2
D25.9	Leiomyoma of uterus, unspecified	1
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism		4
D50.8, D50.9	Iron deficiency anemias	3
D62	Acute posthemorrhagic anemia	1
Endocrine, nutritional and metabolic diseases		1
E55.9	Vitamin D deficiency, unspecified	1
Diseases of the circulatory system		1
I05.0	Rheumatic mitral stenosis	1
Diseases of the skin and subcutaneous tissue		1
L02.2	Cutaneous abscess, furuncle and carbuncle of trunk	1
Diseases of the genitourinary system		20
N13.1	Hydronephrosis with ureteral stricture, not elsewhere classified	1
N13.6	Pyonephrosis	1
N39.3	Stress incontinence	1
N70.1	Chronic salpingitis and oophoritis	1
N76.4	Abscess of vulva	2
N84.0	Polyp of corpus uteri	1
N90.7	Vulvar cyst	4
Pregnancy, childbirth and the puerperium		156
O00.1	Tubal pregnancy	1
O02.1	Missed abortion	1
O09.6	"Duration of pregnancy 37 to 41 completed weeks, 253 to 287 completed days"	4
O09.7	"Duration of pregnancy More than 41 completed weeks More than 287 completed days"	1
O12.1	Gestational proteinuria	1
O14.0, O14.1, O14.9	Pre-eclampsia	4
O24.0	Pre-existing type 1 diabetes mellitus, in pregnancy, childbirth and the puerperium	1
O24.4	Gestational diabetes mellitus	8
O30.0	Twin pregnancy	1
O32.1	Maternal care for breech presentation	1
O33.5	Maternal care for disproportion due to unusually large fetus	2
O34.2	Maternal care due to uterine scar from previous surgery	3
O34.30	Maternal care for cervical incompetence, unspecified trimester	1
O34.7	Maternal care for abnormality of vulva and perineum	1
O36.5	Maternal care for known or suspected poor fetal growth	4
O36.6	Maternal care for excessive fetal growth	2
O41.0	Oligohydramnios	2
O41.1	Infection of amniotic sac and membranes	1
O42.0, O42.11, O42.12	Premature rupture of membranes, onset of labor within 24 hours of rupture	13
O43.21	Placenta accreta	1
O44.11	Complete placenta previa with hemorrhage, first trimester	2
O48	Post-term pregnancy	4
O60.1	Preterm labor with preterm delivery	2
O61.0	Failed medical induction of labor	2

Table 3 (continued)

Variables		N
O62.8	Other abnormalities of forces of labor	2
O63.0	Prolonged first stage (of labor)	4
O63.1	Prolonged second stage (of labor)	13
O64.8	Obstructed labor due to other malposition and malpresentation	1
O65.4	Obstructed labor due to fetopelvic disproportion, unspecified	1
O66.2	Obstructed labor due to unusually large fetus	1
O66.5	Attempted application of vacuum extractor and forceps	1
O68.0	Labour and delivery complicated by fetal heart rate anomaly	16
O68.2	Labour and delivery complicated by fetal heart rate anomaly with meconium in amniotic fluid	3
O70.0	First degree perineal laceration during delivery	13
O70.1	Second degree perineal laceration during delivery	11
O70.2	Third degree perineal laceration during delivery	1
O70.3	Fourth degree perineal laceration during delivery	2
O70.9	Perineal laceration during delivery, unspecified	2
O71.1	Rupture of uterus during labour	1
O72.0, O72.1	Third-stage haemorrhage	3
O75.6	Delayed delivery after spontaneous or unspecified rupture of membranes	1
O75.7	Vaginal delivery following previous caesarean section	2
O80	Single spontaneous delivery	3
O98.8	Other maternal infectious and parasitic diseases complicating pregnancy, childbirth and the puerperium	1
O99.0	Anaemia complicating pregnancy, childbirth and the puerperium	5
O99.1	Other diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism complicating pregnancy, childbirth and the puerperium	1
O99.2	Endocrine, nutritional and metabolic diseases complicating pregnancy, childbirth and the puerperium	1
O99.8	Other specified diseases and conditions complicating pregnancy, childbirth and the puerperium	4
Congenital malformations, deformations and chromosomal abnormalities		1
Q50.5	Embryonic cyst of broad ligament	1
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified		1
R74.0	Elevation of levels of transaminase and lactic acid dehydrogenase [LDH]	1
Injury, poisoning and certain other consequences of external causes		1
S72.3	Fracture of shaft of femur	1
Factors influencing health status and contact with health services		18
Z37.0	Single live birth	4
Z65	Problems related to other psychosocial circumstances	1
Z91.70	Personal history of female genital mutilation, type unspecified	1
Z91.71	Personal history of female genital mutilation, type 1	1
Z91.72	Personal history of female genital mutilation, type 2	2
Z91.73	Personal history of female genital mutilation, type 3	9

in obstetrics (19%), had a primary or secondary diagnosis of anemia complicating pregnancy and childbirth.

Several coded diagnoses in our sample might be possible long-term complications of FGM/C found in the FGM/C "tip-sheet" [25] (Table 5). The most frequently coded diagnoses (primary and secondary combined) were: perineal laceration during delivery (n = 50, 37.5% of FGM/C type III), prolonged second stage of labour (n = 21, 28.6% of FGM/C type III), postpartum

Table 4 Secondary diagnoses of inpatients with a condition/diagnosis of FGM/C presented by chapter of the ICD-10

Variables		N
ICD-10 chapter and codes	ICD-10 diagnoses	
Certain infectious and parasitic diseases		27
A39.0	Meningococcal meningitis	2
A60.9	Anogenital herpesviral infection, unspecified	1
B18.1	Chronic viral hepatitis B without Delta virus	1
B65.0	Schistosomiasis due to Schistosoma haematobium [urinary schistosomiasis]	1
B68.1	Taenia saginata taeniasis	1
B95.1	Streptococcus, group B, as the cause of diseases classified elsewhere	17
B95.91	Other specified gram-positive anaerobic, non-spore forming pathogens causing diseases, classified elsewhere	1
B96.2	*Escherichia coli* [*E. coli*] as the cause of diseases classified elsewhere	2
B98.0	*Helicobacter pylori* [*H. pylori*] as the cause of diseases classified in other chapters	1
Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism		33
D50.0	Iron deficiency anemia secondary to blood loss (chronic)	9
D50.8, D50.9	Iron deficiency anemias	10
D52.9	Folate deficiency anemia, unspecified	1
D57.1	Sickle-cell disease without crisis	1
D62	Acute posthemorrhagic anemia	3
D64.8, D64.9	Anemia, other or unspecified	6
D68.4, D68.9	Coagulation defect	2
D90	Immune compromise after radiation, chemotherapy and other immunosuppressive measures	1
Endocrine, nutritional and metabolic diseases		16
E03.8, E03.9	Hypothyroidism	6
E11.60	Type 2 diabetes mellitus with other specified complications	1
E44.0	Moderate protein-calorie malnutrition	1
E53.8	Deficiency of other specified B group vitamins	1
E55.9	Vitamin D deficiency, unspecified	2
E66.00, E66.91	Obesity	2
E83.38	Other disorders of phosphorus metabolism and phosphatase	1
E87.6	Hypokalemia	2
Mental, Behavioral and Neurodevelopmental disorders		3
F32.8	Other depressive episodes	1
F43.1	Post-traumatic stress disorder (PTSD)	1
F53.8	Other postpartum mental and behavioral disorders, not elsewhere classified	1
Diseases of the nervous system		3
G01	Meningitis in bacterial diseases classified elsewhere	2
G57.2	Lesion of femoral nerve	1
Diseases of the circulatory system		5
I05.0, I07.1	Heart valve diseases	2
I10.90	Essential hypertension, unspecified: No indication of a hypertensive crisis	1
I48.9	Unspecified atrial fibrillation and atrial flutter	1
I95.8	Other hypotension	1
Diseases of the respiratory system		1
J90	Pleural effusion, not elsewhere classified	1
Diseases of the digestive system		5
K21.9	Gastro-esophageal reflux disease without esophagitis	1

Table 4 (continued)

Variables		N
K59.0	Constipation	1
K64.3	Fourth degree hemorrhoids	1
K66.1	Hemoperitoneum	1
K66.8	Other specified disorders of peritoneum	1
Diseases of the skin and subcutaneous tissue		2
L20.8	Dermatitis	2
Diseases of the musculoskeletal system and connective tissue		1
M54.2	Cervicalgia	1
Diseases of the genitourinary system		49
N06.8	Isolated proteinuria with other morphologic lesion	1
N13.6	Pyonephrosis	1
N18.9	Chronic kidney disease, unspecified	1
N39.0	Urinary tract infection, site not specified	1
N73.6	Female pelvic peritoneal adhesions	1
N80.3	Endometriosis of pelvic peritoneum	1
N83.8	Other noninflammatory disorders of ovary, fallopian tube and broad ligament	1
N87.0	Mild cervical dysplasia	1
N90.7	Vulvar cyst	1
N90.8	Other specified noninflammatory disorders of vulva and perineum	1
N90.80	Female genital mutilation, type unspecified	3
N90.81	Female Genital Mutilation, Type 1	3
N90.82	Female Genital Mutilation, Type 2	5
N90.83	Female Genital Mutilation, Type 3	16
N90.88	Other specified non-inflammatory diseases of the vulva and perineum (FGM, Unspecified or other)	6
N92.0	Excessive and frequent menstruation with regular cycle	2
N94.1	Dyspareunia	2
N94.4	Primary dysmenorrhea	1
N97.1	Female infertility of tubal origin	1
Pregnancy, childbirth and the puerperium		281
O08.1	Delayed or excessive haemorrhage following abortion and ectopic and molar pregnancy	1
O09.1	"Duration of pregnancy 5 to 13 completed weeks, 35 to 91 completed days"	2
O09.2	"Duration of pregnancy 14 to 19 completed weeks, 92 to 133 completed days"	4
O09.3	"Duration of pregnancy 20 to 25 completed weeks, 134 to 175 completed days"	2
O09.4	"Duration of pregnancy 26 to 33 completed weeks, 176 to 231 completed days"	6
O09.5	"Duration of pregnancy 34 to 36 completed weeks, 232 to 252 completed days"	3
O09.6	"Duration of pregnancy 37 to 41 completed weeks, 253 to 287 completed days"	72
O09.7	"Duration of pregnancy more than 41 completed weeks, more than 287 completed days"	15
O13	Gestational [pregnancy-induced] hypertension without significant proteinuria	1
O14.9	Unspecified pre-eclampsia	1
O16	Unspecified maternal hypertension	2

Table 4 (continued)

Variables		N
O24.1, O24.3	Pre-existing diabetes mellitus, in pregnancy, childbirth and the puerperium	4
O24.4	Gestational diabetes mellitus	6
O32.2	Maternal care for transverse and oblique lie	2
O33.4	Maternal care for disproportion of mixed maternal and fetal origin	3
O34.2	Maternal care due to uterine scar from previous surgery	4
O34.6	Maternal care for abnormality of vagina	3
O34.7	Maternal care for abnormality of vulva and perineum	3
O36.0	Maternal care for rhesus isoimmunization	2
O36.5	Maternal care for known or suspected poor fetal growth	1
O36.6	Maternal care for excessive fetal growth	1
O41.0	Oligohydramnios	2
O42.0, O42.11	Premature rupture of membranes, onset of labor within 24 hours of rupture	3
O43.20	Placenta accreta	2
O44.11	Complete placenta previa with hemorrhage, first trimester	1
O45.9	Premature detachment of the placenta, unspecified	1
O48	Post-term pregnancy	10
O60.1	Preterm labor with preterm delivery	1
O60.3	Preterm delivery without spontaneous labour	5
O61.0	Failed medical induction of labor	2
O62.1	Secondary uterine inertia	3
O63.0	Prolonged first stage (of labor)	2
O63.1	Prolonged second stage (of labor)	8
O64.1	Obstructed labour due to breech presentation	1
O64.8	Obstructed labor due to other malposition and malpresentation	1
O66.8	Other specified obstructed labor	2
O68.0	Labour and delivery complicated by fetal heart rate anomaly	2
O69.8	Labour and delivery complicated by other cord complications	1
O70.0	First degree perineal laceration during delivery	14
O70.1	Second degree perineal laceration during delivery	7
O71.3	Obstetric laceration of cervix	1
O71.8	Other specified obstetric trauma	2
O72.0, O72.1	Third-stage haemorrhage	9
O72.3	Postpartum coagulation defects	1
O73.0	Retained placenta without haemorrhage	1
O73.1	Retained portions of placenta and membranes, without haemorrhage	1
O75.7	Vaginal delivery following previous caesarean section	3
O85	Puerperal sepsis	1
O86.2	Urinary tract infection following delivery	1
O87.2	Haemorrhoids in the puerperium	1
O90.2	Haematoma of obstetric wound	1
O98.3	Other infections with a predominantly sexual mode of transmission complicating pregnancy, childbirth and the puerperium	1
O98.4	Viral hepatitis complicating pregnancy, childbirth and the puerperium	1
O98.8, O98.9	Maternal infectious and parasitic diseases complicating pregnancy, childbirth and the puerperium	2
O99.0	Anaemia complicating pregnancy, childbirth and the puerperium	24
O99.2	Endocrine, nutritional and metabolic diseases complicating pregnancy, childbirth and the puerperium	7

Table 4 (continued)

Variables		N
O99.3	Mental disorders and diseases of the nervous system complicating pregnancy, childbirth and the puerperium	2
O99.6	Diseases of the digestive system complicating pregnancy, childbirth and the puerperium	2
O99.7	Diseases of the skin and subcutaneous tissue complicating pregnancy, childbirth and the puerperium	2
O99.8	Other specified diseases and conditions complicating pregnancy, childbirth and the puerperium	12
Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified		3
R30.0	Dysuria	1
R74.8	Abnormal levels of other serum enzymes	1
R82.3	Abnormal findings on cytological and histological examination of urine	1
Definition of HIV infection stages		2
U60.9, U61.9	HIV classification	2
External causes of morbidity		2
Y57.9	Drug or medicament, unspecified	1
Y84.9	Medical procedure, unspecified	1
Factors influencing health status and contact with health services		290
Z21	Asymptomatic human immunodeficiency virus (HIV) infection status	1
Z22.3, Z22.8	Carrier of other infectious diseases	17
Z25.8, Z27.3, Z27.4	Need for immunization against specified viral diseases	8
Z30.4	Surveillance of contraceptive drugs	1
Z34	Supervision of normal pregnancy	3
Z35.2, Z35.4, Z35.8	Supervision of high-risk pregnancy	4
Z37.0	Single live birth	91
Z37.2	Twins, both liveborn	1
Z59	Problems related to housing and economic circumstances	1
Z64.8, Z65	Problems related to certain psychosocial circumstances	4
Z86.1	Personal history of infectious and parasitic diseases	1
Z86.7	Personal history of diseases of the circulatory system	2
Z87.8	Personal history of other specified conditions	1
Z91.70	Personal history of female genital mutilation, type unspecified	17
Z91.71	Personal history of female genital mutilation, type 1	22
Z91.72	Personal history of female genital mutilation, type 2	47
Z91.73	Personal history of female genital mutilation, type 3	63
Z91.74	Personal history of female genital mutilation, type 4	3
Z92.1	Personal history of long-term (current) use of anticoagulants	2
Z94.0	Kidney transplant status	1

haemorrhage (n = 12, 41.7% of FGM/C type III), and vulvar cysts (n = 5, 80% of FGM/C type III).

Medical or surgical interventions were carried out in 110 (56,5%) patients with FGM/C: 47 interventions in Geneva, 42 in Lausanne and 22 in Zürich (Table 6). The most frequent obstetrical intervention was caesarean section (n = 29, 48.3% of FGM/C type III). 14 patients had an episiotomy (35.7% of FGM/C type III) and 15 required unspecified manual assistance during delivery (20% of FGM/C type III). The most frequent intervention aimed at treating complications of FGM/C was surgery of the clitoris (n = 11, 36.4% of FGM/C type III). In Geneva, four inpatients underwent defibulation.

Discussion

Main findings

In four Swiss university hospitals, 207 inpatients had a primary (n = 22, 10.6%) or secondary (n = 185, 89.4%) diagnosis of FGM/C coded at admission between 2016 and 2018 [26]. As discussed in our related paper on Swiss university hospitals' capacities of coding FGM/C,

Table 5 Specific codes for long-term complications to FGM/C when FGM/C was coded as primary or secondary diagnosis

Variables		Primary diagnosis of FGM/C (n = 22)	Secondary diagnosis of FGM/C (n = 185)	Percentage of FGM/C Type III
ICD-10 chapter and diagnoses	ICD-10 code			
Certain infectious and parasitic diseases				
Human immunodeficiency virus (HIV) disease	B20-24	0	0	
Mental, Behavioral and Neurodevelopmental disorders				
Recurrent depressive disorder	F32-33	0	1	50% (n = 1)
Generalized anxiety disorder	F41.1	0	0	
Post-traumatic stress disorder	F43.1	0	1	100% (= 1)
Sexual dysfunction, not due to an organic condition	F52	0	0	
Diseases of the genitourinary system				
Cystitis	N30	0	0	
Urinary tract infection, site not specified	N39.0	0	1	100% (n = 1)
Other inflammation of vagina and vulva	N76	0	0	
Dysplasia of cervix uteri	N87	0	1	0% (n = 0)
Other specified non-inflammatory disorders of vagina	N89.8	0	0	
Vulvar cyst	N90.7	4	1	80% (n = 4)
Non-inflammatory disorder of vulva and perineum, unspecified	N90.9	0	0	
Dyspareunia	N94.1	0	2	50% (n = 1)
Dysmenorrhea, unspecified	N94.6	0	0	
Other specified conditions associated with female genital organs and menstrual cycle	N94.8	0	0	
Pregnancy, childbirth and the puerperium				
Prolonged second stage of labour	O63.1	13	8	28.6% (n = 6)
First degree perineal laceration during delivery	O70.0	13	14	29.6% (n = 8)
Second degree perineal laceration during delivery	O70.1	11	7	44.4% (n = 8)
Third degree perineal laceration during delivery	O70.2	1	0	100% (n = 1)
Fourth degree perineal laceration during delivery	O70.3	2	0	50% (n = 1)
Perineal laceration during delivery, unspecified	O70.9	2	0	0% (n = 0)
Obstetric high vaginal laceration	O71.4	0	0	
Other specified obstetric trauma	O71.8	0	2	50% (n = 1)
Obstetric trauma, unspecified	O71.9	0	0	
Postpartum haemorrhage	O72.0, O72.1	3	9	41.7% (n = 5)
Low forceps delivery	O81.0	0	0	
Other and unspecified forceps delivery	O81.3	0	0	
Vacuum extractor delivery	O81.4	0	0	
Single delivery by caesarean section	O82	0	0	
Disruption of perineal obstetric wound	O90.1	0	0	
Certain conditions originating in the perinatal period				
Birth trauma	P10-15	0	0	

this was much less than expected when compared with the number of inpatients who could have undergone FGM/C based on their nationality and indirect estimates (n = 4947) [26]. Either fewer women than expected have undergone FGM/C, or healthcare professionals did not identify and/or record it, or professional coders failed to code FGM/C, resulting in suboptimal coding. Nearly all patients with a coded condition/diagnosis of FGM/C were admitted to an obstetrics and/or gynaecology division, and most of their primary and secondary diagnoses were related to pregnancy and delivery.

Limitations and strengths

Limitations included the absence of participation from Basel; of interventions' data from Bern; the exclusion of outpatients, which would inform on the health conditions treated and interventions performed (e.g. defibulation) in ambulatory care; and of non-university

Table 6 Main intervention reported among patients with FGM/C according to hospital

Variables	Geneva (n = 111)	Lausanne (n = 42)	Zürich (n = 22)	Percentage of FGM/C Type III
Obstetrical interventions				
Cerclage of the cervix	1	0	0	100% (n = 1)
Pharmaceutical induction of labour	0	1	0	100% (n = 1)
Manual assistance during delivery:				
With episiotomy and instrumentation	0	5	2	42.9% (n = 3)
With episiotomy only	0	1	6	28.5% (n = 2)
Unspecified	0	13	2	20% (n = 3)
Caesarean section	20	8	1	48.3% (n = 14)
Perineal tear repair	2	6	0	37.5% (n = 3
Curettage for retained placenta	1	1	0	0% (n = 0)
Gynaecological interventions				
Ovarian cyst excision	1	0	0	100% (n = 1)
Myomectomy	1	0	0	100% (n = 1)
Salpingectomy	1	0	1	50% (n = 1)
Interventions related to FGM/C				
Clitoral surgery	8	3	0	36.4% (n = 4)
Vulvar cyst excision	2	0	0	100% (n = 2)
Vulvar abscess incision and drainage	1	0	0	0% (n = 0)
Defibulation	4	0	0	100% (n = 4)
Interventions possibly related to FGM/C				
Hymenectomy	0	0	1	100% (n = 1)
Repair of vulva and perineum	0	0	5	100% (n = 5)
Incision of vulva and perineum	0	0	4	75% (n = 3)
Other interventions				
Femoral fracture repair	0	1	0	
Hematopoietic stem cell transplant	0	1	0	
Lymph node biopsy	0	1	0	
Mitral valvuloplasty	1	0	0	
Retrograde ureteropyelography	1	0	0	
Ureteral pigtail placement	1	0	0	
Transvaginal suspension for urinary incontinence	0	1	0	
Trunk abscess incision and drainage	1	0	0	

Table 7 Number of deliveries between 2016 and 2018 according to center [27–33]

	2016	2017	2018
Geneva (HUG)	4101	4182	4213
Vaud (CHUV)	3230	3227	3375
Bern (Inselspital)	1810	1827	2004
Zürich (USZ)	2960	2971	2969

hospitals, where most deliveries of women in the cantons of Bern and Zürich occur (Tables 7, 8) [27–34]. Future studies could assess the prevalence of FGM/C and associated health outcomes in all hospitals, and study regional variations, such as in areas near asylum centres. Application of our method is mostly limited by undercoding of FGM/C, which most likely results from insufficient training about FGM/C [26]. Besides gynaecology and obstetrics, health professionals working in paediatrics, travel medicine, infectious diseases, primary care, and migrant health programmes, could benefit from such training.

This study's main strength was the use of ICD-10 codes to identify health complications of FGM/C, an affordable and objective method, easily reproducible over time, and at national and international level, with good comparability of data. Impact of training, specific care, as well as financial costs resulting from health complications of FGM/C might also be assessed using ICD codes. They could be used in both diaspora and

Table 8 Living births according to canton and nationality category of the mother [34]

	2016			2017			2018		
	Total	Swiss[a]	Foreigners[b]	Total	Swiss	Foreigners	Total	Swiss	Foreigners
Geneva (Geneva)	5361	2253	3108	5441	2350	3091	5353	2331	3022
Vaud (Lausanne)	8730	4401	4329	8686	4350	4336	10,145	5879	4266
Bern (Bern)	10,113	7038	3075	10,141	7115	3026	10,145	7189	2956
Zürich (Zürich)	17,051	9602	7449	17,070	9490	7580	16,919	9402	7517

[a] Infants born to women with a Swiss nationality

[b] Infants born to women without a Swiss nationality

FGM/C high prevalence countries, as an alternative to the FGM/C cost calculator developed by WHO only for high prevalence countries [35].

Interpretation

Women with FGM/C might consult, be admitted or referred more frequently when pregnant, resulting in better FGM/C coding in obstetrics divisions. Furthermore, Swiss basic health insurance covers most pregnancy-related costs, facilitating access to healthcare [36]. Obstetricians and gynaecologists routinely perform genital examinations and are more likely trained to diagnose FGM/C [26]. FGM/C is also more likely to be recorded in obstetrics charts, because it can influence childbirth [1]. For instance, UK's report on FGM/C prevalence in the National Health System (NHS) showed that 1630 women and girls had a consultation where FGM/C was recorded between October and December 2020, with 74.9% of attendances in midwifery or obstetrical units [37]. Antenatal consultations provide major opportunities to identify and care for individuals with FGM/C who might not seek or receive medical attention otherwise [1, 38].

Meta-analyses including studies from FGM/C practicing countries, and diaspora countries showed that FGM/C was significantly associated with prolonged labour, perineal tears, episiotomy, and non-significantly associated with caesarean section [19, 20]. Obstetric outcomes coded in our study were mainly prolonged second stage of labour (n = 21) and perineal lacerations (n = 50) especially of first- or second-degree (90%). 29 inpatients required a caesarean section, 14 episiotomy, and 15 assistance during delivery. We were not able to calculate the prevalence of complications from FGM/C for several reasons. Our data was fully anonymized, and thus some records could potentially be returning patients, so we cannot know the exact denominator of pregnant women in our sample. Second, the study was cross-sectional, and some pregnant women might have delivered after the end of the study, leaving their birth outcomes unknown.

Among 85,990 deliveries in 2017 in Swiss medical institutions, 54.7% of women had a perineal tear mainly of first- or second-degree (94.7%); 32.3% a caesarean section; 11.1% an assisted delivery, and 17% an episiotomy [39]. Considering that at least 135 women were pregnant (135 inpatients admitted in obstetrics, and 30 in gynaecology and/or obstetrics), and subject to the limitations stated above, our data do not suggest high rates of obstetric complications.

Studies about obstetric complications of FGM/C sometimes show diverging results. A prospective study conducted in six African countries found a significant association between obstetric complications and FGM/C, especially type III [40], whereas retrospective studies from high-income countries such as Sweden, the UK, and Switzerland showed similar obstetric outcomes among women with and without FGM/C [41–43]. FGM/C has been significantly associated with higher rates of caesarean sections in studies conducted in both practicing and diaspora countries [40, 44, 45], and meta-analyses show a non-significant trend towards higher rates [19, 20]. Future studies could assess if training of health professionals and access to interpreters could improve obstetric outcomes of individuals with FGM/C. Indeed, health professionals unfamiliar with FGM/C might perform caesarean sections for inappropriate reasons, especially in cases of infibulation [46]. Moreover, migrant women in high-income countries often have higher rates of caesarean sections than non-migrants [47]. Communication barriers, economic difficulties, and exposure to violence can result in poor maternal health and/or care quality for some migrants regardless of FGM/C [48–52].

Only five minor inpatients had an FGM/C code. Outpatient clinics may attend more children with FGM/C than hospitals, but paediatricians may also not know when and how to discuss FGM/C with parents and their children, not recognize it if they perform a genital examination, or simply not record it [53–55]. Alternatively, they could be second-generation migrants and beyond, and therefore less exposed to the practice. A UK study

showed that among 55 children with FGM/C referred to specialized clinics, 21% suffered from mental health symptoms such as anxiety, sleep and behaviour disorders, and 13% from physical symptoms such as problems with micturition, menstruation and genital pain [14]. Except one post-traumatic stress disorder, psychological symptoms were not coded in our minor population, and rarely among adults. Swiss university hospitals' health professionals may lack time or training on how to detect and treat such symptoms and other FGM/C complications. Or, they may identify and manage psychological complications, without however identifying or documenting the FGM/C as an associated condition [54–60].

Coding of surgical interventions was incomplete. Perineal tears were more coded (n = 50) than perineal tears repairs (n = 8). Other repairs were either not coded, or coded as secondary interventions, which were not provided. Because no CHOP codes exist for defibulation and clitoral reconstruction, we had to hypothesize that codes such as repair (n = 5), or incision (n = 4) of vulva and perineum had been used to indicate these surgeries. Geneva provided the interventions' names instead of codes, and reported 8 clitoral surgeries and 4 defibulations among inpatients, and additionally reported 12 clitoral surgeries, 25 defibulations and 8 other surgeries for scar complications of FGM/C in outpatient care. Some Swiss insurance companies have tried to refuse to reimburse these surgeries. Specific CHOP codes would facilitate medical coding and reimbursement.

Sensitisation and training of healthcare professionals and professional coders on FGM/C could improve identification, documentation and coding of FGM/C and its complications in Swiss university hospitals; inform and improve the quality of future policies, services and interventions. Future prospective and case–control studies could assess coding of FGM/C and associated health outcomes according to training and specialised care resources.

Conclusion

Most of the 207 women and girls admitted to Swiss university hospitals between 2016 and 2018 with a primary or secondary diagnosis of FGM/C were admitted to obstetrics divisions. Pregnancy and delivery seem to be key moments to care for and counsel a population that might not consult or be identified otherwise. FGM/C coding capacities in Swiss university hospitals are low, and some complications of FGM/C are probably not diagnosed, or diagnosed alone, without FGM/C.

Abbreviations

CHOP: Swiss Classification of Surgical Interventions; CHUV: University Hospital of Lausanne; FGM/C: Female genital mutilation/cutting; HUG: Geneva University Hospitals; ICD: International Classification of Diseases; NHS: National Health System; USB: University Hospital of Basel; USZ: University Hospital of Zürich; UK: United Kingdom; WHO: World Health Organization.

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Author contributions

JA designed and directed the project. SCC collected the data, together with JA and MH. SCC did the data analysis, in collaboration with MH. MH, SCC and JA wrote the manuscript. All the authors reviewed and approved the manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This cross-sectional study was approved in December, 2018 by the Swiss Ethics Committees (SwissEthics) with the protocol number 2018-01851, and conducted according to the protocol, the Swiss legal requirements, and the World Medical Association Declaration of Helsinki. An exemption of informed consent was granted by the state of Geneva Swiss Ethics committee for the use of anonymized data extracted from the university hospitals databases.

Consent for publication

Not applicable.

Competing interests

No competing interests to declare.

Author details

[1]Faculty of Medicine, University of Geneva, Geneva, Switzerland. [2]Division of Gynaecology, Department of the Woman, The Child and the Adolescent, Geneva University Hospitals, 30 Bld de la Cluse, 1211 Geneva, Switzerland. [3]Swiss Tropical and Public Health Institute, University of Basel, Basel, Switzerland.

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Publisher's Note

Chapter 8: Female Genital Mutilation/Cutting in the Swiss HIV Cohort Study: a cross-sectional study

Fabio Mauri[1], Sara Cottler-Casanova [1,2,3], Matthias Cavassini[4], Marcel Stoeckl[5], Gilles Wandeler[6], Patrick Schmid[7], Dominique L Braun[8, 11], Alexandra Scherrer[5], Enos Bernasconi[9], Alexandra Calmy[10*], Jasmine Abdulcadir[1*§] and the Swiss HIV Cohort Study

1. Department of Paediatrics, Obstetrics and Gynaecology, Geneva University Hospitals, Geneva, Switzerland
2. Department of Epidemiology and Public Health, Swiss Tropical and Public Health Institute, Basel, Switzerland
3. University of Basel, Basel, Switzerland
4. Division of Infectious Diseases, Lausanne University Hospital, Lausanne, Switzerland
5. Division of Infectious Diseases and Hospital Epidemiology, University Hospital Basel, Switzerland
6. Department of Infectious Diseases, Bern University Hospital and University of Bern, Switzerland
7. Division of Infectious Diseases and Hospital Epidemiology, Kantonsspital St. Gallen, Switzerland
8. Division of Infectious Diseases and Hospital Epidemiology, University Hospital of Zurich, Switzerland
9. Division of Infectious Diseases, Regional Hospital Lugano, Lugano, Switzerland
10. HIV/AIDS Unit, Division of Infectious Diseases, Geneva University Hospitals, Switzerland
11. Institute of Medical Virology, University of Zurich, Switzerland

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ORIGINAL PAPER

Female Genital Mutilation/Cutting in the Swiss HIV Cohort Study: A Cross-Sectional Study

Fabio Mauri[1] · Sara Cottler-Casanova[1,2,3] · Matthias Cavassini[4] · Marcel Stoeckle[5] · Gilles Wandeler[6] · Patrick Schmid[7] · Dominique L Braun[8,11] · Alexandra Scherrer[5] · Enos Bernasconi[9] · Alexandra Calmy[10] · Jasmine Abdulcadir[1]

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Abstract

FGM/C is a harmful practice that involves injury of the external female genitalia without medical purpose. It is mainly practiced in Africa, Asia, and the Middle East. However, with the migratory flows, women and girls with FGM/C and its consequences live all over the world. The lack of knowledge on how to care for women and girls living with FGM/C extends among all categories of health professionals involved in women's health, including infectious disease specialists. This is a national, exploratory descriptive cross-sectional study aimed to generate descriptive statistics about FGM/C among HIV-infected migrant women included in the Swiss HIV Cohort Study (SHCS). Among the 387 women interviewed about FGM/C and who provided an answer, 80 (20.7%) reported to have undergone FGM/C. Fifty-six of the 80 women (70.0%) who reported having undergone FGM/C, also reported that they had never discussed their cutting with a health professional before. Our study demonstrates how common female genital mutilation is in women living with HIV and who have migrated to Switzerland and suggest how care and prevention could be improved significantly.

Keywords Female genital mutilation/cutting · FGM/C · HIV · Human immunodeficiency virus · Swiss HIV Cohort Study

Introduction

Female genital mutilation or cutting (FGM/C) is the practice of partial or total removal of the external female genitalia or injury to the genitals for non-medical reasons. The World Health Organization (WHO) classifies FGM/C into four types [1] (Table 1). This harmful practice has been documented in at least 27 African and 3 Asian countries and, as a result of migration, in high-income countries. The countries with the highest prevalence are Somalia (98%), Guinea (96%), Djibouti (93%), Egypt (91%), Eritrea (89%), Mali (89%), Sierra Leone (88%) and Sudan (88%) [2]. Estimates

✉ Jasmine Abdulcadir
jasmine.abdulcadir@hcuge.ch

1 Department of Pediatrics, Obstetrics and Gynecology, Geneva University Hospitals, Bld de la Cluse, 1211, 0041-22- 3724049 Geneva, Switzerland

2 Department of Epidemiology and Public Health, Swiss Tropical and Public Health Institute, Basel, Switzerland

3 University of Basel, Basel, Switzerland

4 Division of Infectious Diseases, Lausanne University Hospital, Lausanne, Switzerland

5 Division of Infectious Diseases and Hospital Epidemiology, University Hospital Basel, Basel, Switzerland

6 Department of Infectious Diseases, Bern University Hospital and University of Bern, Bern, Switzerland

7 Division of Infectious Diseases and Hospital Epidemiology, Kantonsspital St. Gallen, St. Gallen, Switzerland

8 Division of Infectious Diseases and Hospital Epidemiology, University Hospital of Zurich, Zurich, Switzerland

9 Division of Infectious Diseases, Regional Hospital Lugano, Lugano, Switzerland

10 HIV/AIDS Unit, Division of Infectious Diseases, Geneva University Hospitals, Geneva, Switzerland

11 Institute of Medical Virology, University of Zurich, Zurich, Switzerland

Table 1 The WHO classification of female genital mutilation

Type I. Partial or total removal of the clitoral glans, and/or the prepuce/clitoral hood
Type Ia. Removal of the prepuce/clitoral hood only.
Type Ib. Removal of the clitoral glans with the prepuce/clitoral hood.
Type II. Partial or total removal of the clitoral glans and the labia minora, with or without removal of the labia majora
type IIa. Removal of the labia minora only.
type IIb. Partial or total removal of the clitoral glans and the labia minora
type IIc. Partial or total removal of the clitoral glans, the labia minora and the labia major
Type III. (Often referred to as infibulation). Narrowing of the vaginal opening with the creation of a covering seal. The seal is formed by cutting and repositioning the labia minora, or labia majora.
Type IIIa. Removal and repositioning of the labia minora.
Type IIIb. Removal and repositioning of the labia majora.
Type IV. All other harmful procedures to the female genitalia for non-medical purposes, for example pricking, piercing, incising, scraping and cauterization

from the United Nations Children's Fund (UNICEF) report that more than 200 million women and girls have undergone FGM/C globally [3] and that the number of migrants coming from FGM/C-practicing countries to high income countries will continue to increase [4]. Estimates from 2018 show that of the 36,898 women and girls living in Switzerland coming from one of the 30 high prevalence FGM/C countries, an estimated 21,706 have been cut or might be at risk of the practice [5]. However, indirect prevalence for women and girls living with FGM/C may not reflect the actual FGM/C prevalence among migrants in Switzerland and surveying samples of migrants might inform future estimates and care and prevention interventions.

Since the 1st of July, 2012, a specific article (art. 124) of the Swiss Penal Code states that it is an illegal and punishable offense «to mutilate the genitals of women or girls, impair their natural function considerably and lastingly or harm them in any manner» [6]. In 2016, the Swiss Network against Female Genital Cutting was created with the support of the Federal Office of Public Health [7]. As part of their activities, they conduct training of healthcare providers, healthcare students, certified interpreters and cultural navigators. Healthcare professionals are in fact not often trained about FGM/C and are therefore unaware of the different types of cutting, their possible negative health consequences and the existing management options. They also lack training on cultural, psychosexual, and legal information as well as counselling and prevention methods [8, 9]. Several studies have shown how such lack of knowledge is extended among all categories of health professionals involved in women's health: gynecologists, pediatricians, general practitioners, infectious disease specialists, social workers, nurses and midwives [10–14]. This lack of training makes it difficult for health care providers to identify, diagnose and treat patients with FGM/C. A missed diagnosis of FGM/C can result in missed opportunities for the treatment and care of women as well as the prevention of FGM/C for her daughter(s) [15].

FGM/C can cause various negative health complications including adverse obstetric outcomes [16], long lasting psychological impact [17–19], painful vulvar scarring and pain, sexual dysfunction, genitourinary complications [17] [20] and infections, including the possibility of acquiring human immunodeficiency virus (HIV). The hypothesized mechanisms of HIV transmission related to FGM/C are the use of non-sterile equipment at the moment of the cutting, the need for blood transfusion in the event of hemorrhage and, increased risk of genital trauma due to vulvar scarring, with increased risk of sexually transmitted infections including HIV [21–24]. Some studies also show an association between FGM/C and HPV infection and cervical dysplasia [25], which might be worsened in case of an associated HIV infection. Some countries with a high prevalence of FGM/C, such as Ethiopia and Burkina Faso also register a high prevalence of HIV. [26, 27] Therefore, we hypothesize that infectious disease specialists, particularly HIV and travel medicine specialists regularly encounter women and girls potentially at risk or having already undergone FGM/C.

Our study aims to generate descriptive statistics about FGM/C among HIV-infected migrant women included in the Swiss HIV cohort study (SHCS). This will help to inform our estimates for the number of women living with FGM/C in Switzerland.

Methods

This is a national, exploratory descriptive cross-sectional study. It has been approved by the Swiss Ethics Committees (Swissethics) and conducted according to the protocol, the Swiss legal requirements, the World Medical Association Declaration of Helsinki and the principles of Good Clinical Practice. The study was conducted in all Swiss Cantons after approval of the local ethical committees (2018 – 01851) and (01-142).

Settings

The SHCS is a prospective cohort study with ongoing community and hospital enrolment of HIV-positive individuals in Switzerland. It has remained representative of the HIV patient population since its inception in 1988, and currently covers at least 75% of all patients receiving combination antiretroviral therapy (cART) and 69% of patients living

with AIDS in Switzerland [28]. When an HIV infection is diagnosed, the concerned person is also informed of the existence of the SHCS and proposed to be enrolled and followed up by an infectious disease specialist at the main Swiss hospitals. If the person agrees, she signs a written and informed consent.

The number of migrant persons living with HIV (PLWH) is significant and has grown over time. However, their number is under-represented in the SHCS due to the trend of delaying access to health care HIV-related services in comparison with Swiss citizens or because it is easier to lose them to follow-up [29–31].

Prior to implementing the questionnaire, the Swiss infectious disease specialists were trained through a course on FGM/C that included information on the practice, cultural issues, countries at risk, complications, Swiss law and sites of referral to facilitate communication with the patients. Specific attention was paid to how to screen and discuss FGM/C in a culturally sensitive way. A PowerPoint presentation summarizing chapter two of the WHO clinical handbook for care of girls and women living with FGM (Communicating with girls & women living with FGM) was sent to all providers involved in administering the questionnaire [32]. The training was considered executed on the declaration of the specialists, without direct assessment by the authors.

Participants

In this study, migrants are defined as non-Swiss citizens living on the Swiss territory for any length of stay regardless of permit or visa.

All women 18 years or above, originating from one of the 30 high-risk countries where FGM/C is practiced [29] were eligible. The questions were administered verbally by the patient's physician during SHCS visits between June and December 2019 after written informed consent. In instances where language was a potential barrier, cultural mediators and certified interpreters were available without additional costs to the patients. For every affirmative response by a woman about whether she has undergone FGM/C, the healthcare provider would present the patient with information on counseling and healthcare services where she could be referred. The list of such services was provided together with the training PowerPoint presentation mentioned above.

Measures

The routine SHCS questionnaire conducted every 6-months by the patient's physician was enriched with the following additional questions over a 6-month period:

- Have you experienced female circumcision/genital cutting during your childhood?
- If the answer is yes; have you ever had the chance to discuss about it with a healthcare professional (doctor, nurse, etc.)?

The questions were developed by the principal investigators, submitted to the infectious disease specialists of the SHCS taking part to the training session, five adult patients of the outpatient clinic for women and girls with FGM/C and two certified interpreters of Geneva University hospitals to receive feedback before implementation.

Analysis

The data was automatically extracted from the SHCS database and analyzed using an Excel spreadsheet.

Results

The SHCS includes 9,690 people in active follow-up, of whom 5,471 hold Swiss citizenship (56.5%) and 4,219 (43.5%) hold a citizenship other than Swiss. Of 2675 women currently followed in the SHCS, 583 were considered for the two specific questions on FGM/C during the 6-month study duration based on their origin. Overall, 196 (33.6%) were not administered the questionnaire by the practicing physician for unknown reasons. Due to the fact that the data are anonymized except from the geographical origin of respondents, we could not discuss such result with the healthcare providers of the patients.

Among the 387 women interviewed about FGM/C and who provided an answer, 80 (20.7%) reported to have undergone FGM/C while 288 (74.4%) reported not having been cut. Nine women preferred not to answer and the remaining 10 did not understand the question according to the comment left by the interviewer. Fifty-six of the 80 women (70.0%) who reported having undergone FGM/C, also reported that they had never discussed their cutting with a health professional before.

Most women of the SHCS who reported living with FGM/C came from Eastern Africa, particularly Eritrea (41.3%) and Ethiopia (24.1%); followed by Ivory Coast (17.2%). The countries with the highest prevalence of FGM/C in the SHCS are Burkina Faso, Eritrea and Somalia which presents elevated rates of FGM / C in PLWH as expected, respectively of 31.3%, 41.3% and 62.5%. (Table 2).

The rate of missing questions is fairly evenly distributed with the origins of the patients, settling at around 30%, with

Table 2 Participants' origins

Nation	Total	History of FGM/C	missing
Central Africa			
Cameroon	193	2 (1.0%)	70
Central African Republic	3	1 (33,3%)	1
Guinea	9	2 (22.2%)	5
Eastern Africa			
Comore	1	0 (0.0%)	1
Eritrea	75	31(41.3%)	21
Ethiopia	58	14 (24.1%)	24
Kenya	67	2 (3.0%)	23
Somalia	8	5 (62.5%)	3
Sudan	1	1 (100.0%)	0
Tanzania	6	0 (0.0%)	2
Uganda	15	0 (0.0%)	5
Western Africa			
Benin	2	0 (0.0%)	0
Burkina Faso	16	5 (31.3%)	7
Ivory Coast	58	10 (17.2%)	20
Gambia	1	0 (0.0%)	0
Ghana	11	0 (0.0%)	6
Guinea-Bissau	5	2 (40.0%)	3
Liberia	2	0 (0.0%)	1
Niger	3	1 (33.3%)	1
Nigeria	16	3 (18.75%)	9
Senegal	6	1 (16.7%)	1
Togo	22	0 (0.0%)	12
Southeast Asia			
Indonesia	4	0 (0.0%)	0
Total	582	80 (13.7%)	215

peaks related to unrepresentative samples (for example 1 patient out of 1 in Comoros).

Discussion and Conclusion

Our findings confirm that FGM/C is common in the SHCS patient population, even though our data may underestimate its presence given the large number of non-respondents.

20.9% of women in the SHCS said they had undergone FGM/C but in comparison to indirect prevalence estimates of FGM/C in Swiss university hospitals, the calculated prevalence according to ICD coding's was 2.29% (95%CI: 1.98–2.62) [5]. This has been estimated as the proportion of the total number of FGM/C cases coded on the total number of women and girls from the targeted countries in four Swiss university hospitals between 2016 and 2018. This is a great example of how indirect estimates should be conducted alongside direct estimates as they may provide more accurate estimates that could guide policy- and clinical decision-making.

The strength of this study is the use of a standardized questionnaire (SHCS), employed since 1988 by healthcare professionals that are well trained in its administration, who received additional training for the questions on FGM/C for this study. A limitation is that we do not have information about the type and eventual complications of FGM/C among the participants. In our sample there are no Asian participants with FGM/C. Another limitation is related to the fact that the number of patients with FGM / C in our sample is probably underpowered for several factors. In addition to what is mentioned above, it is not possible to establish whether a woman with FGM/C reports that she has not been excised for fear or stigma, or because she does not remember because too young when it occurred.

Despite the research setting, a standardized questionnaire with only 2 binary questions to administer, and specific training for the healthcare professionals; more than one third of eligible participants were not interviewed about FGM/C. The reason for this lack of answers is not clear, but it can be deduced to be from the operator's side as the patient's refusal to answer was one of the possible alternatives. It is also possible that some awareness on epidemiology, complications and types of FGM/C are not enough when it comes to address, discuss and treat the issue of FGM/C and training should also focus on improving communication with women and girls with or at risk of having FGM/C.

It is difficult to understand why 10 people reported that they did not understand the question. It could be a problem of language barrier, of taboo linked to the topic (also considering the presence of interpreters in some cases) or of insufficient explanation by the physician. Additionally, more than two thirds of the included participants had never discussed their cutting with a health professional before. As shown in a previous study in France, where only 50% of general practitioners or travel doctors were aware of FGM/C and only 42.9% said they had seen it [11], our findings support the possibility that there is a lack of knowledge, practice and/or time among practicing physicians in charge of HIV patients (including gynecologist, infectious disease specialist, or general practitioners) when it comes to FGM/C. Although they might be used to asking questions about sexual and reproductive health, they may need more information and training on communication, screening, diagnosis, care, referral and prevention about FGM/C [10]. To plan appropriate future training interventions, it will be interesting to explore the barriers that prevent healthcare professionals from asking about genital cutting during consultations. Future research might also include men from countries with a high prevalence of FGM/C. They may have female partners and daughters who may be at risk or have experienced FGM/C and they could also benefit from discussing this subject with their health professional. Travel medicine specialists and general practitioners see families before travelling to home countries and discuss vaccines and malaria

prophylaxis. These visits are a key moment to assess the eventual risk of FGM/C and take actions for prevention or protection from "vacation cutting", which is when the child is taken abroad to undergo FGM/C [28]. However, both the lack of training, sensitization and limited time during visits makes FGM/C infrequently discussed and recorded [11].

There are lot of missed opportunities for discussing FGM/C with patients and, because of that, many opportunities of screening, detecting, treating and preventing FGM/C and its complications, particularly as genitourinary infections or cervical dysplasia in immunocompromised patients that might lead to worsened consequences [33].

FGM/C is common in the SHCS female population originating from Africa, but often overlooked by health professionals working with this population. Most women of the SHCS who reported living with FGM/C came from Eastern Africa, this is not surprising considering that more than 16,000 of the 36,898 migrant women from FGM/C high prevalence countries living in Switzerland in 2018 are originally from Eritrea [5]. Looking at the countries of origin, we can hypothesize that many of these women have undergone FGM/C types II and III which are frequent in Eastern and Western Africa, particularly in Eritrea, Ethiopia and the Ivory Coast. This is important as type II and particularly type III are the forms of cutting mostly associated with health complications including recurrent genitourinary infections [34, 35]. Recent studies have also suggested a possible association between FGM/C and cervical dysplasia and cancer, that again, in a female HIV positive population, deserves particular attention for screening and follow-up [25]. In FGM/C type III, defibulation (surgical opening of infibulation) could be proposed not only to treat eventual symptoms but also to facilitate cervical cancer screening and treatments [36].

FGM/C screening, diagnosis, care and prevention could be improved significantly through training and information. Various useful training material provided by the WHO [17] [32], other organizations [37] and some of the authors [38] are available. Training and continuing education courses are equally important for keeping up-to-date knowledge on this topic [39].

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Authors Contribution FM analyzed the data and wrote the manuscript. SC conceived the study, handled the data and revised the manuscript. MC revised the manuscript. MS revised the manuscript. GW revised the manuscript and data analysis. PS revised the manuscript. DB revised the manuscript. AS revised the manuscript. EB revised the manuscript. AC conceived the study and revised the manuscript. JA conceived the study, analyzed the data and wrote the manuscript. All authors read and approved the final manuscript.

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Data Availability The datasets used during the current study are available from the corresponding author on reasonable request.

Declarations

Conflict of interests AC receives research funds from MSD for women in clinical research (qualitative study). DB receive an honoraria from MSD, ViiV healthcare and Gilead. The other authors declare that they have no competing interests.

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Alexandra Calmy and Jasmine Abdulcadir are sharing the last authorship.

Discussion

The aim of this PhD was to evaluate the available FGM/C data in Switzerland to help improve future FGM/C monitoring and routine data collection. We employed indirect, direct and routine hospital data collection methods. We updated the indirect estimates for women and girls living with FGM/C in Switzerland, using prevalence estimates from FGM/C practicing countries obtained through population-based surveys and applied them to migrant women and girls living in Switzerland from those same countries. We found a significant increase in the absolute number of women and girls with FGM/C over the past decade, mostly as a result of increased migratory flows. Because of the limitations associated with indirect estimates, we also aimed to analyze routine hospital data looking for recorded diagnoses of FGM/C in Swiss university hospitals, as well as any recorded comorbidities. We found exceptionally low reporting and recording of FGM/C among women and girls from high FGM/C prevalence countries in Swiss hospitals. And finally, we conducted a cross-sectional survey of the number of women with FGM/C in the Swiss HIV Cohort Study. We found that FGM/C is common (20.9%) among this population, despite the considerable number of non-respondents (33.6%).

Main findings

Increase in number of women and girls with FGM/C living in Switzerland since 2010

Results from our Swiss national FGM/C indirect estimates show that, from 2010 to 2018, there have been significant increases in the estimated number of women and girls living with FGM/C in Switzerland. In 2010, out of 19,506 migrant women and girls living in Switzerland from one of 30 countries where FGM/C has been documented, 9,059 (46.4%) were estimated to have undergone some form of FGM/C. In 2018, the total number of migrant women and girls living in Switzerland estimated to have undergone some form of FGM/C was 21,706, out of 36,898 women and girls from FGM/C practicing countries (58.8%); corresponding to an increase of 26.7%.

More than 16,000 (>43%) of the 36,898 migrant women from the FGM/C high prevalence countries in 2018 come from Eritrea. The indirect estimation of Eritrean women living in Switzerland, where FGM/C estimated prevalence is among the highest in the world (83%, 2010), is 13,730. The second highest migrant group of this population came from Somalia, where the FGM/C estimated prevalence is almost 98%. Out of 3,290 women and girls living in Switzerland from Somalia, the applied indirect estimate was 3,220 women and girls. In Switzerland, between 2010 and 2018, the total number of female migrants from FGM/C high prevalence countries has grown, particularly women originating

from Eritrea (5-fold increase), with smaller increases from Ethiopia, Egypt, Gambia, Iraq, Kenya, Nigeria, Senegal, Somalia, and Sudan & South Sudan. The number of women from Chad, Sierra Leone and Liberia has slightly decreased, while others have remained steady.

Because of the global commitment to end the practice of FGM/C and work towards its abandonment, some nations have reduced their countries' FGM/C prevalence, directly impacting the indirect estimation of the number of women and girls living with FGM/C in Switzerland. For example, estimates for migrant women from Ethiopia, where the prevalence of FGM/C was 74.2% in 2010 and decreased to 65% in 2016 were impacted. In 2010, out of 1495 women and girls from Ethiopia, 1110 were estimated to be living with FGM/C (74.2%). Fast forward to 2018, 1365 women and girls are estimated to be living with FGM/C out of 2095 total migrant women from Ethiopia (65%). While the rates are still very high, they are trending in the right direction.

Our estimates also reported that in 2018, of the 11,022 girls living in Switzerland coming from one of the 30 high prevalence FGM/C countries, 3,512 are estimated to be at risk or have been subjected to the harmful practice (31.9%). Migrant girls from countries such as Eritrea, Gambia, Guinea, Senegal and Somalia all saw increases in the number of girls aged 0-14 that are estimated to be living or at risk of FGM/C in Switzerland between 2010 and 2018. Over the past 10 years, there was a decrease in the number of girls aged 0-14 estimated to be living with FGM/C in Switzerland, from countries such as Egypt, Ethiopia, Kenya, Liberia, and Yemen.

Substantial underreporting of FGM/C in Swiss University Hospitals

We applied the same methods used in our Swiss national indirect estimate analysis to the Swiss university hospitals. We collected anonymized data from inpatient women and girls from the 30 FGM/C high-prevalence countries. We applied the same FGM/C prevalence estimates for each country where FGM/C is practiced to the female inpatient population in Swiss university hospitals. Our indirect estimate of the number of women and girls that have undergone FGM/C or could be at risk of undergoing FGM/C that were inpatients in the Swiss university hospitals from 2016 through 2018 was 4947 women and girls (1648 in 2016, 1671 in 2017, and 1628 in 2018).

With the anonymized data from the Swiss university hospitals, we measured the number of inpatients with a primary or secondary diagnosis of FGM/C on their medical files. We found

surprisingly different results of coded ICD data in Swiss university hospitals from 2016 through 2018. In Swiss hospitals, healthcare professionals record diagnoses in patients' electronic medical charts, and professional coders code this information with the German modification of the Tenth Edition of the International Classification of Diseases (ICD-10-GM). (54,57) We found that only 207 patients (2.29%, 95%CI: 1.98-2.62) out of the 4947 estimated women and girls with FGM/C had a recorded diagnosis of FGM/C. This very low number of ICD coded FGM/C cases suggests that FGM/C is not accurately diagnosed, recorded and/or coded in Switzerland. Moreover, most women and girls came from Eritrea (n=85) and Somalia (n=54), where FGM/C prevalence exceeds 80%, and where type III is frequent. FGM/C type III is easier to identify, and it is associated with more long-term health complications. Infibulation (type III) was the most frequent type of FGM/C among inpatients from East Africa (n=79, 50.6%). There was a statistically significant increase in FGM/C prevalence from 2016 to 2018: 1.24% in 2016, 2.32% in 2017, and 3.32% in 2018 (P<0.001).

Not surprisingly, FGM/C coding was significantly higher in gynecology and obstetrics departments compared to other departments (P<0.001). Obstetricians and gynecologists regularly examine the external genitalia and should be better equipped to recognize FGM/C. Furthermore, our results indicate that pregnancy and delivery are critical times for recording FGM/C—as was evident from the higher rates detected by obstetricians than gynecologists.

FGM/C diagnosis may also be more likely during pregnancy and childbirth as there are fewer barriers to seeking treatment—healthcare visits during pregnancy and up to 10 days after childbirth are completely covered by the minimum basic health insurance, which is mandatory for everyone living in Switzerland. (58). Any additional expense that the patient may incur could potentially discourage them from seeking treatment. Outside of pregnancy and childbirth, patients must contribute to the costs for all other health care expenses (59), which could deter some migrant women and girls with FGM/C from getting the medical care that they require.

There was a statistically significant difference in the number of FGM/C cases recorded between hospitals; with the most diagnoses of FGM/C in Geneva (n=111), followed by Lausanne (n=35) and Bern (n=32), with the fewest in Zurich (n=22). Established training programs and protocols for the documentation and care for women and girls with FGM/C in Geneva and Lausanne, could explain the higher FGM/C prevalence in these hospitals in comparison to Bern, despite Bern's higher population

of women and girls from FGM/C countries. The University of Geneva hospitals have pictures of FGM/C types and subtypes linked to the gynecology and obstetric medical record, which may have facilitated screening and recording, explaining why FGM/C codes almost tripled between 2017 and 2018.

We also used the anonymized data from the Swiss university hospitals to analyze primary and secondary diagnoses among inpatient women with an FGM/C diagnosis to gain a better understanding of their health complications. Out of the 207 patients with a coded diagnosis of FGM/C, FGM/C was the primary diagnosis for 22 of these women and girls (10.6%), and secondary diagnosis for 185 (89.4%). Of these 185 women for whom FGM/C was not their primary diagnosis, 156 had a primary diagnosis related to pregnancy and childbirth. The top four most common primary diagnoses were: perineal laceration during delivery (n=29, 18.6%), labour and delivery complicated by fetal heart rate anomaly (n=16, 10.3%), prolonged second stage of labour (n=13, 8.3%) and premature rupture of membranes (n=13, 8.3%).

Women with FGM/C had on average 2.59 additional diagnoses (median 2, range 0-15), spanning 16 chapters of the ICD-10-GM. 281 pregnancy and childbirth codes were listed on women and girls' medical records as secondary diagnoses, including 114 codes describing duration of pregnancy (O09.1-O09.7, O48). The next most frequently coded secondary diagnoses were perineal laceration during delivery (n=21), prolonged second stage of labour (n=8), and anaemia complicating pregnancy, childbirth and the puerperium (n=24).

Outside of obstetrics and gynecology departments, only two girls in pediatrics and two women in urology were coded with FGM/C. The prevalence of FGM/C codes among minors (0.66%) was significantly lower than in adult women (2.46%). Only five minor inpatients were coded with FGM/C. Abandonment of the practice among a new generation of immigrants, length of stay and laws banning the practice of FGM/C in Switzerland could explain why it is less frequent among minors. (60–62) However, insufficient screening and routine genital examinations by pediatricians, or absent documentation could also explain the low detection. (63)

Similarly to the underreporting of FGM/C coded diagnoses, few medical interventions were coded. There were only 8 interventions recorded using the CHOP (Swiss Classification of Surgical

Interventions) of perineal lacerations repair, versus 62 ICD codes of perineal lacerations. The remaining repairs were either not coded, or coded as secondary interventions, which were not provided in our anonymized data set. No specific CHOP codes exist for defibulation or clitoral reconstruction. Therefore, we were only able to assume that in Zurich and Lausanne, repair of vulva and perineum (n=5), and incision of vulva and perineum (n=4) were related to patients with FGM/C type II or III. In Geneva, unpublished data from the FGM/C specialized clinic provided exact descriptions of the interventions: 8 clitoral surgeries, and 4 defibulations were carried out among inpatients, compared with 12 clitoral surgeries, 25 defibulations and 8 other vulvar surgeries for scar complications of FGM/C among outpatients at the same time.

Higher FGM/C prevalence among women in Swiss HIV Cohort than in Swiss university hospitals

Our findings from the cross-sectional study about FGM/C among HIV-infected migrant women revealed that 20.9% of women in this study said they had undergone FGM/C vs. 2.29% of women and girls from Swiss university hospitals with an FGM/C diagnosis. Out of 9,690 people in the SHCS being actively followed-up, 5,471 are Swiss (56.5%). From the 2,675 registered women (27.6% of the SHCS), 583 were eligible for the two-question survey, meaning they were over 18, provided consent, and were from one of the 30 FGM/C prevalence countries. Of these women, 196 (33.6%) were not administered the questionnaire by the practicing physician (for unknown reasons). Among the 387 women interviewed about FGM/C and who provided an answer, 81 (20.9%) said they had undergone FGM/C; 287 (74.1%) said they had not. Nine women preferred not to answer and the interviewer said that the remaining 10 did not understand the question. This study was carried out to help to inform our estimates and our knowledge of the number of women living with FGM/C in Switzerland.

Fifty-six of the 81 women (69.1%) who reported having undergone FGM/C, also reported that they had never discussed their cutting with a health professional before. Our results indicate that FMG/C was common in the SHCS patient population, even though the data may have underestimated its presence given the large number of non-respondents.

In this PhD, we explored methods for estimating prevalence of FGM/C among women and girls in Switzerland using a cross-sectional study among women in the Swiss HIV Cohort study; we tested the use of administrative data such as hospital records to describe prevalence. However, because FGM/C is not sufficiently documented, it could not be used as a proxy indicator for prevalence and

incidence of FGM/C at this time. Instead, we generated indirect estimates for women and girls with FGM/C in Swiss University hospitals and compared them to our anonymized data for all inpatient women and girls with a diagnosis of FGM/C in the same hospitals.

Comparison with other studies

Our study of indirect estimates applied an established methodology, known as the "extrapolation method". Swiss indirect estimates were also conducted in 2001, concluding that an estimated 5,718 women and girls with FGM/C could be living in Switzerland out of the 10,501 migrant women from the then-28 FGM/C prevalent countries. (64) Another study from 2002 estimated 6,711 women and girls with FGM/C out of 12,340. (65) Our estimates from 2018 are more than triple these estimates from the early 2000's, proving that these numbers will only continue to grow.

Former Swiss National Councilor Natalie Rickli filed postulate 18.3551 "Measures Against Female Genital Mutilation" on June 14, 2018, entrusting the Federal Council to look into the criminal prevention and prosecution of female genital mutilation. (48) The Federal Department of Police (Fedpol) was appointed to produce a report on FGM/C whistleblowing behavior, prosecution and crime prevention where they also calculated indirect estimates of women and girls with FGM/C in Switzerland for 2018. (66) Fedpol estimates that 22,400 women and girls are living in Switzerland that have been exposed to FGM/C. (66) Their indirect estimates also use the "extrapolation method", however they yielded different results because they included women and girls from Indonesia. We did not include women and girls from Indonesia because they only have nationally representative data on girls 0-14. Fedpol was able to produce these indirect estimates in a time sensitive manner, without handsearching the DHS and MICS database. In 2020, UNICEF released a tool revolutionizing the way scientists and policy makers access nationally representative data on FGM/C. (32) Their platform allows users to query based on FGM/C indicator, country, and year(s), making it easy to update country prevalence rates used to make indirect estimate calculations. Although country prevalence data is now easily accessible, we must be careful with how the indirect estimates are reported, discussed and calculated.

The United States is home to an estimated 513,000 migrant women and girls who have undergone FGM/C or are at risk for the procedure. These estimates were conducted in 2012, and showed an

increase of more than three times since the estimates were last updated, in 1990. (67) Even more striking was the increase in the number of women and girls younger than 18 years of age at risk for FGM/C, which was more than four times that of previous estimates. (67) They conducted two indirect estimates—one where the country FGM/C prevalence was applied to all women and girls 15-49 and a second where they used the country prevalence for girls 15-19 and applied it to all migrant girls from those same countries age 20 and below. (67) For all women above 20 years old, they applied the country-prevalence for women ages 15-49. Our methods were similar, as we conducted two separate estimates, one for women and girls 15-49 and another for girls aged 0-14, where we applied the prevalence estimates of girls 0-14 to all migrant girls 0-14 living in Switzerland from the same countries. Where no prevalence estimates for girls 0-14 were available, we applied the prevalence estimates for girls 15-19. Age disaggregated data helps to reflect recent decreases (or increases) in FGM/C.

In the European Union, indirect estimates have been carried out sporadically. The European Institute for Gender Equality (EIGE) spearheaded the "extrapolation method", and released their first indirect estimates in 2012. (68) They have continued to refine their methods, but currently only release estimates for the number of girls at risk of undergoing FGM/C. Their next estimates will include Austria, Denmark, Luxembourg and Spain (expected 2021), and their most recently published estimates using the risk estimation methodology were implemented for Ireland, Portugal and Sweden, Belgium, Cyprus, France, Greece, Italy and Malta. (61) Approximately 570,000 women and girls live in the European Union who have been exposed to FGM/C, according to estimates from 2016. (46)

Efforts to look for new ways to improve indirect estimates or use direct survey methods are being established. The Daphne Project FGM-Prev aims to develop a reproducible methodology to estimate FGM/C in Europe. Colleagues from Italy and Belgium combined indirect estimation of prevalence with direct estimation of prevalence. (50,52). What they found has relevance to our Swiss migrant population. Their results show that for Burkina Faso, Eritrea, Senegal and Somalia, indirect estimates with corrections fall within the confidence interval of the direct estimation, although they may be close to the outside bounds. (50) As Eritrean and Somalian women make up the vast majority of the population of women estimated to be living with FGM/C in Switzerland, we can be reassured to know that indirect estimates should provide a fairly accurate picture for a large part of our female

migrant population. This further underscores the importance of making indirect estimates, as the current level of documentation and recording of FGM/C in patient records is not sufficient.

In the UK, estimates conducted in 2011 showed that the total number of women and girls with FGM/C increased by more than 100,000 since 2001. Such a significant change in absolute numbers illustrates the importance of updating indirect estimates on a regular basis. (69) This led them to create an FGM Enhanced Dataset (SCCI 2026) to provide a national picture of the prevalence of FGM/C within the NHS system. (70) Since its inception (in 2015), 26,445 women and girls have been identified by General Practitioners or by NHS trusts as having FGM/C, with a total of 60,035 visits to health care providers. (70) Approximately 87% of these visits were in midwifery or obstetric departments. (70) This underscores our results, where the majority of FGM/C cases were seen by obstetricians and gynecologists. In 2016, in the specialized FGM/C outpatient clinic at the Geneva University Hospitals (HUG), demonstrated that pregnancy was the primary reason for presenting to the clinic (n = 84; 65.1%), further underlying the potential for FGM/C screening and recording during the pregnancy visits. (71)

Similar to the UK, the United States has dedicated resources to collecting FGM/C data among migrant women and girls, and information on their health experiences and needs by conducting the Women's Health Needs Study (WHNS). (72) The WHNS is designed as a multi-centric study to collect data on women from FGM/C-practicing countries about their behaviours, attitudes, and health care needs to help inform treatment and prevention efforts, and is scheduled to begin in 2020. (72)

It is clear that more research needs to be conducted on the health complications and health needs of women living with FGM/C, particularly in the context of pregnancy and childbirth. Some encouraging results from studies in Sweden and Australia indicate that high-quality obstetric care where health practitioners have expertise in treatment of women with FGM/C can reduce obstetric complications. (73–75) They found that women in an Australian hospital from 2006-2012 with FGM/C (mostly types II and IIII) had similar obstetric outcomes to women without FGM, with the exception of caesarean section and first and second degree perineal tears. (75)

Coding and documentation of FGM/C is currently a major problem, as seen from our results. According to a survey run by the Swiss Network against Female Circumcision in 2017 (unpublished,

data obtained from the authors), FGM/C was taught at the medical faculties of the Universities of Geneva, Lausanne and Fribourg but not in Bern, whose university hospital admitted 4388 women and girls from FGM/C practicing countries between 2016 and 2018. The fact that FGM/C is taught in the medical curricula, may partially explain how and why healthcare providers were able to recognize and code FGM/C among women in Geneva and Lausanne. Zürich's medical faculty did not reply to this survey.

A study conducted in Belgium between 2012 and 2015 showed that coding of FGM/C cases significantly increased after training sessions on accurate registration of FGM/C. (76) In Switzerland, healthcare workers admit to not recording and documenting FGM/C. (77) A study conducted in 2016 by UNICEF Switzerland and Santé Sexuelle Suisse surveying Swiss maternity hospitals found that 68.5% of respondents replied that within the past two years, women with FGM/C had given birth in their hospital, though they did not document the cutting. 26% of the respondents did not know if FGM/C cases are registered, with only 8% reporting that they recorded a delivery by a women with FGM/C. (77) 78.7% of participants responded that no one is specialized in FGM/C at their hospital. (77)

Strengths and Limitations

Strengths

Our Swiss national FGM/C indirect estimates were made using the most recent prevalence figures available from nationally representative surveys. We manually searched DHS and MICS databases to find the most recent prevalence figures for all countries that had implemented the FGM/C module in their nationally representative surveys. To the best of our knowledge, no scientific publications on indirect estimates have been published at this time that present the updated list of DHS and MICS FGM/C prevalence rates past 2015-2016. Experts in field of "extrapolation-of-country-prevalence-data-method" and who publish extensively on methods are still using prevalence figures from 2015, as recently as 2020 (41,78). This is mostly due to the fact that manually searching the DHS and MICS databases is time consuming.

Having updated estimates allows us to keep track of the situation in "real-time". The fluctuating migration flows from certain high-prevalence countries, in addition to changes in the prevalence rates of FGM/C in migrant's countries of origin, necessitates routine updating of the national indirect

estimates in diaspora countries to help inform policy and public health programmes. The number of migrants is continuously changing. Our study shows estimates for every year between 2010 and 2018, which allows us to keep abreast with the demographic shift. Even if prevalence rates decline, increased fertility and population growth will lead to an increase in absolute numbers of women and girls with FGM/C, many of whom will emigrate to diaspora countries.

Our study was the first ever study of the use of the ICD to identify health complications of FGM/C. Our methods showed that coding FGM/C using the ICD is feasible and can be replicated over time and between countries. ICD coding also permits the evaluation of the financial costs of FGM/C, as most countries use diagnostic related groupings (DRGs) for reimbursement that are linked to the classification. Given the established and compulsory use of the ICD around the world, our recommended ICD coding method of FGM/C related conditions and procedures would be easily feasible for many, if not most, countries.

Coders often keep coding rules, tips, and advice to help in coding, which they refer to as "cheat sheets". We compiled a "tip-sheet" for coding FGM/C. Based on the available literature on complications of FGM/C, we composed a full list of diseases, disorders and health-related consequences of FGM/C in alignment with ICD-9 and ICD-10 to provide assistance for health care providers to find the correct category when diagnosing FGM/C, or other diagnostic conditions. This could facilitate greater diagnostic detail when recording diagnoses for statistical and reimbursement purposes. Bundling this information together in this format is useful because the ICD divides codes into various chapters based on etiology and codes for the manifestation of certain disorders may be spread out among multiple different chapters. (79) This helps synthesize information for health care providers and coders to better record data without errors to help improve the knowledge base around FGM/C, and its complications. The public health relevance is that it will facilitate better management, treatment and prevention.

Accurate documentation and coding of FGM/C by caregivers can provide more reliable data than those obtained through self-reports which may be compromised due to unawareness, shame or fear of legal consequences. (80) Traditional studies conducted to directly assess the prevalence and consequences of FGM/C incur substantial human and financial resources, which then require repeating. If healthcare professionals invest time and monetary resources in maintaining this

standardized ICD method, we believe this will result in a reproducible, sustainable, and comparable data source.

This study also provided new insights into the FGM/C population of women in Switzerland, particularly within the Swiss HIV Cohort. Healthcare professionals were well trained in the administration of the standardized questionnaire that has been in use by the SHCS since 1988. They received additional training for the two FGM/C-related questions. In May 2019, prior to implementing the questionnaire, a one hour course on FGM/C was given to the Swiss infectious disease specialists. They were also instructed on the practice itself, cultural issues, countries at risk, complications, Swiss law and sites for eventual care or referral for patients. One important aspect of this study was the specific attention to how to discuss FGM/C in culturally sensitive ways. A presentation on how to communicate with girls and women living with FGM/C (a summary of chapter two of the WHO clinical handbook for care of girls and women living with FGM) was sent to everyone involved in the administration of the survey. (2)

Limitations

Several limitations must be acknowledged. The real prevalence and incidence of FGM/C and the number of minors at risk remains unknown in Switzerland. We did not account for the demographic characteristics that can influence a woman or girl's likelihood of having undergone FGM/C. The migrant population in Switzerland may or may not be representative of the population in their country of origin due to socio-economic status, regional origin, religion or ethnicity and therefore may not accurately emulate the prevalence of FGM/C in their home country. (81) To enhance the "extrapolation method," corrections could improve the precision of the indirect estimates. (53,56,82) In particular, although we conducted a separate analysis for girls 0-14, we did not conduct indirect estimates according to 5-year age disaggregated groupings.

Immigrant populations are not always representative of their country of origin. (81) Migrants are usually wealthier, younger, more educated and from more urban areas compared to their non-migrant counterparts. This information should be taken into account when making FGM/C estimations among migrant populations through further corrections to the "extrapolation method". (83,84) For example, based on evidence from the DHS and MICS surveys, FGM/C rates are lower among younger, urban, educated and wealthier women (33,34,85) Researchers suggest making several adjustments involving

the selection of the DHS or MICS prevalence rate from the highest wealth, education and urban setting. (50,81)

The migrant women and girls living in Switzerland who came from an FGM/C practicing country may have originated from regions where it was either almost nonexistent or where it was universal. (46,86) For example, in Kenya, the FGM/C national prevalence for women and girls 15-49 is 21% overall (DHS, 2014), though in certain regions, it ranges from 0.8% (Western Kenya), to 97.5% (Border with Somalia). (33) Adjusting for ethnicity could also prevent under- or over- estimation of FGM/C. For countries that have very high (Guinea, Somalia) or low (Togo, Uganda) national prevalence rates of FGM/C, making corrections based on region or ethnicity will not significantly affect the indirect estimates, as they are very homogeneous. Indirect estimates for women and girls from countries with more heterogeneity, where there is large regional or ethnic variation in rates of FGM/C, would enjoy more reliable indirect estimates if these corrections were made. (41,78,87) Although this correction effort would improve the indirect estimates, Switzerland's statistical office does not publish information on which region the migrants are from, nor on their ethnicity—information that would help estimation.

However, even if we did disaggregate data by age, ethnicity and region, and make corrections based on wealth and education, the "extrapolation method" may still not fully account for factors that may influence a migrant's change of behavior, attitudes or beliefs towards FGM/C, also known as the "migration and acculturation impact-factor". (41,53,81) Once women emigrate to a country such as Switzerland, there are laws and prevention programmes in place prohibiting the practice of FGM/C, which effect the likelihood that they abandon the practice. However, laws alone are not solely responsible for the abandonment of the practice, as similar trends have been observed in countries with and without legislation forbidding the practice. (88) Social pressure can influence women to either abandon or continue to carry out the traditional practice (89). The longer migrants stay in Switzerland, the more acculturation is likely to occur, which could lead either to the abandonment of the practice, or to the preservation of the tradition (90).

In addition to limitations surrounding indirect estimates, we believe the underlying reason for the lack of ICD-coding is insufficient training of health personnel on FGM/C. (91) Education on FGM/C is seldomly incorporated in medical curriculum in most countries. Healthcare professionals state difficulties in screening, diagnosing classifying and documenting FGM/C find it difficult to screen, ask

about, diagnose, classify and document FGM/C correctly (92). First, healthcare professionals should be trained on the diagnosis of FGM/C and its related conditions, and ensure respectful communication to minimize risk of re-traumatisation. Learning tools that include drawings, pictures and videos (93,94) are already being used for training in low and high prevalence countries.

This is also the case among physicians working with HIV patients. Despite being conducted in a research setting, and only two short questions, more than one third of eligible participants were not interviewed about FGM/C. Our findings confirm that there is a lack of sensitivity, knowledge, practice and/or time among practicing physicians in charge of HIV patients (including gynecologists, infectious disease specialists, and general practitioners) regarding FGM/C. (95)

Despite our best efforts, and with the help of the FOPH, we were unable to obtain data from the University of Basel. After many attempts to engage them, they did not share their data because of logistical issues. However, we suspect that we would have found similarly low coding of FGM/C among patients.

Implications for research

The Swiss Federal Statistical Office (FSO)'s Interactive Database (STAT-TAB) offers the possibility to monitor annually updated administrative data, including for migrants in Switzerland. With UNICEF's new Global FGM/C database, calculating indirect estimates of the number of women and girls living with FGM/C in Switzerland could be carried out on an annual basis by the FOPH or Fedpol. Yearly indirect estimates would allow for a quick turnaround for targeted prevention and policy programmes.

When the ICD-11 is implemented (as early as 2022 for some countries), it will include all four types of FGM/C. This major advancement will be the first opportunity for most countries to use the full range of codes. We recommend healthcare professionals and medical coders use our proposed list of ICD codes (tip sheet) to document and code FGM/C, its associated procedures and complications to avoid errors and encourage improved documentation. The introduction of the ICD-11 will facilitate longitudinal prospective studies on FGM/C and its health complications, as well as to help capture accurate prevalence and incidence data and build case-finding algorithms. However, training will need to be a major focus to improve screening and diagnosis, coding and documentation of FGM/C.

A validated scale to assess knowledge, attitude and confidence of health care providers for the care of women and girls living with FGM/C was recently developed. (96) We believe that Switzerland should implement a study to investigate factors that may affect the care and treatment that women and girls with FGM/C may experience. Given that healthcare providers consistently undercoded and underreported FGM/C, it would be important to learn about the relationship between health care providers' attitudes and confidence, and how that impacts their treatment of women and girls with FGM/C. To plan appropriate future training interventions, it will be important to investigate obstacles preventing healthcare providers from enquiring about FGM/C during appointments. Future research must also include men from FGM/C-practicing countries who have female partners and/or daughters who may be at risk or have undergone FGM/C.

Implications for policy and practice

To enhance the "extrapolation method" used in the Swiss national indirect estimates, corrections could be used to improve the precision of the indirect estimates. (53,56,82) The Swiss government could implement these corrections in their future calculations. However, a recent publication from de Schrijver et al., from 2020 summarized best practices for making indirect estimates states that countries with a low expected prevalence of women who have undergone FGM (such as Switzerland), should use the "extrapolation method", as it will provide a sufficient estimate of the number of women who are living with FGM/C. (41) The authors also affirm that the method could be done based on the raw FGM percentages as mentioned in the DHS, or a correction based on age, wealth, level of education or urbanization". (41,97) The estimate obtained through the "extrapolation method" would be adequate for informing public health policy and prevention programmes to give a good indication of the number of girls and women living with FGM/C in Switzerland.

Switzerland should conduct annual FGM/C indirect estimates. With UNICEF's FGM/C Global Database, scientists and policy makers can easily access nationally representative data on FGM/C.
Indirect estimates that are disaggregated by Swiss canton would help with the implementation of more targeted interventions.

Several clinical care handbooks are available on FGM/C to help caregivers acquire the necessary training, including how to document FGM/C. (2,11,14) Medical coders (and healthcare providers in

countries where they also code) should receive appropriate training on the use of ICD codes for FGM/C. Training healthcare providers on how to use culturally appropriate terminology and language is imperative due to the sensitive nature of the topic. Although healthcare providers in Switzerland may be accustomed to asking their patients questions about sexual and reproductive health, they may not have the tools for communicating with their patients about FGM/C. Patients may fear stigmatization or may be afraid that they will face legal action because the practice is banned, and may not answer truthfully. (98) In Liberia, the DHS used local terminology to discuss FGM/C, avoiding the term genital cutting or mutilation altogether. Women were asked if they belonged to the Sande secret society as a proxy for FGM/C. (33) The importance of using same-sex interviewers from the same ethnic background and/or providing the possibility to have certified translators cannot be understated, and could be a focal area for future research.

Switzerland could benefit from implementing its own national FGM/C dataset. While the UK's FGM/C Enhanced Dataset does allow for the recording and documentation of FGM/C and its health complications and provides the NHS with the ability to implement evidence-based policies and prevention programmes—there are some drawbacks. (99) The UK's database requires all recordings of FGM/C to be reported without anonymization and in some cases requires genital examinations, even when FGM/C is not the reason for consultation—which can be stigmatizing, invasive and resource-intensive. Disaggregation of data on genital piercings is important, which cannot currently be done in the UK system. The recording and coding of FGM/C in Switzerland should be scaled-up, particularly in the context of obstetric and gynecological appointments. A specific code for "risk of FGM/C" might facilitate screening and prevention among minors.

With the new 2020 comprehensive guide for the diagnosis, management and treatment of FGM/C in children developed by the American Academy of Pediatrics (AAP), the first of its kind, it is expected that greater attention to detection will find more cases. (14) The AAP recommended a complete external genital exam for girls until the age of 21, including the identification of the prepuce, clitoris, and labia minora and majora. (14) The guide underscores the challenges in identifying certain anatomical structures in prepubertal girls, as well as efforts to record and document FGM/C types. Swiss pediatricians should receive training for diagnosis, management and treatment of FGM/C in children.

Conclusions

The aim of this PhD was to evaluate the available FGM/C data in Switzerland to help improve future FGM/C monitoring and routine data collection. We employed indirect, direct and routine hospital data collection methods. Each methodology has its strengths and weaknesses. For comparability between countries, regions, and hospitals, similar methods should be used.

We updated the indirect estimates for women and girls living with FGM/C in Switzerland, using prevalence estimates from FGM/C practicing countries obtained through population-based surveys and applied them to migrant women and girls living in Switzerland from those same countries. We found a significant increase in the absolute number of women and girls with FGM/C over the past decade, mostly as a result of increased migratory flows. As the number of migrant women and girls from FGM/C prevalent countries continue to increase, FGM/C will remain an important topic for policy makers and health care providers. Relying on recent estimates go make evidence-based decisions will become increasingly important. We recommend conducting annual FGM/C indirect estimates, particularly as it requires few resources now that the most recent DHS and MICS country prevalence figures are readily available. We recommend Switzerland to include 5-year age disaggregated groupings in their annual indirect estimates to account for recent changes in prevalence trends among younger generations. The estimate obtained through the "extrapolation method" is suitable for planning the FGM/C surveillance, treatment and prevention programmes in Switzerland.

Indirect estimates in combination with direct estimates can yield improved results. The results from our cross-sectional study of women with FGM/C in the SHCS showed that training healthcare providers on how to use culturally appropriate terminology and language is imperative. We recommend the sensitization and training of obstetricians and gynaecologists, paediatricians, infectious disease and travel medicine specialists, urologists, emergency medicine, forensics and primary care providers, as well as nurses, and midwives in these departments/services, as they often carry out genital examinations. Pregnancy and childbirth is the most crucial moment for the screening, diagnosis and the documentation of FGM/C and training and protocols should be readily available.

The ICD can be used to identify and diagnose women with FGM/C and health complications. These methods can be replicated over time and between countries. Given the established and compulsory use of the ICD around the world, our recommended ICD coding method of FGM/C related conditions and procedures would be easily feasible for many, if not most, countries. For now, hospital data cannot serve as a proxy indicator for FGM/C prevalence as FGM/C is seriously undercoded. The introduction of the ICD-11 will facilitate the use of administrative and hospital data FGM/C to capture accurate prevalence and incidence data around the world. However, training, particularly among obstetricians and gynecologists will need to be a major focus to improve screening, diagnosis, documentation and care for women living with FGM/C.

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