Access to female genital cutting specialized services in Norway

Doctoral thesis by

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2021

A thesis submitted to the University of Oslo for the Degree of Philosophiae Doctor (Ph.D.)

Series of dissertations submitted to the
Faculty of Medicine, University of Oslo

ISBN 978-82-348-0075-7

Cover: Hanne Baadsgaard Utigard.
Print production: Graphics Center, University of Oslo.

Abstract

Background

Female genital cutting (FGC) is primarily practiced in 31 countries, mainly in Africa. Nevertheless, FGC is also prevalent among minority immigrant groups in other parts of the world, including Norway. Girls and women with FGC risk experiencing gynecologic, obstetric, sexual, and psychological health problems. Moreover, stigma and low self-esteem seem to increase the risk of mental and sexual health problems in countries of immigration where the majority population holds negative attitudes towards the practice. Subsequently, many girls and women with FGC, particularly those living in Western countries, could need specialized healthcare. To meet the needs of those suffering from FGC-related health problems, several Western high-income countries, including Norway, have established dedicated clinics to provide appropriate and sensitive FGC-related healthcare services. Such services include surgical (e.g., deinfibulation) and non-surgical (e.g., psychological and sexual counseling) interventions recommended by the World Health Organization (WHO). Of these services, deinfibulation is the FGC-specialized intervention provided in Norway. It is provided at seven women's outpatient clinics to prevent obstetrical complications, manage obstructive urological and menstrual problems, and facilitate sexual intercourse. In these clinics, gynecologists with special competence in FGC would assess the patients' condition and need for deinfibulation and treat them accordingly. In addition, instead of the typically required referral from a general practitioner (GP), some of these clinics allow girls and women with FGC to contact them directly to increase the accessibility of these services. Unfortunately, we know very little about women's access to FGC-specialized services.

Research on FGC-related healthcare in Norway has focused on exploring women's and healthcare providers' maternity-related healthcare experiences and access to the Norwegian healthcare system by Sub-Saharan African (SSA). Nevertheless, there is a remaining knowledge gap related to women's access to FGC-specialized services for non-maternity-related purposes, including GPs' role and practices in assessing FGC as a differential diagnosis among relevant patient groups presenting with potential FGC-related health problems.

In this doctoral dissertation, I aim to fill this knowledge gap and provide the knowledge necessary to better understand factors influencing access to FGC-related healthcare services in Norway beyond the maternity context. I specifically aim to 1) identify factors that hinder or facilitate access to the FGC-specialized services for non-maternity purposes among Somali and Sudanese subjected

to FGC. 2) identify factors influencing GPs' routines and comfort/discomfort concerning FGC assessment as a potential cause of health problems.

Methods

I have used both qualitative and quantitative methods to address the two specific objectives.

For the first specific objective, I used qualitative methods and utilized repeat semi-structured interviews with 26 Somali and Sudanese participants to explore and compare the perceptions and experiences of those who received FGC-specialized healthcare and those who did not. I primarily explored motivations, navigation decisions, and experiences of seeking medical attention for health problems potentially associated with FGC. Then, I thematically analyzed the data and approached access as a dynamic process of negotiations between patients and the healthcare system from the initial perception of need until the reception of appropriate healthcare. The findings were validated through three focus group discussions with additional 17 Somali and Sudanese participants and presented in papers I-II.

For the second specific objective, I analyzed data from a quantitative cross-sectional online survey among GPs in Norway, where 222 GPs completed the survey. I adopted a Knowledge, Attitude, and Practice theoretical framework for the analyses. All analyses were conducted using IBM SPSS statistics version 26. Firstly, I conducted descriptive analyses for the explanatory variables (i.e., sociodemographic characteristics, levels of received training, self-assessed knowledge, and experiences with patients suffering from FGC-related health problems and the outcome variables (GPs' routines and feelings of comfort/discomfort concerning asking relevant patient groups about their FGC status when they present during pregnancy or with potential FGC-related health problems). Secondly, I examined the association between demographic and other explanatory variables using the Chi-square test and binary logistic regression to identify potential confounders. Finally, I used binary logistic regression analyses to examine the associations between the outcome and explanatory variables, adjust for possible confounders, and look for interactions between the explanatory variables. The findings were summarized and presented in paper III.

Main findings

The findings from the qualitative study (papers I-II**)** depicted that the participants were motivated to seek healthcare for problems that persisted despite self-management attempts, interfered with their ability to perform expected duties and roles, and caused severe pain. However, lack of knowledge on FGC-related health problems or a conflict between information and experiences, observations, and messages from doctors and peers hindered their identification of these problems as FGC-related; and hence whether to seek help at FGC-specialized clinics. Instead, the participants booked appointments with their regular GPs, expecting the GPs to assess whether their health problems were FGC-related and provide appropriate assurance, treatment, or referral. However, hindered by feelings of shame, embarrassment, and fear of judgment, only a few participants, had disclosed their FGC status to their GPs. Similarly, the GPs typically did not address FGC or link the health problems to FGC, leading most participants to conclude that the GPs lacked knowledge of FGC or that their health problems were not FGC-related. Consequently, the participants and the GPs mutually missed an early opportunity to assess whether the health problems were FGC-related. Still, GPs often referred participants to gynecologists, who mostly referred them to FGC-specialized clinics after several months of waiting time.

At the FGC-specialized clinics, participants received offers of deinfibulation. Typically, the participants' intentions to accept or refuse various FGC-related healthcare interventions, including deinfibulation, were influenced by four distinct sets of sexual norms (sexual scripts/scenarios). These scenarios are 1) the virgin scenario (e.g., premarital chastity), 2) the passive sexual partner scenario (e.g., premarital chastity, marital sexual availability, and passive sexual behavior), 3) the conditioned active sexual partner scenario ((e.g., premarital chastity, marital sexual availability, yet active sexual behavior), and 4) the equal sexual partner scenario (e.g., gender equality).

Still, despite finding deinfibulation acceptable per sexual norms, some participants refused the procedure because of negative experiences with healthcare providers at these clinics. Overall, participants characterized their experiences as negative when they felt the healthcare providers disrespected them and did not appropriately address their fears and concerns regarding aesthetics, retraumatization, and pain. In addition, negative experiences negatively affected the participants' overall satisfaction with the FGC-specialized services, including those who accepted the deinfibulation offers. In contrast, when the healthcare providers met them with respect, provided them with sufficient information about their health problems and deinfibulation, and involved them in the decision-making, the participants felt satisfied and had readily accepted offers of deinfibulation. Finally, the findings indicated unmet needs for psychosexual counseling.

The findings of the quantitative study (Paper III) highlighted that the female respondents were more likely than male respondents to have FGC training and experience with patients with FGC-related health problems. Similarly, they were more likely to ask relevant patients groups about their FGC status during consultations concerning pregnancy and genitourinary and sexual health problems. In addition, length of experience and age were positively associated with asking relevant patient groups about their FGC status when presenting with mental health problems. Moreover, any postgraduate FGC training and training on FGC health problems, knowledge of FGC medical codes, and experience with FGC-related health problems were positively associated with asking about FGC status during pregnancy and consultations for genitourinary, sexual, and mental health problems.

After adjusting for other explanatory factors, female GPs were less likely than their male counterparts to ask about FGC status when the patients presented with mental health problems. Feeling discomfort talking to patients about FGC was significantly higher among GPs reporting a need for more knowledge on FGC typology and significantly lower among those with knowledge of FGC medical codes. Furthermore, experience with FGC-related health problems and knowledge of FGC medical codes were positively associated with GPs asking relevant patient groups about their FGC status during consultations concerning genitourinary, mental, and sexual health problems.

Conclusion

This doctoral dissertation illustrates that despite the availability of FGC-specialized clinics in Norway and the exemption from the requirement of GP's referral to access some of these clinics, women still seek healthcare for potential FGC-related health problems first from their GPs. It also highlights that assessing whether FGC is the cause of experienced health problems requires diagnostic competency. If such assessment was left to the patients, it could lead to prolonged suffering and delayed access to the appropriate services. Therefore, there is a need to recognize and acknowledge the role of GPs as per facto gatekeepers for the FGC-specialized services and provide them with the necessary comprehensive training on FGC and available services.

Similarly, the doctoral dissertation emphasizes a need for healthcare providers at some Norwegian FGC-specialized clinics to respect national and international guidelines and provide the women with adequate information and the opportunity necessary to make informed and deliberate decisions regarding their healthcare.

Lastly, the dissertation illustrates that girls and women with FGC in Norway have unmet psychological and sexual healthcare needs, suggesting that expanding the current national healthcare offer on FGC to include psychosexual counseling could be highly beneficial for affected girls and women.

Sammendrag

Bakgrunn

Female genital cutting (FGC) som jeg bruker i denne teksten betegnes som kvinnelig omskjæring og kjønnslemlestelse på norsk og praktiseres hovedsakelig i 31 land, primært i Afrika. Likevel er FCG også utbredt blant migranter i andre deler av verden, inkludert Norge. Jenter og kvinner som er utsatt for dette kan utvikle gynekologiske, fødselsrelaterte, seksuelle og psykiske helseproblemer. I tillegg ser det ut til at stigma og lav selvfølelse øker risikoen for psykiske og seksuelle helseproblemer blant de berørte som bor i land hvor majoritetsbefolkningen har negative holdninger til praksisen. For mange jenter og kvinner utsatt for FGC, spesielt bosatte i vestlige land, kan slike komplikasjoner føre til behov for spesialiserte helsetjenester. For å imøtekomme deres behov relatert til FGC har flere vestlige høyinntektsland, inkludert Norge, etablert spesielle klinikker som tilbyr et spesialisert og tilpasset tilbud. Dette inkluderer kirurgiske (f.eks. deinfibulasjon) og ikke-kirurgiske (f.eks. psykologisk og seksuell rådgivning) behandlinger som er anbefalt av Verdens helseorganisasjon (WHO). Av disse tjenestene er det primært deinfibulasjon som tilbys i Norge. Slike inngrep er tilgjengelig ved syv poliklinikker og har til hensikt å forebygge fødselskomplikasjoner, løse obstruktive urologiske og menstruelle problemer samt lette samleie. På disse klinikkene vil gynekologer med spesiell kompetanse på FGC vurdere pasientenes tilstand og behov for deinfibulasjon og behandle dem i samsvar med dette. Noen av klinikkene har etablert unntak fra regelen om henvisning slik at berørte jenter og kvinner kan kontakte dem direkte. Dette for å åpne for lettere tilgang til tjenestene. Dessverre vet vi svært lite om kvinners tilgang til de spesialiserte tjenestene.

Forskning på FGC-relaterte helsetjenester i Norge har primært fokusert på infibulerte kvinners og helsepersonells opplevelser på fødselsklinikkene og tilgangen til det norske helsevesenet for kvinner fra land i Afrika sør for Sahara (SSA). Likevel er det fremdeles store kunnskapshull knyttet til kvinners tilgang til FGC-spesialiserte tjenester for ikke-fødselsrelaterte formål. Blant annet gjelder det kunnskap om fastlegenes rolle og praksis ved vurderingen av FGC som en differensialdiagnose hos pasienter som kan ha relaterte helseproblemer.

I denne doktorgradsavhandlingen tar jeg sikte på å fylle disse kunnskapshullene for å sikre bedre forståelse for hvilke faktorer som påvirker tilgangen til FGC-relaterte helsetjenester, utover det som skjer i fødselssammenheng, i Norge. Jeg tar spesielt sikte på: 1) Identifisere faktorer som hindrer eller letter tilgangen til spesialiserte tjenester for ikke-fødselsrelatert behandling blant

somaliske og sudanske kvinner. 2) Identifisere faktorer som påvirker fastlegenes rutiner og komfort/ubehag vedrørende vurdering av FGC som en potensiell årsak til helseproblemer.

Metode

Jeg har brukt både kvalitative og kvantitative metoder for å undersøke de to spesifikke målene.

For det første spesifikke målet brukte jeg kvalitative metoder med gjentatte semistrukturerte intervjuer av 26 somaliske og sudanske deltakere for å undersøke og sammenligne oppfatningene og opplevelsene hos de som mottok, og de som ikke mottok FGC-spesialiserte helsetjenester. Primært undersøkte jeg motivasjonsfaktorer, navigasjonsbeslutninger og erfaringer med å søke legehjelp for helseproblemer som kan være relatert til FGC. Deretter analyserte jeg dataene tematisk. Jeg så på tilgang som en dynamisk prosess med forhandlinger mellom pasienter og helsevesenet, fra oppfatning av behov til mottak av relevante helsetjenester. Funnene ble validert gjennom tre fokusgruppediskusjoner med ytterligere 17 somaliske og sudanske deltakere. Disse ble presentert i artikkel I og II.

Når det gjelder det andre spesifikke målet, analyserte jeg data fra en kvantitativ, nettbasert tverrsnitt-undersøkelse blant fastleger i Norge, der 222 fastleger deltok. Analysen fokusert på respondentenes kunnskap, holdninger og praksis. Alle analyser ble gjennomført ved hjelp av IBM SPSS Statistics versjon 26. Først gjennomførte jeg deskriptiv statistikk for de forklaringsvariablene (dvs. sosiodemografiske faktorer, nivåer for mottatt opplæring, egenvurdert kunnskap samt erfaringer med pasienter som lider av FGC-relaterte helseproblemer) og utfallsvariabler (fastlegenes rutiner og følelse av komfort/ubehag når det gjelder å snakke med relevante pasientgrupper om FGC ved graviditet eller potensielle FGC-relaterte helseproblemer). Deretter undersøkte jeg sammenhenger mellom de demografiske variablene og de øvrige forklaringsvariablene ved hjelp av Chi-kvadrattesten og binær logistisk regresjon for å identifisere potensielle konfundere (bakenforliggende forklaringsfaktor). Til slutt gjorde jeg binære logistiske regresjonsanalyser for å undersøke forbindelsene mellom utfallsvariabler og forklaringsvariabler, justere for mulige konfundere og se etter interaksjoner mellom forklaringsvariablene. Funnene ble sammenfattet og presentert i artikkel III.

De viktigste funnene

Funnene fra den kvalitative studien (artikkel I-II) viste at deltakerne var motivert til å søke helsehjelp for problemer som gjorde det vanskelige å utføre forventede oppgaver og roller, medførte store smerter, og vedvarte tross forsøk på egenhåndtering. Manglende kunnskap om

FGC-relaterte helseproblemer, sprik mellom informasjon og erfaringer samt observasjoner og meldinger fra leger og kolleger hindret imidlertid at disse problemene ble identifisert som FGC-relatert. Dette forhindret videre jenter og kvinner å søke hjelp på de spesialiserte klinikkene. I stedet bestilte deltakerne time hos sin fastlege og forventet at disse skulle vurdere om helseproblemene var FGC-relaterte, og ut fra dette gi egnet vurdering, behandling og eventuelt henvisning. På grunn av skam, forlegenhet og frykt for fordømmelse hadde bare noen få deltakere fortalt om sin FGC til fastlegen. Tilsvarende tok fastlegene vanligvis ikke opp inngrepet som mulig årsak til helseproblemer. Det førte til at de fleste deltakerne konkluderte med at fastlegene manglet kunnskap om FGC, eller at deres helseproblemer ikke var FGC-relaterte. Følgelig gikk både deltakerne og fastlegene glipp av en tidlig mulighet til å vurdere om helseproblemene var relatert til FGC. Fastlegene henviste imidlertid hyppig deltakerne til gynekologer som ofte hadde flere måneders ventetid. Likevel, hadde gynekologene til slutt henvist deltakerne videre til FGC-spesialiserte klinikker.

På de spesialiserte klinikkene fikk deltakerne tilbud om deinfibulasjon. Deltakernes aksept eller ikke av ulike typer helsehjelp, inkludert deinfibulasjon, var påvirket av fire ulike sett med seksuelle normsett (scenarioe) 1) jomfruscenarioet (f.eks. førekteskapelig kyskhet), 2) passiv seksualpartner scenario (f.eks. førekteskapelig kyskhet, ekteskapelig seksuell tilgjengelighet og passiv seksuell atferd), 3) det betingede aktive seksuelle partnerscenarioet (f.eks. førekteskapelig kyskhet, ekteskapelig seksuell tilgjengelighet, men likevel aktiv seksuell atferd), og 4) det likeverdige seksuelle partnerscenarioet (f.eks. likestilling mellom kjønnene).

Blant deltakere som vurderte deinfibulasjon som akseptabelt i henhold til seksuelle normer, var det likevel noen som nektet å ta imot behandlingen på grunn av negative erfaringer med helsepersonell på klinikkene. Samlet sett karakteriserte deltakerne erfaringer sine som negative, når de følte at helsepersonellet ikke respekterte dem, og ikke behandlet deres frykt og bekymringer angående estetikk, retraumatisering og smerte på en egnet måte. Dessuten ble deltakernes generelle tilfredshet med de spesialiserte tjenestene negativt påvirket av slike negative erfaringer. Dette gjaldt også de som aksepterte tilbud om deinfibulasjon. Når helsepersonellet derimot møtte dem med respekt, ga dem tilstrekkelig informasjon om deres helseproblemer og deinfibulasjon og involverte dem i beslutningsprosessen, følte deltakerne seg fornøyde og aksepterte villig tilbudet om deinfibulasjon. Avslutningsvis indikerte funnene udekkede behov for psykoseksuell rådgivning.

Funnene fra den kvantitative studien (artikkel III) understreket at det var mer sannsynlig at de kvinnelige enn de mannlige fastlegene hadde fått opplæring om FGC og hadde erfaring med pasienter med relaterte helseproblemer. På samme måte var det mer sannsynlig at de ville spørre relevante grupper av pasienter om deres status under konsultasjoner om graviditet, urogenitale og seksuelle helseproblemer. Dessuten var det positiv sammenheng mellom fastlegenes alder og erfaring og deres rutiner for å spørre relevante pasientgrupper om deres FGC-status ved konsultasjoner om psykiske problemer. Videre var etterutdanning om FGC-opplæring som omfattet kunnskap om relaterte helseproblemer og medisinske koder positivt assosiert med å spørre om FGC-status under graviditet og ved konsultasjoner for urogenitale, seksuelle og psykiske helseproblemer.

Etter justering for andre forklaringsvariabler, var det mindre sannsynlig at kvinnelige enn mannlige fastleger spurte om FGC-status når pasientene la frem psykiske problemer. Følelsen av ubehag ved å snakke med pasienter om FGC var betydelig høyere blant fastleger som rapporterte om behov for mer kunnskap om FGC-typologi – og betydelig lavere blant de med kunnskap om relevante medisinske koder. Videre var erfaring med FGC-relaterte helseproblemer og kunnskap om de medisinske kodene for FGC-medisinske koder positivt assosiert med å spørre relevante pasientgrupper om deres FGC-status ved konsultasjoner for urogenitale, mentale og seksuelle helseproblemer.

Konklusjon

Denne doktorgradsavhandlingen illustrerer at til tross for tilgjengeligheten i Norge til FGC-spesialiserte klinikker for behandling og fritak fra kravet om henvisning til noen av disse, søker kvinner fortsatt først og fremst hjelp hos sine fastleger. Avhandlingen viser også at en vurdering av om inngrepet er årsaken til opplevde helseproblemer, krever diagnostisk kompetanse. Dersom en slik vurdering blir overlatt til pasientene, kan det føre til langvarig lidelse og forsinket tilgang til de aktuelle tjenestene. Derfor er det behov for å gjenkjenne og anerkjenne fastleger som reelle portvakter for de FGC-spesialiserte tjenestene og gi dem nødvendig og omfattende opplæring og kunnskap om tilgjengelige tjenester.

På samme måte viser doktorgradsavhandlingen et behov for at helsepersonell ved enkelte norske FGC-spesialiserte klinikker overholder nasjonale og internasjonale retningslinjer og gir kvinnene tilstrekkelig informasjon og mulighet til å ta informerte og gjennomtenkte beslutninger om egen helse.

Til slutt illustrerer avhandlingen at jenter og kvinner med FGC i Norge har udekkede psykologiske og seksuelle helsebehov. Det tyder på at det kan være svært gunstig å utvide det nåværende nasjonale helsetilbudet til å inkludere psykoseksuell rådgivning for dem som er berørt.

Acknowledgment

The work in this thesis was financed by a grant from the Norwegian Research council to the Kjønslemlestelse-HelseVel project at the Norwegian center for violence and traumatic stress studies (NKVTS).

I would first like to thank the Somali and Sudanese women who participated in the qualitative study. Thank you for your generosity with your time and for entrusting me with intimate details about your lives. I hope that this work will help improve access to healthcare for all women with FGC in Norway. Similarly, I would like to thank the general practitioner who participated in the quantitative study for taking time out of their busy schedules to contribute much-needed knowledge.

My deepest gratitude to Elise Johansen, my supervisor, mentor, and friend. Thank you, Elise, for taking a leap of faith in hiring me in 2014 and for your unwavering generosity ever since with your knowledge, reflections, and time. I can never thank you enough. A special thanks to my co-supervisor, Johanne Sundby, for her support and encouragement and for linking me with other Ph.D. candidates in the field of global health.

Special thanks to Inger-Lise Lien, the project leader of the Kjønslemlestelse-HelseVel project, and the project members Bothild Bendiksen, Mona Berthelsen, and Cecilie Hertzberg. Thank you all for providing a stimulating and supportive environment. Inger-Lise, we had so much fun pre-Covid! Thank you. Thank you too, Bothild, for supervising my work on the quantitative study, your friendship, pep talks, and dinner invitations.

I also want to thank the leadership at NKVTS for being supportive when I needed it most and helping in every way they could. Thank you, Inger Elise Birkeland and Arnfinn Andersen. I am also thankful to all colleagues at NKVTS, particularly Marianna Opaas and Alexander. Thanks, Alexander, for the “coffeedence” intervals meetings and statistical advice. I am also grateful to current and previous IT and administration teams, particularly Alexander, Tore, Cecilie, and Leo.

Wolela Haile, Fozia Said, and Leoul Mekonen, thank you for your unwavering support throughout the Ph.D. study with recruiting participants and presenting my work via your platforms.

Jehan and Ehssan, my sisters, Magdi, my brother, and Nagla and Dalia, my cousins, thank you all for your unconditional love and emotional support during this journey and throughout my life. You are my rock.

My mother, my strength and inspiration, you were impatiently waiting for this day. I dearly wish you were still here, but I continue rejoicing in your love, and your memory is always with me. May your soul rest in eternal peace.

My dear friends, confidants, and support system, way beyond this Ph.D. journey, Mekdes, Rua, Lee, and Espen, I am so lucky to have you in my life.

Last but not least, thank you to my extended adoptive family in Norway (a few of you have relocated but continue to enrich my life): Gisela, Ahmed Umar, Sheema, Amal, Medina, Asma, Selma, Ali, Hisham, Hanan, Eman, Amina, Basra, Bahia, and Abeer.

Oslo, December 2021
Mai Mahgoub Ziyada

Part I – The extended summary

Table of Contents

Part III- Appendix

List of figures

List of Tables

List of abbreviations

CI	Confidence Interval
CBT	Cognitive Behavioral Therapy
COREQ	Consolidated criteria for reporting qualitative research
DHS	Demographic Health Survey
EU	European Union
FGC	Female Genital Cutting
FGCS	Female Genital Cosmetic Surgery
FGD	Focus Group Discussion
FGM	Female Genital Mutilation
FGM/C	Female Genital Mutilation/Cutting
FSFI	Female Sexual Function Index
GP	General Practitioner
HIV	Human Immunodeficiency Virus
IEC	Information, Education, and Communication
KAP	Knowledge, Attitude, and Practice
MICS	Multiple Indicator Cluster Survey
NSD	Norwegian Social Science Data Services
OR	Odds Ratio
PTSD	Post Traumatic Stress Disorder
REK	Regional Ethical Committee
RHA	Regional Health Authorities
SDGs	Sustainable Development Goals
SMD	Standardized Mean Difference
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infection
UN	United Nations
US	United States
UTI	Urinary Tract Infection
WHO	The World Health Organization

List of articles

Article 1

Ziyada MM, Johansen REB (2021). Barriers and facilitators to the access to specialized Female Genital Cutting healthcare services: Experiences of Somali and Sudanese women in Norway. PloS one. 2021;16(9): e0257588.

Article II

Ziyada MM, Lien IL, Johansen REB. Sexual norms and the intention to use healthcare services related to female genital cutting: A qualitative study among Somali and Sudanese women in Norway. PloS one. 2020;15(5):e0233440.

Article III

Ziyada MM, Johansen REB, Berthelsen M, Lien IL, Bendiksen, B. Factors associated with general practitioners' routines and comfortability with assessing female genital cutting: A cross-sectional survey. Manuscript.

Introduction

Female Genital Cutting (FGC), female genital mutilation (FGM), and female genital mutilation/cutting (FGM/C) are synonyms for a collection of cultural procedures that alter the external female genitalia for non-medical reasons [1-3]. In this doctoral dissertation, I use FGC almost exclusively to refer to these procedures.

Although primarily practiced in 31 countries, mainly in Africa [4], FGC is also prevalent among minority immigrant groups in Europe [5-8], the United States [9, 10], Australia [11], and Canada [12]. Current estimates indicate that in addition to the over 200 million girls and women who had undergone FGC and lived in their countries of origin [13], over a million immigrant girls and women in European countries and the United States live with FGC [5, 14].

Girls and women with FGC risk experiencing gynecologic, obstetric, sexual, and psychological health problems [15-22]. In addition, stigma and low self-esteem seem to increase the risk of mental and sexual health problems in countries of immigration where the majority population holds negative attitudes towards the practice [23-27]. Subsequently, many girls and women with FGC, particularly those living in Western countries, could need specialized healthcare. However, for decades, the international policies on FGC had focused primarily on prevention and elimination [1]. Fortunately, the focus on providing specialized healthcare for those suffering from FGC-related health problems has gradually increased. Several Western high-income countries, including Norway, have established dedicated clinics to provide appropriate and sensitive FGC-related healthcare services for those in need [28, 29]. These countries have also developed guidelines and training modules to help their healthcare providers care for girls and women with FGC [28].

Unfortunately, we know very little about women’s access to FGC-specialized services. Still, many had explored the acceptability of specific healthcare interventions, healthcare providers’ knowledge and experiences with care delivery, and women’s experiences with receiving maternity care.

Research findings indicate that women find specific FGC-related healthcare interventions unacceptable when they conflict with certain sexual and cultural norms [30, 31]. Research findings from high-income countries also consistently report gaps in healthcare providers’ competence and knowledge of clinical guidelines and clinical, cultural, and legal aspects of FGC [32-50], resulting in a suboptimal care provision to the target population [51-53]. In addition, communication difficulties and uncoordinated care seem to contribute to the suboptimal care in these countries

[51]. Similarly, researchers consistently report women's poor healthcare experiences related to FGC in high-income countries [54-57]. Although mostly satisfied with the quality of care in these high-income countries [58-61], women often perceive the healthcare providers to lack knowledge and competence in FGC and subsequently fear mismanagement. For example, women dreaded that healthcare providers' inadequate knowledge and competency would expose them to unnecessary caesarian sections [54]. Women were also often frustrated over difficult communication, perceived disrespect, and lack of power [54-56]. However, most reported experiences are from maternity settings [54, 55, 62], and we know very little about the women's and healthcare providers' experiences outside this context. In Norway, research on FGC-related healthcare had focused on exploring women's and healthcare providers' maternity-related healthcare experiences [60, 63, 64], the acceptability of deinfibulation [30, 31], and access to the Norwegian healthcare system by Sub-Saharan African (SSA) women [65-67]. Still, there is a remaining knowledge gap related to accessing FGC-specialized services, particularly for non-maternity-related purposes and identifying factors that can improve GPs' practices in assessing FGC as a differential diagnosis among relevant patient groups presenting with potential FGC-related health problems.

Therefore, I aim to better understand factors influencing access to FGC-related healthcare services in Norway beyond the maternity context in this doctoral dissertation.

The doctoral dissertation includes three parts: the extended summary (part I), the three papers (part II), and the Appendix (part III). I have organized the extended summary into seven main sections. The first section provides more detailed background information on FGC such as definitions and types, health impact, terminologies and epidemiology, the conceptualization of equity in health access for immigrants, national and international policies, FGC-related healthcare services, and the empirical evidence on access to these services. Then, I present the study rationale, the research questions, and the overall and specific objectives in section two. Section three elaborates on methodological issues that I have not addressed in the three papers, such as methodological choices and justifications. Section four is reflections on ethical considerations. I then present a summary of the main findings in section five. Section six includes the methodological discussion and discussion of findings. Finally, I conclude in section seven and highlight the implications of the main results for policy and research.

1 Background

1.1 Definitions and types of FGC

The outer part of the female reproductive system, the vulva or the female external genitalia, extends from the mons pubis to the anus [68, 69]. It includes a visible part of the clitoris (the glans), outer- (labia majora) and inner- (labia minora) folds and the vestibule that surrounds the openings of the urethra, the vagina, and the Bartholin's glands. The anterior margins of labia minora form a skin hood (the prepuce) that overhangs the clitoris glans. Beneath the posterior conjuncture of the labia minora is the perineum that extends up to the anus [68, 69].

Except for female genital cosmetic surgeries (FGCS), the World Health Organization (WHO) include all other procedures that involve the partial or total removal of the female external genitalia or other injuries to the female genital organs for non-medical reasons in its definition of FGC [1]. The WHO classifies FGC into four types according to the extensiveness of the cutting/injury [1]. While the severity of the cutting in these types increases in the first three, with type III (infibulation) being the most extensive form, it decreases considerably in type IV [3]. Figure 1 shows the WHO definitions of each type and sub-type. Re-infibulation, not a type per se, is included in these definitions.

Globally, types I and II account for about 90 percent of all affected girls and women, while infibulation accounts for only 10 percent of all cases [4]. However, infibulation is more prevalent in some countries, such as Somalia, Sudan, and Djibouti. Furthermore, Sudanese and Somalis commonly classify FGC into two major types, *pharaonic* and *Sunna* [2]. Pharaonic typically refers to infibulation, while Sunna theoretically denotes a lesser extensive form but, in practice, could be anything between type IV and III [70-72].

Figure 1. WHO classifications of FGC.

Definitions of the different types plus re-infibulation:

Type I: Partial or total removal of the clitoris (clitoral glans)*, the prepuce, or both.

Type I a: Removal of the prepuce.

Type I b: Removal of the clitoris (clitoral glans)* and the prepuce.

Type II: Partial or total removal of the clitoris (clitoral glans)* and the labia minora, with or without the labia majora.

Type II a: Removal of the labia minora only.

Type II b: Partial or total removal of the clitoris (clitoral glans)* and the labia minora.

Type II c: Partial or total removal of the clitoris (clitoral glans)*, the labia minora, and the labia majora.

Type III (infibulation): Narrowing of the vaginal orifice through creating a covering seal following the cutting and the apposition of the labia minora, the labia majora, or both, with or without excising the clitoris (clitoral glans)*.

Type III a: Removal and apposition of the labia minora with or without excising the clitoris (clitoral glans)*.

Type III b: Removal and apposition of the labia majora with or without excising the clitoris (clitoral glans)* and the labia minora.

Re-infibulation (re-suturing): After the infibulation seal is cut open (e.g., during childbirth), the vaginal orifice is re-narrowed.

Type IV: All other harmful procedures to the female genitalia for non-medical purposes (e.g., pricking, piercing, incising, scraping, and cauterization).

*Source: WHO [3]. *Research findings [73] had demonstrated that only the external part of the clitoris (glans) is affected in the different types of FGC.*

1.2 Health impact

FGC exposes affected girls and women to a series of immediate and long-term health problems at various points along their life course [2, 15, 16, 18, 74]. The severity and frequency of these problems vary according to FGC type and specific conditions under the procedure (e.g., level of hygiene, use of anesthesia, and anatomical knowledge of the circumciser) [29].

The rationale for the adverse impact of FGC on health is that the genital tissues have a dense nerve and blood supply [2, 3]. Hence, any injury or damage to these tissues could cause immediate complications such as severe pain, bleeding (hemorrhage), and hemorrhagic shock [1-3]. In addition, unsterile conditions could lead to infections and septic shock [2, 3, 75]. Similarly, a local inflammatory response to the injury or an acute local infection could lead to genital swelling, potentially leading to acute urinary retention [76]. Alternative explanations for urinary retention are direct injury to the urethra, occlusion of the urethra during infibulation, and fear of passing urine because of pain [3, 76].

In the long term, the inflicted injury could lead to the formation of inelastic scar tissue, adhesions, keloids, cysts, and neuromas [2, 3]. Together with the covering seal in type III, these conditions could cause various health problems related to urination, menstruation, sexual function, and childbirth [2]. Moreover, the pain and trauma experienced during the genital cutting and the sociocultural context (e.g., living in Western countries where the majority condemn FGC) could lead to psychological health problems, including mental health problems and mental health disorders [2, 3, 25, 77, 78].

Overall, researchers have linked FGC to numerous immediate and long-term health problems [2, 3, 15, 16, 18-20, 74]. For example, several studies [57, 79-84] link FGC and several immediate health problems, including severe pain, bleeding, genital tissue swelling, fever, infections, urinary retention and hesitancy, urinary tract infections (UTIs), wound healing problems, and hemorrhagic and septic shocks. In addition, a few studies [85-87] directly link FGC to documented deaths. Moreover, research findings associate FGC and long-term gynecologic problems such as vulvar and clitoral cysts [84, 88-101], neuromas [102-106], chronic clitoral and vulvar pain [107-109], vaginal discharge [110, 111], genital ulcers [110, 111], fistulae [112, 113], infections [81, 82, 111, 114-119], infertility [120, 121], and urinary [79, 84, 122-125] and menstrual difficulties [84, 109, 126-128]. Still, some studies [111, 116, 129-132] have found no association between FGC and some of these problems, particularly infertility. Similarly, some findings [73, 110, 133-135] highlight that women with FGC could experience sexual pleasure and orgasm just like those without FGC. On the other hand, numerous studies suggest that women with FGC are more likely to suffer from reduced sexual function or sexual quality of life than those without FGC [73, 109, 119, 126, 127, 136-147]. Furthermore, several studies [109, 126, 148-161] have linked FGC with at least one adverse obstetric and perinatal outcome, including prolonged labor, perineal tears/lacerations, cesarean section, episiotomy, instrumental delivery, and postpartum hemorrhage, difficult delivery, prolonged maternal hospitalization, stillbirth, and low birthweight. Yet, a few studies from high-income countries [158, 162-164] and Western Africa [111, 165, 166] have found no association between FGC and most adverse obstetric outcomes. Similarly, although a few studies [141, 167, 168] could not link FGC and negative mental health outcomes, many others did. For example, multiple findings [23, 77, 78, 126, 149, 169-177] strongly indicate an association between FGC and mental health problems (e.g., sadness, anger, distress, flashbacks, and low self-esteem) and mental health disorders such as depression, anxiety disorders, and post-traumatic stress disorder (PTSD). In addition, evidence [23-27, 178, 179] increasingly indicates that stigma and low self-esteem in countries of immigration where the majority negatively regards FGC contribute to an increased risk of psychological and sexual health problems among girls and women subjected to FGC. Finally, empirical findings [112, 140, 144, 146, 148, 166, 180] suggest a dose relationship between FGC and the commonly reported adverse health outcomes (i.e., more extensive cutting is associated with increased frequency and severity of health problems).

Nevertheless, despite the large body of empirical data indicating an association between FGC and various adverse physical and psychological health outcomes, many are apprehensive that these findings are inconsistent, as demonstrated above, or of low scientific quality [15-19, 181, 182].

1.2.1 Quality of the scientific evidence on the health impact of FGC

Researchers encounter numerous challenges that hamper the production of good quality scientific evidence on the health impact of FGC [182]. The first challenge is the suitability and applicability of the study design. Although experimental randomized clinical trials provide the best scientific evidence about a causal relationship between an exposure and a health outcome [183], ethical considerations preclude its usage in determining the health impact of FGC [182], hence limiting researchers' choices to comparative observational studies.

Out of comparative observational study designs, only cohort and case-control studies can provide sound evidence on causation, with cohorts being the best [183, 184]. Nevertheless, both designs have limitations. For example, adopting a prospective cohort design in research on the health impact of FGC could be highly challenging. First, researchers risk losing participants to follow-up. Second, the quality of cohort studies is dependent on the accurate ascertainment of the exposure status of each participant, including the degree of exposure, both at baseline and follow-ups. Hence, researchers must examine each participant to determine their exposure status, including the degree of exposure (e.g., FGC type).

Furthermore, to conclude causal relationships when the health outcome under investigation is rare, researchers might need to extend the study over a long period to register a sufficient number of cases. Researchers could also need to prolong prospective studies in countries where FGC is almost universal and countries of immigration where FGC is only prevalent among minority groups. In these countries, the enrollment of participants might need to continue for years to obtain sufficient numbers of unexposed in high prevalence countries and vice versa in countries of immigration. Subsequently, prospective cohort studies could require substantial financial and human resources often unavailable for researchers.

Most of these challenges are avoidable in retrospective cohort studies. Here, researchers ideally rely on national or hospital registries. First, they identify exposed and unexposed groups of participants in the registry, then those with the adverse health outcome in both groups, and finally compare the occurrence rate of the negative health outcome in both groups. Therefore, these studies have the advantage of being inexpensive and fast. Also, since the exposure and the health outcome are registered independently of the study, researcher bias is not an issue. However, despite these advantages, not many researchers have access to such data as exposure to FGC is rarely systematically recorded [28].

In case-control studies, researchers start by enrolling/identifying a group of people (cases) with a particular adverse health outcome and then select a comparison group without that outcome (controls). Here, it is crucial to identify an appropriate control group similar to the case group in most respects. After that, researchers compare previous exposures to FGC and other possible etiological factors (confounders) between the two groups and determine the causal relationship.

Like retrospective cohort studies, case-control studies are inexpensive, fast, and more suited to rare outcomes. However, case-control studies are commonly associated with recall bias (i.e., individuals with a disease/specific outcome could remember being exposed to certain factors when asked than their counterparts). Still, this bias might be more relevant to other exposures (confounders) than FGC since the latter is typically a significant life event.

Although cross-sectional studies have generated a large body of evidence on FGC health risks, classical epidemiology textbooks [185] recommend using cross-sectional studies to generate causal hypotheses rather than test or conclude causal relationships. The reason for such advice is that it is hard to assess the time dimension in cross-sectional studies since researchers collect data on both the exposure and the health outcome simultaneously at a set point of time. In addition, recall bias is a crucial drawback of cross-sectional studies. Individuals exposed to certain factors could remember experiencing specific outcomes when asked than their unexposed counterparts. Nevertheless, some epidemiologists argue that causal inference in cross-sectional studies is possible with appropriate statistical measures and models [186, 187].

Besides these challenges, high heterogeneity (inconsistent findings across studies) due to methodological, geographical, and population differences, participant selection bias, non-validated instruments, and inadequate control of confounders in the empirical data collectively affect the quality of the evidence on the health impact of FGC [15-17, 19, 21, 170]. Moreover, researchers [15, 19-21, 170, 182] struggle to find reliable data on the effect of different types of FGC on the reported adverse health outcomes since FGC types and health outcomes are commonly self-reported and inconsistently defined. Also, studies rarely stratify health outcomes by FGC type. Finally, researchers [178, 182, 188-190] have heavily criticized conceptual frameworks underpinning many studies examining the association between FGC and sexual dysfunction for their reductionist focus on biological factors (the anatomy of the genitalia) instead of the multidimensional aspects of female sexual function.

Despite these limitations, the increasing number of studies examining the health impacts of FGC has gradually accumulated data on specific health outcomes sufficient for systematic reviews and meta-analyses [15-22] to assess differences in risk relative to FGC exposure and provide summaries of the best available evidence.

1.2.2 Best available evidence: Immediate health problems

So far, only one meta-analysis [15] has included immediate health problems. In this meta-analysis based on representative studies of high and moderate methodological quality, the authors identified the following health problems as the most common complications associated with FGC: excessive bleeding, urine retention, genital tissue swelling, problems with wound healing, and pain. Their findings also indicated that type III was associated with a greater risk of immediate harm than types I and II. On the other hand, the risk of immediate complications was marginally different between types I–II and type IV.

1.2.3 Best available evidence: Gynecologic problems

Currently, two meta-analyses [15, 19] have examined gynecologic problems. The first [15] included studies published between inception and January 2012 and the second [19] to December 2019.

The first meta-analysis [15] analyzed 17 comparative studies measuring a genitourinary outcome, 11 comparative studies measuring Human Immunodeficiency Virus (HIV) and Sexually

Transmitted Infections (STIs), and 12 measuring infertility. Unfortunately, the authors found the available data insufficient to conclude risk differences relative to FGC with neither infertility nor numerous genitourinary outcomes (e.g., keloids, cysts, fistulae, and vaginal obstruction). Furthermore, the meta-analysis failed to establish a difference relative to FGC with HIV and STIs. Still, the meta-analysis showed a significantly greater risk of UTIs and bacterial vaginosis with FGC. Moreover, the analysis revealed a tendency towards a greater risk of vaginal itching and discharge and menstrual problems (e.g., dysmenorrhea and difficulty in passing menstrual blood) with FGC.

On the other hand, the second meta-analysis [19] included studies reporting three genitourinary outcomes: dysmenorrhea (26 studies), UTI (15 studies), and painful micturition/dysuria (18 studies). The analysis showed a significantly greater risk of dysuria with FGC but insufficient evidence to conclude regarding dysmenorrhea (Odds ratio (OR): 1.66, 95% confidence interval (CI): 0.97-2.84, and p-value = 0.06) and UTI (OR: 2.11, 95% CI: 0.80-5.54, and p-value = 0.10).

1.2.4 Best available evidence: Sexual health problems

Four meta-analyses [17, 19, 20] have examined the association between FGC and sexual health problems. The first meta-analysis [17] included studies published between the inception of the databases and March 2011, the second [22] from 2000 to September 2019, the third [19] to December 2019, and the fourth [20] to June 2020.

Berg and Denison (2012) [17] included 15 comparative studies reporting 53 dichotomous outcomes for potential FGC sexual consequences but using variously validated and non-validated instruments. Unfortunately, only seven of these outcomes (dyspareunia, satisfaction, no sexual desire, never initiate sex, no orgasm, and clitoris or breast are the most sensitive area of the body) were sufficiently included in the various studies to warrant pooling effect sizes in meta-analyses. The authors found that women subjected to FGC were significantly more likely to experience dyspareunia, less sexual satisfaction, and no desire than women not subjected to FGC. However, they found no significant difference relative to FGC concerning never initiating sex and breasts as the most sensitive area of the body or significant effect but high heterogeneity regarding no orgasm and the clitoris as the most sensitive part.

Nzinga et al. (2021) [22] included five studies reporting differences in female sexual function relative to FGC assessed by the Female Sexual Function Index (FSFI). However, as one of the included studies did not have a group without FGC, the authors excluded it from the meta-analyses. The pooled result of the total FSFI score was significantly lower in women with FGC than those without FGC. Still, the authors did not report on pooled results of each of the six FSFI domains (desire, arousal, lubrication, orgasm, satisfaction, and pain). Furthermore, as the analyses showed high heterogeneity, the authors could not conclude a causal relationship between FGC and female sexual dysfunction.

Lurie et al. (2020) [19] included 47 studies that reported dyspareunia as either a binary outcome (39 studies) or FSFI quantitative pain score (eight studies). After adjusting for study design, the authors found dyspareunia and FSFI pain score statistically associated with FGC on pooled analysis.

Finally, Perez-Lopez et al. (2020) included 15 studies reporting on the outcomes of the 19-item FSFI. They found the standardized mean difference (SMD) for the total score of the FSFI significantly lower in girls and women with FGC than girls and women without FGC. Similarly, the SMD for each of the six FSFI domains was significantly lower in girls and women subjected to FGC on pooled analysis.

1.2.5 Best available evidence: Obstetric problems

Four meta-analyses [15, 18, 19, 21] have examined the association between FGC and adverse obstetric outcomes. The first two meta-analyses [15, 18] included studies published from inception to January 2012, the third [21] between August 1995 and July 2019, and the fourth [19] to December 2019.

The first two meta-analyses included 28 [18] and 26 [15] comparative studies reporting several obstetric events (prolonged labor, tears/lacerations, cesarean section, episiotomy, instrumental delivery, hemorrhage, and difficult labor). Pooled analyses of adjusted (controlled for confounders) or unadjusted estimates showed that women subjected to FGC are at a significantly greater risk of experiencing prolonged and difficult labor than those not subjected to FGC. On the other hand, whereas the pooled analyses of unadjusted estimates found a significant difference in tears/lacerations relative to FGC, pooled analyses of adjusted estimates failed to establish a similarly significant difference. In addition, pooled analyses for adjusted or unadjusted estimates could not demonstrate significant differences in cesarean section relative to FGC. However, the pooling of adjusted estimates from two prospective results suggested a statistically significant difference concerning cesarean section. Moreover, whereas the pooling of unadjusted estimates showed a significant difference in episiotomy between women subjected to FGC and their counterparts, the pooling of adjusted or unadjusted estimates was inconclusive regarding instrumental delivery. Finally, pooling of adjusted or unadjusted estimates from all studies reporting postpartum hemorrhage established a significantly greater risk of postpartum hemorrhage among women subjected to FGC.

In the third meta-analysis, Sylla et al. (2020) [21] included 11 comparative studies that reported maternal and perinatal complications related to FGC adjusted for most relevant confounders. Pooling results of all studies showed heterogeneity and elevated but non-significant risks relative to FGC of instrumental delivery, cesarean section, episiotomy, postpartum hemorrhage, perineal tears/laceration, low Apgar score, and miscarriage/stillbirth. However, subgroup analyses stratified by study geography (Africa and Europe) and parity showed reduced heterogeneity and significantly elevated risks of episiotomy in Europe, postpartum hemorrhage in Africa, and cesarean section among primiparous women.

Finally, Lurie et al. (2020) [19] conducted pool analyses of outcome estimates of cesarean section (42 studies), episiotomy (38 studies), instrumental delivery (20 studies), prolonged labor (20 studies), and perineal tears/laceration (19 studies). After adjustment for study design, pooled analyses showed that FGC is significantly associated with increased risks of perineal tears/lacerations, episiotomy, and prolonged labor. However, inadequate statistical power resulted in inconclusive pooled results regarding the associations between FGC and cesarean section and instrumental delivery.

1.2.6 Best available evidence: Mental health problems and disorders

Unfortunately, only one meta-analysis [16] predating the influx of recent and highly relevant studies has assessed the scientific evidence on the association between FGC and mental health problems and disorders. Berg et al. (2010)[16] included four comparative studies reporting on psychological consequences published from inception through February 2010. Non-pooled analyses indicated that girls and women subjected to FGC are more likely than their counterparts to have a psychiatric diagnosis, suffer from somatization, low self-esteem, anxiety, and Phobia. However, pooled analyses showed high heterogeneity and were thus inconclusive.

1.3 Terminologies and epidemiology

FGC, FGM, FGM/C, and female circumcision are synonyms with different connotations and acceptance levels [2, 4, 182, 191]. Female circumcision is the one most similar to local terms in practicing communities. However, the WHO and other United Nations (UN) agencies strongly oppose using this term to emphasize the physical harms of the practice, its violation of the rights of girls and women, and to prevent equating it to male circumcision [2, 4]. Instead, they favor FGM but still recognize the need for non-judgmental terms and recommend using FGM/C or FGC while discussing the topic with practicing communities [2].

On the other hand, some scholars are vastly critical of the mutilation terminology and discourse perpetuated by the WHO and other UN agencies [192]. They argue that this term is *misleading, inaccurate, sexist, ethnocentric, and harmful*. For example, the term mutilation misleadingly attributes an intent to inflict harm to parents and practitioners. Similarly, it inaccurately refers to procedures that do not involve tissue removal, lasting functional injuries, or visible morphological changes. Furthermore, they argue that the term is *sexist* and *ethnocentric* because the WHO and other UN agencies do not apply it to medically unnecessary procedures with similar motivations or degrees of cutting among males (male circumcision) and Western populations (FGCS). Finally, it is *harmful* because it exposes those already subjected to the procedure to stigmatization, feelings of inadequacy, and body shame, eventually leading to psychosexual suffering.

This latter argument on the harmful effect of the mutilation terminology is the main reason that I have used FGC instead of FGM or FGM/C in this thesis.

Globally, the evidence base of available prevalence and risk estimations of FGC is direct or indirect methods [8, 193]. The direct methods typically estimate the prevalence and risk of FGC from data collected through systematic and randomized surveys among nationally representative population samples. The most common among such surveys are the Demographic Health Survey (DHS) and the Multiple Indicator Cluster Surveys (MICS) that include a standard module exploring FGC attitudes and practices in relevant countries every five years. National representative data from such surveys are currently available from 27 African, two Middle Eastern (Iraq and Yemen), and two Asian countries (Indonesia and the Maldives). These national representative data show that over 200 million girls and women had been subjected to FGC, with the highest prevalence reported in Somalia, Guinea, Djibouti, Sierra Leone, Mali, Egypt, Sudan, and Eritrea.

Moreover, national representative data demonstrate that most practicing communities perform FGC on minor girls under 15 years [193]. Still, the timing and the reasons for the practice vary across countries, regions, and ethnic groups [1, 194]. For example, some communities perform FGC on girls younger than five years old, while others carry it out on girls between 5 and 14. Similarly, reasons for practicing FGC vary from practicing it as a rite of passage into womanhood, a tradition, a religious obligation, and a safeguard for virginity and faithfulness to aspirations for social inclusion, cleanliness, beauty, and marriageability.

On the other hand, direct but non-representative studies suggest that specific local communities in other countries (e.g., Colombia, India, Malaysia, Thailand, and Saudi Arabia) also practice FGC but do not provide prevalence or risk estimates [193, 195]. Furthermore, increased emigration from the 31 previously mentioned countries resulted in FGC-affected minority groups in other parts of the world, including Europe [5, 7, 8, 196-198], the United States (US) [10, 14], Australia [199], and Canada [200]. Although evidence [201, 202] shows that Western countries (e.g., the UK and USA) performed FGC type I during the nineteenth century to treat epilepsy, sterility, and masturbation, FGC is currently only prevalent among immigrants. Hence, the number of those subjected to FGC in these countries is low compared to the general population. Thus, conducting nationwide randomized surveys to estimate FGC prevalence would be time-consuming, costly, and inefficient. So far, the method most commonly used in countries of immigration is an indirect estimation method that extrapolates DHS and MICS prevalence data and combines it with data on resident population migrating from FGC practicing countries [5, 8, 203]. Such extrapolation-based studies estimate that over half a million girls and women living in the European Union (EU), Switzerland, and Norway per 2011 had undergone FGC before immigration [5]. Likewise, in 2012 over half a million girls and women living in the US had either undergone or were at the risk of undergoing FGC [14].

In Norway, 40% of girls and women who resided in the country in 2013 and emigrated from FGC-practicing countries are estimated to have undergone FGC before immigration. Over 50% of these girls and women (9000) had most likely experienced infibulation. Similarly, over 50% of girls and women who had undergone FGC had emigrated from Somalia, followed by migrants from Eritrea (23.1%), Ethiopia (11.6%), Iraq (3.4%), and Sudan (3.3%). However, most of those who had undergone infibulation (i.e., more likely to need FGC-specialized healthcare) had emigrated from Somalia, followed by Eritrea, Sudan, and Ethiopia.

1.4 The WHO's health policies on FGC

The wide distribution of FGC rendered it a global concern rather than an African issue [13], and its complete abandonment by 2030 is a target of the 5th goal of the UN sustainable development goals (SDGs) [204]. During the last decades, several countries of immigration have developed policies to prevent and protect girls from being subjected to FGC and provide care for those already subjected to the practice [28]. The WHO and other central UN agencies' policies on FGC inform most of these policies.

From 1979 to 2000, the WHO's FGC policies focused predominantly on promoting abandonment through community mobilization, legislation, and health education about FGC-related health risks. However, the health risks approach seems to have unintentionally led to repeated appeals for allowing less extensive types of FGC, such as pricking, and a new trend of healthcare providers replacing traditional practitioners in performing FGC (medicalization) in the guise of harm reduction [3]. By the end of the previous millennium, realizing the need for involving healthcare providers in preventing FGC, the WHO policies on FGC had gradually shifted towards greater health sector involvement [28]. This shift witnessed a clear emphasis on prohibiting medicalization, training healthcare providers on FGC, assigning new FGC-related duties to healthcare providers, and providing FGC-specialized healthcare to those in need [1, 28, 76, 205-207].

The WHO launched a series of policy and clinical guidelines and training modules for healthcare providers [2, 3, 76, 205, 206]. These guidelines and training modules collectively aimed to increase the healthcare providers' competence in FGC, outline the multi-faceted roles of healthcare providers in FGC management, and recommend best clinical practices. Furthermore, the WHO and other relevant UN agencies steadfastly condemned the medicalization of FGC, arguing that it perpetuates and sanctions a harmful practice, which could hamper the global efforts towards complete abandonment [1, 207-209]. Although they incorporated gender equality and children's rights approach, they continued to perpetuate health risk models to raise the awareness of practicing communities about the obstetric, sexual, and mental health problems associated with all types of FGC to spur abandonment [208, 210].

Nevertheless, the clinical focus of the WHO's policy and clinical guidelines and training modules between 2001 and 2015 was almost exclusively on managing the obstetric complications of type

III [76, 205, 206]. During this period, the WHO aimed to teach nursing and midwifery students how to open the infibulation seal and expose the vaginal and urethral openings (deinfibulation) to facilitate childbirth and treat or prevent complications associated with type III. In addition, the WHO aimed to equip nursing and midwifery students to educate patients on FGC-related health problems and document FGC in the medical records.

In 2016, the WHO, for the first time, launched clinical guidelines and recommendations addressing the management of all categories of complications associated with all types of FGC [3]. Furthermore, the target audience for the guidelines was all healthcare providers involved in the care of girls and women subjected to FGC in both high prevalence countries and countries of immigration.

The primary purpose of the guidelines is to provide evidence-informed recommendations and best practices statements on the management of FGC-related health problems [3]. Therefore, a WHO steering group first conducted a scoping review of the literature and a scoping survey among international FGC experts to identify and prioritize health problems and corresponding interventions for the guidelines. After that, they retrieved and synthesized up-to-date evidence from existing or commissioned literature reviews and drafted an initial statement on each prioritized topic. Then, a guideline development group consisting of 15 international stakeholders (healthcare providers, researchers, health program managers, human rights lawyers, and women's health advocates) systematically reviewed and voted on each drafted statement in light of a set of established criteria. These criteria included the quality of available evidence, the balance between benefits and harms, and the acceptability and feasibility of the proposed interventions. The guideline development group issued final recommendations or best practice statements by the end of this systematic process. When the evidence was non-existent or of low quality, the guideline development group used their practical judgment and the established criteria to issue best practice statements. Finally, the WHO steering group drafted a complete guideline document, sent it to an external review group for peer-review, carefully evaluated and incorporated the input from the peer review, and finalized the guidelines. The final document includes five recommendations and eight best practice statements regarding deinfibulation, mental health, sexual health, and education and information.

Like previous guidelines, and based on the causal relationship between type III and some adverse obstetric outcomes [148], as well as evidence from one of the commissioned systematic reviews and meta-analyses [211], the new guidelines strongly recommend deinfibulation to prevent and treat obstetric complications in infibulated women [3]. On the other hand, since another systematic review and meta-analysis [212] showed no significant difference between deinfibulation before and during childbirth for obstetric outcomes, the WHO recommends certain factors to guide final decisions about the timing of the procedure. These factors are the preference of the woman, access to healthcare services, place of delivery, and healthcare providers' competency. Finally, lacking direct evidence on the effects of deinfibulation on urologic outcomes [213], the WHO based its third recommendation on the indirect evidence of increased risk of symptoms of urinary obstruction among women subjected to type III [15] and the clinical experience of medical practitioners among the guideline development group. Hence, the guidelines recommend deinfibulation to prevent or treat recurrent UTIs and urinary retention among infibulated women. In addition to these three recommendations, the guidelines include two best practice statements regarding deinfibulation. First, candidates for deinfibulation should receive adequate preoperative counseling on the procedure's expected benefits and potential risks, including the postoperative anatomical and physiological changes. Second and last, healthcare providers should perform deinfibulation under local anesthesia. However, in resource-limited settings where local anesthesia might not be available and when deinfibulation is critical (e.g., for the progression of labor), healthcare providers should perform deinfibulation regardless of the unavailability of anesthesia.

Regarding mental health, the guidelines include one recommendation and one best practice statement [3]. First, the WHO recommends considering cognitive behavioral therapy (CBT) for treating girls and women subjected to FGC with an established diagnosis of anxiety disorder, depression, or PTSD, but only by adequately qualified healthcare providers. However, there was no direct evidence on the effect of CBT for these disorders in girls and women subjected to FGC [214], and the WHO had to rely on indirect evidence among other populations [215-217] to issue this recommendation. Second, since girls and women could experience surgical interventions in the genitalia as stressful life events that remind them of the initial FGC trauma, the WHO's guidelines emphasize that psychological support should be available for girls and women before and after any surgical genital intervention. Again, there was no direct evidence on the effect of psychological interventions on postoperative outcomes for girls and women who had a surgical intervention to manage FGC-related complications. Hence, the WHO had to rely on indirect evidence from other populations on the effects of psychological interventions on postoperative recovery [218, 219] to issue this statement.

For sexual health, the WHO recommends sexual counseling to prevent or treat female sexual dysfunction among girls and women subjected to FGC [3]. However, lacking direct evidence [220] clinical experience and indirect evidence on the effect of sexual counseling on treating sexual dysfunction in other populations [221-224] informed this recommendation instead. Furthermore, the WHO emphasizes that offering sexual counseling as an alternative to surgical interventions is a priority since women's sexuality commonly depends on the interactions of anatomic, cognitive, and relational factors.

Moreover, the guidelines include five best practice statements on information and education [3]. First, based on the positive effects of well-designed information, education, and communication (IEC) interventions on prevention [225], the WHO recommends providing these interventions to girls and women subjected to any type of FGC. Second, to safeguard the girls' and women's free and informed decision-making and potentially reduce requests for reinfibulation [226], girls and women with type III should receive health education on deinfibulation. Health education should be scientific and noncoercive information about deinfibulation necessary to understand the procedure, its benefits, and potential complications, including postoperative anatomical and physiological changes and postoperative care. Third, healthcare providers are responsible for conveying correct and nonambiguous information to girls and women subjected to FGC, using language and approaches they can easily understand. Fourth, to better equip healthcare providers to identify, record, treat, or refer girls and women with FGC-related health problems [227], they should receive adequate information on different types of FGC and their associated short and long-term health risks. Also, regular and continuous capacity-building programs on FGC for healthcare providers should be a priority in both high prevalence countries and countries of immigration. Fifth and last, to avoid medicalization as an unintended effect of providing healthcare providers with information on FGC, such information should clearly indicate that medicalization is unacceptable.

Finally, the WHO decided not to issue any recommendations regarding clitoral reconstruction because of safety concerns [3]. Clitoral reconstruction is a surgical procedure that can help reduce vulvar and clitoral pain and improve body image and sexual function in women and girls with any type of FGC involving the removal of the clitoris [73, 228-231]. As the clitoral glans is the only part of the clitoris removed during FGC, reconstruction of a new glans is possible by removing the scar tissue, exposing and mobilizing the clitoral stump, and creating a neo-prepuce [230]. However, despite the promising evidence [228] indicating improved dyspareunia and chronic clitoral pain following clitoral reconstruction, the WHO [3] remains apprehensive of the procedure because of methodological limitations and excessively high rates of reported complications in the original studies.

On the other hand, while the recommendations and best practices statements on the management of FGC-related health problems are well thought, systematic, and largely evidence-based, the statement regarding FGCS is not. Noting parallels between FGC and FGCS, the guidelines surprisingly emphasize that since FGC is performed without full informed consent and for underlying reasons that perpetuate “deep-rooted inequality between the sexes,” these “critical differences” warrant a differentiation between the two [3]. This differentiation is particularly surprising for many reasons. First, the guidelines note that FGCS comprises procedures similar to FGC, such as labial reduction or vaginal tightening, and the motivations behind FGCS include non-medical reasons such as social, cultural, and community norms promoting a particular aesthetic model of female bodies. Second, the WHO’s policies on FGC have condemned all types of FGC, including procedures (e.g., piercing and pricking) that involve lesser genital injuries than FGCS, even in the lack of empirical evidence on health complications. Third, most communities that practice FGC also practice male circumcision, sometimes for similar motivation and degree of cutting. Fourth, as noted in the same guidelines, aesthetic reasons are among the sociocultural drivers for FGC. Hence, it is pretty understandable that scholars have considered the WHO’s differentiation between FGC and FGCS as double standards [192]. Despite the importance of this discussion, it slightly falls outside the scope of this thesis. For further readings on the topic, see [192, 232].

1.5 Migrant’s equitable access to healthcare: concepts, barriers, and strategies

Increasing emigration from FGC-practicing countries has led many receiving countries in the West to develop health policies on FGC that focus on both prevention and healthcare [28]. Furthermore, ensuring equitable access to healthcare for immigrant groups, including girls and women with FGC, is gaining political attention and commitment in several European countries [233-235].

Scholars commonly define equity as fairness and differentiate between horizontal and vertical equity [234]. Whereas horizontal equity refers to equal access to equal needs, vertical equity means different access to different needs. However, there are wide variations in the interpretation and conceptualizations of access to healthcare per se [236-238]. Examining the literature on access, Penchansky and Thomas (1981)[238] have found that some scholars position realized access as the initiation of healthcare and conceptualize access as attributes of the healthcare system that allow entry into the healthcare system if desired. These attributes include availability, supply, and resources. On the other hand, other scholars interpret access as the result of factors affecting the utilization rates of the healthcare services given equal needs/health states (i.e., the discrepancy between entry or use and need). Moreover, others see access relating also to patients' attributes such as ability or willingness to enter into the healthcare system.

Hence, recognizing the need for a new concept incorporating all essential factors, Penchansky and Thomas (1981)[238] propose an alternative definition of access. First, they position utilization proportioned to need as realized access and define access as the degree of fit between patients and the healthcare system. In addition, they suggest that this degree of fit summarizes the relationship between patients and the healthcare system regarding specific areas such as availability, accessibility, accommodation, affordability, and acceptability. They then define each of these areas. For example, they define availability as the fit between volume and type of existing services and the patients' volume and type of need. Similarly, whereas accessibility is the fit between the location of services and the location of the patients, accommodation is the fit between the ability of the healthcare system's organization to accept patients and the patients' ability to accommodate demands arising from such organization/structure. Moreover, affordability is the fit between the costs of healthcare services and the patients' ability and willingness to pay. Finally, acceptability is the fit between healthcare providers' attitudes towards the personal characteristics of the patients and the patients' attitudes towards the providers' characteristics and perceived competence.

Building on Penchansky and Thomas's (1981) understanding of access, Levesque et al. (2013) [236] conceptualize it as "the opportunity to reach and obtain appropriate health care services in situations of perceived need for care." They again position healthcare utilization appropriate to the perceived need as realized access. However, instead of seeing access as a fit between patients' characteristics/dimensions and the healthcare system's characteristics/dimensions, they see it as an outcome of the interactions between these dimensions. Hence, capturing determinants of both supply and demand sides, they differentiate between five dimensions of the healthcare system (accessibility) and five corresponding dimensions of the patients (ability). They identify the five dimensions of accessibility of services as approachability, acceptability, availability and accommodation, affordability, and appropriateness. On the other hand, the corresponding abilities of the patients include the ability to perceive healthcare needs, the ability to seek healthcare, the ability to reach, the ability to pay, and the ability to engage.

Most quantitative studies examining immigrants' access to preventive services, general practitioners (GPs), emergency services, and inpatient and outpatient specialist services employ such models of utilization per needs [234]. Overall, barriers to immigrants' access to healthcare include legal restrictions on entitlements to healthcare (e.g., undocumented immigrants), socioeconomic factors, health beliefs, health-seeking behavior, and language, communication and navigation factors, particularly among newly arrived immigrants.

Nevertheless, some scholars [237, 239] are skeptical towards the overuse of models that see access as realized access, mainly when using objective measures (e.g., utilization rate) but also when using subjective measures (e.g., satisfaction with healthcare). For example, Norman Daniels (1982) [237] argues that the significance of potential factors on healthcare equity in utilization per need models is determined only by their effect on utilization rates. Subsequently, if a factor has a significant impact on satisfaction, quality, or morbidity, but not utilization rates, one could miss the implication of that factor on equity to healthcare. Furthermore, healthcare needs are dynamic and not static [239]. Healthcare needs, or eligibility for medical attention, are negotiated between the patients and the healthcare systems. Both parties continually strive to constitute and define what they perceive as appropriate objects for medical attention. Therefore, instead of utilization per need, Dixon-Wood et al. (2005)[239] propose a process approach that introduces a concept of "candidacy." Candidacy is "a dynamic and contingent process, constantly being defined and redefined through interactions between individuals and professionals, including how cases are constructed." The candidacy concept highlights different stages (i.e., identification, navigation, permeability, appearances, adjudications, and offers) along the patients' journey for medical attention where such negotiations typically occur. Hence, a different set of factors influence candidacy at each stage, i.e., the effect of potential factors on each stage rather than on utilization rates determines their significance for healthcare equity.

Finally, scholars [234, 235] identified different strategies to improve equity in healthcare for immigrants that address various issues such as entitlements, policies, communication between immigrants and healthcare providers, and organization of services. These strategies include expanding the entitlement of undocumented immigrants beyond emergency care, explicitly incorporating migrants' health in national health policies, providing interpreter services, improving the intercultural competence of healthcare providers, providing immigrants with health education and information on the healthcare systems in native languages, collaborating with cultural mediators, prioritizing specific diseases or conditions affecting immigrants, and considering separate services for immigrants instead of mainstream services for all. However, the latter might be unsustainable and vulnerable to political agendas, particularly in the light of increased anti-immigrant sentiments.

1.6 Health policies on FGC in countries of immigration

Prioritization of FGC is an example of strategies targeting specific conditions affecting immigrants. Several countries of immigration have health policies on FGC that adhere to the WHO's recommendations and best practices regarding the prohibition of medicalization, training of healthcare providers, and providing health education and healthcare to girls and women subjected to FGC [28]. Still, there are some variations. For example, in some countries, the prohibition of medicalization covers both minors and adults even when performing FGC on adults is legal. In contrast, in Portugal and the USA, the ban on medicalization only covers children.

Similarly, while some countries of immigration emphasize that the FGC ban includes reinfibulation, other countries, including Belgium, Greece, Spain, Switzerland, and the USA, do not. Likewise, while some countries (e.g., France, the Netherlands, and the UK) train their healthcare providers systematically on FGC, others (e.g., Australia, Norway, and Sweden) do that ad-hoc, and a few (e.g., Germany and Switzerland) do not train them at all. Also, healthcare providers in some countries such as Finland, France, Italy, the Netherlands, Norway, Portugal, Spain, and the USA have to provide health education on FGC to relevant patients, but not in other countries such as Australia, Belgium, Germany, Ireland, Sweden, Switzerland, and the UK.

On the other hand, some countries of immigration [28] assign FGC-related duties to healthcare providers that are not part of the WHO's recommendations and best practices [3]. These duties are the duty to avert and to report [28]. The first is the healthcare providers' duty to dissuade families from subjecting their daughters to FGC, report families to the child protection services or the police when a child is at imminent risk of being subjected to FGC, or both. The second is the healthcare providers' obligation to report detected cases of FGC, mainly in minors, to either child protection services or the police. Unlike health education, the duty to avert and the duty to report expose healthcare providers to ethical dilemmas of balancing medical confidentiality and the best interest of the patient/child. Many countries of immigration have child protection laws that oblige healthcare providers to break medical confidentiality in the best interest of the child when that child is exposed/at the risk of being exposed to serious and repetitive abuse. FGC is an example of serious abuse. However, as it is typically not repetitive, some countries (e.g., Australia, Belgium, Germany, and Norway) only oblige healthcare providers to avert FGC but not to report it once it has already occurred. Furthermore, there are concerns that mandatory reporting might deter parents from seeking necessary healthcare for children subjected to FGC in fear of legal repercussions. Nevertheless, a few countries (e.g., Austria and France) assign their healthcare providers the duty to report but not to avert.

Similarly, the availability of healthcare interventions for girls and women subjected to FGC also varies considerably within and between countries of immigration [28]. For example, deinfibulation is typically available through public healthcare services for different indications. Still, in a few countries, it is only available in private clinics (e.g., Slovakia and Switzerland) or only in the context of pregnancy and childbirth (e.g., Spain and Portugal). Likewise, some countries do not provide psychological or sexual interventions with special competence in FGC (e.g., Australia, Finland, Germany, Norway, Portugal, Spain, and the USA). In contrast, other countries (e.g., Austria, France, Ireland, the Netherlands, Sweden, Switzerland, and the UK) provide such interventions. Still, the national coverage of these services varies within and between these countries. For example, a few countries report good national coverage (e.g., France and the Netherlands), while some report significant regional variations (e.g., Austria, Ireland, Switzerland, and the UK), with most services concentrated in big cities. Finally, in a few countries (e.g., Belgium and Sweden), psychological and sexual counseling with special competence in FGC is only available upon requests for clitoral reconstruction.

Lastly, although the WHO does not yet recommend clitoral reconstruction, it is still available in some countries of immigration in either the public health services (e.g., Australia, Belgium, France, Italy, Sweden, and Switzerland) or private clinics (e.g., Austria, Germany, and the Netherlands) [28].

1.7 Policies on FGC in Norway

In Norway, the national attention towards FGC started in the mid-1990s following the influx of refugees fleeing the Somali civil war and media outrage over rumors that a local hospital performed FGC (reinfibulation) on Somali women [63]. Although the hospital refuted the accusation, this incident and the ensuing debate had probably highlighted the need for legislation against FGC.

In 1995, Norway passed a special law forbidding FGC, regardless of age and consent [240]. Under this law, performing FGC, including reinfibulation, was punishable with imprisonment depending on the associated complications/consequences. For example, if the procedure did not cause health complications, the imprisonment period was set to a maximum of three years. On the other hand, the imprisonment period was increased to a maximum of six years in cases where FGC has resulted in illness, incapacitation for over two weeks, incurable defect, damage, or injury, and to a maximum of eight years if it resulted in significant harm or death.

Between 1995 and 2000, Norway did not take further actions regarding FGC because of a tacit understanding that the law against FGC and migration per se were enough to prevent FGC in the country.

However, since 2000, Norway has had six action plans with earmarked funding to address FGC. [241-245]. The first two of these plans were exclusively on FGC, whereas the third was joined together with forced marriage and the rest with forced marriage and negative social control. The first two plans, launched in 2000 and 2008, followed media debate after two documentaries indicated that girls in Norway were either subjected to FGC or at the risk of being subjected to FGC [246]. Therefore, the main focus of the first two action plans was on prevention and protection. Initially, the first action plan adopted dialogue with relevant groups to change their attitudes towards FGC as the primary preventive measure. However, the public debate perceiving FGC as a vast and urgent problem demanded less dialogue and more protective measures. Subsequently, Norway amended the FGC special law in 2004 to assign a duty to avert to a group of professionals, including healthcare providers, who would risk legal punishment if they had prior knowledge of an impending risk of FGC but failed to prevent it. This amendment also emphasized the precedence of the duty to avert over the confidentiality code. Similarly, subsequent measures included informing the target population about legislation and health complications, shelters and dedicated phone lines for girls at risk, and encouraging the police to confiscate passports - or refuse to issue them- if they suspected FGC was a risk while abroad.

After amending the 1995 special law on FGC again in 2010 to increase imprisonment, Norway abolished this law in 2015. Instead, it added two new articles addressing FGC (§ 284 and § 285) to the criminal law [247]. The first article (§ 284) with the subtitle '*kjønnslemlestelse*' (genital mutilation) states that a person performing a procedure in a girl/woman's genitalia causing harm or leading to a permanent change in the genitalia is susceptible to up to six years imprisonment. Similar to the previous law on FGC, consent is not considered a ground for exemption from punishment. Furthermore, failure to satisfy the duty to avert is punishable by fine or one-year imprisonment. The second article (§ 285), on the other hand, establishes a maximum of 15 years imprisonment regarding what is called aggravated genital mutilation (*grov kjønnslemlestelse*), determined by whether FGC caused: 1) illness or incapacitation over time, 2) incurable defect, damage or injury, and 3) death or significant damage to the body or health. Although FGCS would theoretically fall under these two articles, the legal section of the Norwegian Medical Association found it inappropriate to place FGCS in the same category as 'traditional' FGC [248]. The justification was the presence of decisive differences in motivation and degree of anatomical changes between the two.

Despite the predominant focus on preventive and protective measures, most action plans have also emphasized providing healthcare for those with FGC. Therefore, in 2004, as a national healthcare offer on FGC, several women's outpatient departments started to provide specialized services for affected girls and women [28]. Still, a clear shift towards healthcare focus did not occur until, in the second year of the fourth action plan [243], a report [246] that analyzed the Norwegian policies on FGC concluded that speculations rather than scientific evidence had driven these policies. This conclusion followed an extensive review of research findings in Norway that highlighted an imbalance between the Norwegian preventive and protective measures and the local FGC risk [246, 249-253]. Subsequently, the focus on FGC of the fifth (2017-2020) and sixth (2021-2024) action plans predominantly shifted to healthcare [244, 245]. In the fifth action plan, the measures that explicitly addressed FGC were: systematizing information on FGC-related health complications, strengthening information on the right to healthcare, ensuring equitable healthcare offer for girls and women with FGC, and further developing the healthcare offer based on new knowledge. Finally, emphasizing new knowledge acquired from the research project that includes this Ph.D. study, the last and current action plan [245] for the first time mentions a potential need of girls and women with FGC for sexual and psychological counseling. The action plan also acknowledges that good competence among service providers is crucial for equitable healthcare offers. Subsequently, the primary FGC measure in the current plan is to evaluate and further develop equitable and evidence-based healthcare offer to the target group.

1.8 Healthcare in Norway for girls and women subjected to FGC

1.8.1 Organization of healthcare

Norway has a semi-decentralized health system, where the responsibility for specialist healthcare falls under four Regional Health Authorities (RHAs) and primary healthcare under the municipalities [254]. At the primary healthcare level, general GPs provide care either at their medical practices (within office hours) or urgent care centers (after hours). GPs also act as gatekeepers, referring patients needing more complex care to specialist healthcare (physical, mental, and other specialized medical services) at hospitals' outpatient or inpatient departments. In addition, under a contractual agreement with the RHAs, self-employed specialists such as gynecologists, psychiatrists, psychologists, etc., provide outpatient specialist healthcare in their private practices.

As equal access to high-quality healthcare for all residents is a cornerstone principle of the Norwegian healthcare system [254], the law (The Patients' Rights Act) [255] gives patients certain rights. For example, all residents registered in the National Population Register have rights to primary healthcare, including a regular GP, whom they can freely choose and change up to twice a year. Furthermore, patients in need of specialist healthcare have a legal right to specialist services. Moreover, although patients have to pay consultation fees when using primary or outpatient specialist healthcare services, these fees are subsidized and even waivered for specific patient groups (e.g., pregnant women and children). In addition, once the patients' co-payments reach a set ceiling, they are issued a card that exempts its holder from co-payments and other costs for the remainder of the calendar year. Undocumented immigrants under 18 years also have the same right as other children in Norway except for the right to a GP [256]. However, access to healthcare for undocumented immigrants over 18 is limited to acute emergency care, infection control, and undelayable essential healthcare (e.g., maternal healthcare).

The Patients' Rights Act [254, 255] states that patients have the right to receive the information needed to understand their condition, treatment options, possible risks, and side effects. In addition, this information should be adapted to the patient's characteristics and needs, such as age, experience, language, and cultural background. Finally, patients have the right to participate in the decision-making around their healthcare, including choosing between available and medically sound methods of investigation and treatment.

1.8.2 FGC-specialized healthcare

The current national healthcare offer to girls and women with FGC includes deinfibulation and removal of cysts [28]. To guide the provision of these healthcare interventions, the Norwegian Society of Gynecology and Obstetrics regularly publishes and updates its national guidelines [257]. The regular updates ensure that the guidelines correspond to current scientific knowledge and recommendations. For example, in response to the increasing evidence that the timing of deinfibulation does not affect obstetric outcomes and that most pregnant women prefer deinfibulation during childbirth, the guidelines changed one of the previous advice. The current update [258] recommends waiting until delivery instead of performing deinfibulation while planning for or during pregnancy to prevent obstetric complications. Subsequently, most future obstetric-related deinfibulation will probably occur in the maternity wards. Still, as the final decision on the timing should consider the women's individual preferences, gynecologists could perform deinfibulation during pregnancy but avoid the first trimester because of the generally increased risk of abortion.

Besides obstetric indications, the national healthcare offer on FGC includes deinfibulation for many other reasons, including personal preference, managing obstructive urological and menstrual problems, and facilitating sexual intercourse [258]. Although the offer also provides for the removal of cysts, the guidelines call for caution with surgery in the proximity of the clitoris as it could lead to reduced sexual satisfaction.

This national offer of specialized healthcare services for girls and women with FGC is available in seven women's outpatient clinics [259]. In these clinics, gynecologists with special competence in FGC would assess the patients' condition and need for surgical interventions and treat them accordingly. In addition, to increase the accessibility of these services, some clinics allow girls and women to contact them directly.

The national guidelines help provide a standardized framework for consultations and clinical management of girls and women with FGC. The gynecologists are encouraged to tell the women what they are doing, use non-stigmatizing and understandable vocabulary, use interpreters if necessary, and visual aids when explaining anatomy [258]. Furthermore, they should inform the patients about the possible connection between their current health problems and FGC and the common anatomical and physiological changes after deinfibulation. Moreover, they should consider referral for psychological support. Nevertheless, it is critical to note that the national healthcare offer on FGC does not include pre-or postoperative psychological support or sexual counseling as promoted by the WHO. Still, theoretically, girls and women with FGC have access to mainstream mental health services [65].

The guidelines further emphasize that although gynecologists typically perform deinfibulation under local anesthesia, they should consider spinal or general anesthesia and adequate postoperative pain relief as insufficient pain relief could trigger traumatic flashbacks [258]. Postoperatively, they should also instruct the patients on wound management, sexual activity, and how and when to make further contact. Also, whenever necessary, they should offer a certificate explaining that it was medically necessary to perform deinfibulation.

Finally, in addition to clinical management, the guidelines provide an overview of other FGC duties. These duties include informing the patients about the Norwegian law, clarifying their attitudes towards subjecting their daughters to FGC, and averting imminent FGC. The guidelines also emphasize that although healthcare providers are exempted from confidentiality to avert FGC, they should not report or give information to the police without the patient’s consent when FGC has already taken place.

1.9 Access to FGC-related healthcare interventions in Norway and other Western countries

Overall, hardly any study has directly investigated women’s access to FGC-specialized healthcare interventions in Norway or other western countries. Still, many had addressed different aspects necessary for understanding access to these interventions. These studies include quantitative studies assessing healthcare providers’ knowledge, attitude, and practice (KAP) [40, 260, 261]. Most of these studies focused on gynecologists, obstetricians, and midwives. Only a few included GPs [36-38], pediatricians [37-40, 42, 46], and psychosexual therapists [41]. Findings from these studies consistently reported healthcare providers’ lack of training on FGC and serious gaps in competence and knowledge, particularly clinical guidelines and clinical, cultural, and legal aspects of FGC [32-50], indicating a need for comprehensive training to support care provision to the target population. A few of these studies have examined the association between the received training on FGC and the healthcare providers’ knowledge and attitudes regarding prevention [37, 38, 41, 42, 44, 45] and care provision [262]. The latter study found the healthcare providers' confidence for providing FGC-related healthcare was positively associated with knowledge of health complications, experience with women with FGC, and more than five years of clinical experience. Nevertheless, none of the studies has assessed the healthcare providers’ healthcare provision practices (e.g., diagnosis of complications, referrals, deinfibulation, counseling, etc.) nor the association between these practices and received training, knowledge, and attitudes.

A systematic review of 30 qualitative studies had explored factors influencing the provision of FGC-related healthcare in Western countries from the perspective of healthcare providers [51]. Most studies were from maternity healthcare contexts. The review identified several factors related to the healthcare providers, the healthcare services, and the women. The healthcare providers’ factors included the negative influence of lack of training and knowledge on the healthcare providers’ confidence in delivering appropriate FGC-related healthcare. Also, as FGC evokes strong emotions in healthcare providers, they usually struggle with maintaining professionalism during consultations. Furthermore, perceptions of FGC as a sensitive issue and fear of offending or stigmatizing women often lead healthcare providers not to ask about FGC, assuming the women themselves would bring it up if they had any related problems. Still, the healthcare providers perceived that the women also find it hard to talk about FGC during consultations. On the other hand, factors related to the healthcare services included a lack of clear routines and guidelines concerning identifications of FGC, deinfibulation, and reinfibulation. Another factor was the lack of psychological counseling and support. Finally, women’s related factors from the perspective of healthcare providers included language barriers, cultural differences, not linking health problems to FGC, preferences for female healthcare providers, mistrust of the healthcare system, and the influence of family members on the women’s healthcare decision-making.

A recent realist review explored how, why, and under what circumstances FGC is discussed in general practice [263]. The authors found that although GPs have a vital role in providing healthcare to women with FGC, there was little evidence regarding their knowledge, attitudes, and healthcare practices related to FGC. Also, recently, a Norwegian study [65] explored the perceptions and experiences of a diverse group of healthcare providers (GPs, psychiatrists, psychologists, gynecologists, midwives, and nurses) regarding access to mental healthcare services among women from Sub-Saharan African countries (SSA), focusing on women with FGC. The study findings indicated that GPs do not ask SSA women with mental health problems about their FGC status and that their access to specialist mental healthcare was extremely limited. Moreover, many studies have explored the healthcare experiences of women with FGC in various Western countries. For example, a systematic review [56] of 57 qualitative papers found that women with FGC face several challenges while receiving FGC-related healthcare. Some of these challenges are common among immigrants but not specific to FGC, such as language barriers and unfamiliarity with the health systems. On the other hand, challenges related explicitly to FGC included silence on FGC by both the women and healthcare providers, cultural insensitivity of healthcare providers, cultural norms rendering deinfibulation unacceptable, the influence of family members on decision-making, and feelings of embarrassment and shame connected to FGC. Furthermore, many women had disempowering healthcare experiences where they felt exposed and humiliated, judged and stereotyped, and unsafe and vulnerable. Similar findings were reported in several qualitative papers [60, 63, 64] exploring maternity-related healthcare experiences of infibulated women and healthcare providers in Norway.

Overall, the research focus on FGC-related healthcare in Norway has increased in recent years. For example, a recent paper [259] presented descriptive findings based on data retrieved from the medical journals of 913 women with FGC visiting any of the seven FGC-specialized clinics during 2004-2015. Most women were infibulated and born in Somalia, and about half were pregnant. Most women were referred from primary healthcare services, and only 19% took direct contact. The most common reason for referral or contact among the infibulated women was gynecological problems followed by evaluation of FGC types, seeking deinfibulation, pregnancy, and urinary problems. Two-thirds had deinfibulation and 6% cyst removal. Whereas 76% received local anesthesia under the surgical procedure, 15% received general anesthesia. However, there was a wide variation in the use of general anesthesia between clinics. Furthermore, the authors emphasized an unmet healthcare need among young non-pregnant women since many had FGC-related health problems for a long time, which raises a question about health-seeking behavior and access to the FGC-specialized clinics. Previous findings indicate that some Somali and Sudanese women in Norway find deinfibulation unacceptable because of sexual and cultural norms related to the concepts of virginity, virility, and pleasure [30, 31]. Another paper [67] also gave new insights on other barriers to help-seeking and access to healthcare in Norway among girls and women subjected to FGC, such as lack of information on FGC-related health complications and healthcare services, women's silence on FGC during consultations with healthcare providers because of shyness and shame, healthcare providers' insufficient knowledge of FGC, and healthcare providers preoccupation with the criminal aspects of FGC rather than the women's healthcare needs.

Similarly, a recent paper [66] explored healthcare providers' and SSA women's perceptions on whether SSA women have equal access to healthcare in Norway. The healthcare providers included GPs, psychologists, psychiatrists, gynecologists, neurologists, midwives, nurses, and sexologists. The healthcare providers primarily thought that although SSA women have the right to equal access to healthcare, that was not the case in reality. They blamed the system for favoring resourceful patients and allowing limited time for diagnosis. They also blamed other healthcare providers for stereotyping and stigmatizing SSA women, dismissing their health complaints, setting a high threshold for referrals, and ineffective use of interpreters. However, the healthcare providers also blamed SSA women for unnecessary consultations, health illiteracy, unfamiliarity with the system, distrust of healthcare providers, and communication difficulties. On the other hand, the SSA women (Somali, Gambian, and Eritrean) thought high of the Norwegian system and believed they had equal access to healthcare services in Norway. Still, they identified some challenges, such as long waiting time for appointments, expensive consultations fees, communication difficulties, and lack of competence and silence on FGC among GPs.

While these recent papers improve our understanding of the challenges facing women with FGC in accessing the Norwegian healthcare system, there is still a knowledge gap related to accessing the FGC-specialized services, particularly for non-maternity-related purposes. Furthermore, we need to know more about factors that can improve GPs' practices in assessing FGC as a differential diagnosis among relevant patient groups presenting with potential FGC-related health problems.

2 Aims of the doctoral thesis and research questions

Main Objective

This doctoral thesis aims to better understand factors influencing access to FGC-related healthcare services in Norway beyond the maternity context. Hence, while each of the three included papers addresses a specific objective and research questions, they collectively contribute to this aim.

Specific objectives and research questions

1. To identify factors that hinder or facilitate access to the FGC-specialized services for non-maternity purposes among Somali and Sudanese subjected to FGC (***papers I and II***).
   By comparing the perceptions, attitudes, and experiences of participants who received medical attention at the FGC-specialized services with those of their counterparts, I sought to answer the following research questions:
   - *What motivates Somali and Sudanese girls and women in Norway to seek medical attention for potential FGC-related health problems? (papers I and II)*
   - *Where do they seek medical attention, and why? (paper I)*
   - *How did they experience their encounters with the healthcare providers at the primary and specialist levels? (paper I)*
   - *What are their perceptions and attitudes towards FGC-related healthcare interventions, regardless of their availability in Norway? (paper II)*
   - *What influences these perceptions and attitude*s? *(paper II)*
   - *Are there any unmet FGC-related healthcare needs? (paper II)*
2. To identify factors influencing comfort/discomfort and routines of GPs in Norway concerning FGC assessment as a potential cause of health problems (***paper III***).
   - *What are the levels of training and perceived knowledge on FGC among GPs in Norway?*
   - *To what extent do they have experience with patients with FGC-related health problems?*
   - *What factors are associated with the GPs' feelings of comfort/*discomfort *talking about FGC?*
   - *What factors are associated with the GPs' routines of asking patients with potential FGC-related health problems about their FGC status?*

3 Materials and methods

This doctoral thesis is part of a broad study (Kjønslemlestelse-HelseVel) focusing on physical and psychological healthcare for girls and women subjected to FGC in Norway with funding from the Norwegian Research Council. Hence, it significantly contributes towards the aims of the Kjønslemlestelse-HelseVel study. Still, on its own, this thesis provides comprehensive knowledge on factors influencing access to FGC-related healthcare services in Norway.

Adopting a pragmatic philosophical stance (pragmatism) [264], I have chosen the best-suited methodology to answer the various research questions listed in the previous section.

Pragmatism [264, 265] rejects the claim that epistemology (assumptions about the nature of obtained knowledge) dictates research methodology. Similarly, it rejects purists' dualistic stance claiming that qualitative and quantitative methods embody incompatible epistemologies (e.g., subjectivism and objectivism) and ontologies (assumptions about the nature of the world) such as realism and relativism. Proponents of pragmatism [264] argue that those who exclusively bind quantitative methods to objectivism disregard that researchers make many subjective decisions throughout the quantitative research process (e.g., selecting hypotheses, developing instruments, interpreting scores, etc.). Similarly, those who bind qualitative methods to relativist ontology self-refute the need for such research. Theoretically, they accept all accounts of the same phenomenon as equally valid and disregard the need to ensure and evaluate the research rigor. Hence, pragmatism addresses these pitfalls and instead adopts a pluralistic stance that embraces a middle ground regarding epistemological and ontological assumptions for qualitative and quantitative studies. It views knowledge as "being both constructed and based on the reality of the world we experience and live in" [264] and accepts that some accounts are more authentic than others. Furthermore, refuting that qualitative and quantitative methods inherently embody dualistic ontologies and epistemologies, pragmatism suggests that research questions should guide the selection of suitable methods.

Consequently, to answer the questions related to papers I and II, I have conducted a qualitative study exploring the perceptions and experiences of Somali and Sudanese girls and women in Norway regarding healthcare for FGC-related health problems. On the other hand, I have employed quantitative methodology and used survey data from a substudy in the Kjønslemlestelse-HelseVel to answer the questions addressed in paper III.

3.1 The qualitative study

The qualitative study primarily draws on semi-structured repeat interviews I conducted in 2017-2018. In addition, three validation focus group discussions (FGD) and participant observation have helped inform this study.

Nevertheless, it builds on preliminary findings from a qualitative pilot study [266] I carried out in 2016 before securing funding for my Ph.D. as part of the Kjønslemlestelse-HelseVel study. The pilot study aimed to explore factors influencing the utilization of FGC-specialized services (deinfibulation) among children and youth with FGC in Norway. Hence, I interviewed nine girls (16-25 years old) with FGC, three parents of children with FGC, and four key informants with backgrounds from Somalia, Sudan, Ethiopia, and Eritrea.

Preliminary findings from these interviews indicated that lack of autonomy in decision-making concerning seeking or accepting deinfibulation was not limited to minors. For example, even as 25 years old, two participants were reluctant to undergo deinfibulation as they were concerned about their parents' disapproval. Similarly, key informants shared stories about women in their 30s with potential FGC-related health problems who refused to consider deinfibulation, fearing rejection by a hypothetical future husband who might think their deinfibulated state was related to premarital sexual activity. Subsequently, instead of interviewing women over 25 years only about their perceptions or experiences regarding the deinfibulation of their daughters, I have decided to interview them and others who are not married or have daughters about their personal deinfibulation experiences and perceptions. Furthermore, to facilitate comparisons between groups, I have decided to limit the focus of the Ph.D. qualitative study to Somali and Sudanese; Somali because they constitute the most FGC-affected group in Norway [8] and the Sudanese because of relative similarities with the Somali regarding the common types of FGC. Therefore, although all sixteen participants in the pilot study agreed to subsequent interviews, I only recontacted the Somali and Sudanese participants for further interviews as part of the Ph.D. study. Six of these participants gave their consent and are included in the study, using their interviews from the pilot study as first-round interviews.

3.1.1 Setting, recruitment, sampling, and participants

I have recruited the study participants from three Norwegian cities (Oslo, Drammen, and Trondheim) that host both FGC-specialized clinics [259] and large numbers of girls and women with origins from Somalia and Sudan [267].

First, I recruited participants for the semi-structured repeat interviews through different starting points to ensure sample heterogeneity. For example, I contacted key persons at local immigrant organizations and networks I knew from previous projects, informed them about the study, and invited them to participate. Moreover, I provided them with information letters to distribute to all those meeting the inclusion criteria (Somali and Sudanese girls and women over 16 years who have undergone FGC and live in either Oslo, Drammen, or Trondheim). I also presented my study during various events and provided my contact information. Furthermore, I have asked two minority counselors at high secondary schools I met at a national conference to share the information letters with eligible students.

Once I had established direct contact with the potential participants, we discussed the study's aim and other ethical and practical issues (e.g., voluntary participation, data storage, data management, where and when to meet, etc.). Furthermore, to reach those out of the reach of the immigrant organizations and minority counselors and to ensure a varied sample, I used purposeful sampling [268] and asked the participants to either distribute the information letters or orally inform friends and acquaintances, with specific criteria, about the study and my contact information. For example, at one point, those who underwent deinfibulation and those with lower education levels and shorter lengths of stay in Norway were underrepresented in the sample; hence I was very diligent in recruiting such participants. Only upon observing that interviews with newly recruited participants did not contribute new information (i.e., reached code saturation) did I stop recruitment [269]. However, I continued to repeat interview the participants until I ceased to capture new dimensions that contributed to an improved understanding of the access to FGC-specialized healthcare, i.e., reached "meaning saturation" [269]. Overall, I have recruited and interviewed 26 participants, of whom 11 were Somali and 15 Sudanese (See table 1 for an overview of the characteristics of the 26 participants).

Second, I recruited nine Somali and five Sudanese participants for two validations FGDs through the same immigrant organizations and networks. Finally, my principal supervisor recruited two

Somali and one Sudanese participant through a different organization for the third validation FGD (See paper I for detailed characteristics of the FGDs' participants).

Table 1. Characteristics of participants - semi-structured repeat interviews

Characteristic	No. participants
Background	
Somalia	11
Sudan	15
Age (years)	
16-21	9
22-27	8
28-33	1
34-39	2
40-45	3
≥ 46	3
Marital status	
Married	10
Divorced	5
Single	11
Education	
≤ Middle school	2
High school	9
College	10
Graduate school	5
Type of FGC	
Type I	3
Type II	4
Type III	19
Length of stay in Norway	
< 1 year	1
1-5 years	6
6-10 years	5
>10 years	14

3.1.2 Materials

The empirical data for the qualitative study is primarily the semi-structured repeat interviews, but the validation FGDs and participant observation have helped inform both the interviews and the analysis.

For the semi-structured repeat interviews, the participants essentially decided where and when to meet. Subsequently, most of the interviews took place at my home, while a few were at cafés or the participants' homes. In contrast, all three validations FGDs took place on the premises of local immigrant organizations. Since I am a native Arabic speaker, fluent in English, and have moderate competence in Norwegian, I conducted the interviews and FGDs with the Sudanese participants in Arabic and the Somali participants in English, Arabic, or a mixture of English and Norwegian.

3.1.2.1 Repeat semi-structured interviews

Since the research questions addressed in the qualitative study were explorative, I found the flexibility of semi-structured interviews [270] best suited to incorporate new topics or themes arising during the interviews and along the course of the study. Subsequently, the interview guide (figure 2) did not include preformulated questions but rather a list of themes that stemmed from a literature review and the preliminary findings from the pilot project. Furthermore, I continued to incorporate and pursue insights from participant observations and other interviews.

I also decided to interview the participants on two or more separate occasions, i.e., conduct repeat interviews. Repeat interviews have several advantages [270]. First, the knowledge of future opportunities for further exploration of the research topic often helps the researcher allocate more time during the first rounds of interviews to trust-building. It also helps the researcher allow the participants' narrations rather than the research questions to steer these initial conversations. Second, the intervals between repeat interviews are valuable room for reflections for both the researcher and the participants, leading to new insights and understandings the researcher can further explore in the subsequent meetings. Third, repeat interviews provide the researcher with the opportunity to clarify any unclarities in previous interviews, introduce new themes raised by other participants, and cross-check preliminary interpretation of the data. These advantages are the reason I chose repeat interviews and had primarily shaped the aim of each round of interviews. Overall, I have conducted 61 semi-structured interviews in three rounds. The first-time interviews aimed to build trust; hence they were not audio-recorded. They lasted between 30-90 minutes and included 26 participants (six participants in 2016 as part of the pilot study, and the rest in 2017). Still, I invited them to narrate what they were comfortable sharing concerning their circumcision experiences, experiences of health problems they attributed to the circumcision, how they managed these health problems and why. Since these interviews were unrecorded, I had tried to minimize any recall bias by recording my recollections and interpretations immediately after each interview. The second round of interviews aimed to explore/further explore the research topic. Hence, I used a more structured approach during these interviews and checked the semi-structured interview guide at the end to ensure we covered all relevant issues. I started with a recap of the study aims and what we had talked about in the first interviews. I then encouraged all 26 participants to narrate or elaborate on their FGC-related healthcare experiences. Moreover, I shared new themes brought up by various participants and probed for confirmations, corrections, and elaborations. For example, after a couple of participants explained why they thought their menstrual pain was related to infibulation and how it differed from that in non-infibulated girls, I shared their explanations and descriptions with other participants. I then probed how these explanations and descriptions resonated or did not resonate with their own experiences of menstrual pain. These interviews were recorded and lasted between 60-180 minutes, excluding breaks.

The purpose of the third round of interviews was to member-check my preliminary interpretation and analysis of the overall data rather than to verify the interview transcripts [271]; hence, I had only invited 10 participants, of whom nine agreed to participate. I presented my initial interpretations of identified patterns and themes in these interviews for further discussion and clarification. For example, one of the themes that I had identified after the second round of interviews was the differences between Sudanese and Somali and older and younger participants in sexual norms and the acceptance of various FGC-related healthcare interventions. Hence, in the third round of interviews, I presented this finding to the participants, explored whether it resonates with their experiences, sought elaboration and clarification, and paid particular attention to disconfirming views. These interviews were also recorded and lasted between 60-90 minutes.

3.1.2.2 Validation focus groups discussions

The focus groups discussion aimed to explore how the analyzed data resonated with other Somali and Sudanese girls and women in Norway. Therefore, my supervisor and I presented the interpreted data to 17 Somali and Sudanese participants in three FGDs in 2019. I discussed the findings separately with the Somali and the Sudanese while my supervisor discussed them with a mixed group of Somali and Sudanese. We probed for confirmations, disagreements, modifications, and elaborations. We then recorded our notes and saved them as audio files. Overall, the Somali and Sudanese participants were curious to know about the differences and similarities in the perceptions and experiences of the other group. Furthermore, the findings seemed to resonate with the participants as many told stories that confirmed the various aspects of the analysis.

Figure 2. Semi-structured interview guide

- Background information
- Knowledge, perceptions and expectations regarding female circumcision
    - Prior to own circumcision
    - After own circumcision – in country of origin/where circumcision took place
    - After own circumcision – in Norway and/or other countries of migration
- Own experience with female circumcision
    - Preparation
    - The actual circumcision
    - Immediately after
- Own experiences with perceived circumcision-related health problems (before migration)
    - Immediately after.
    - During childhood up to puberty.
    - Puberty up to first sexual encounter/marriage.
    - During marriage.
    - Pregnancy and childbirth.
- Own experiences with perceived circumcision-related health problems (after migration)
    - During childhood up to puberty.
    - Puberty up to first sexual encounter/marriage.
    - First sexual encounter and afterwards.
    - Pregnancy and childbirth.
- Experiences of close friends and/or family members with perceived circumcision-related health problems
    - Immediately after.
    - During childhood up to puberty.
    - Puberty up to first sexual encounter/marriage.
    - First sexual encounter and afterwards.
    - Pregnancy and childbirth.
- How these health problems, if any, were explained or understood
    - In countries of origin.
    - In Norway.
- How these health problems, if any, were dealt with (also ignored) and why.
    - In countries of origin.
    - In Norway.
- Knowledge, perceptions and expectations regarding circumcision-related healthcare services
    - In countries of origin.
    - In Norway.
- Experiences (positive and negative) with circumcision-related healthcare services
    - In countries of origin.
    - In Norway.
- Unmet healthcare needs
- Other?

3.1.2.3 Participant observation

Participant observation is a valuable tool in qualitative research to explore various topics and themes [270]. However, I have only used participant observation to gain better insights into the local context and discussions regarding healthcare for girls and women with FGC. Hence, I attended over 20 arrangements on FGC arranged by immigrant and non-immigrant organizations and networks between 2017-2019. The target audience in these arrangements varied but included girls and women subjected to FGC, healthcare providers, activists, and politicians. Similarly, the central topic differed among the various seminars and workshops. Still, it included the prevalence and risk of FGC, FGC-related health problems, experiences with the healthcare system, and health policies, e.g., why Norway does not provide clitoral reconstruction. Following each seminar or workshop, I recorded my observation as audio field notes and used them to inform the semi-structured interviews and the data analysis. For example, I met a specific healthcare provider from one of the FGC-specialized clinics in various arrangements. My early notes from these events highlighted how impressed I was with this healthcare provider's apparent competence and interest in FGC, particularly their interest in understanding why some girls and women with FGC do not show up for their deinfibulation appointments. Hence, when several participants seemed to have a negative impression of this exact healthcare provider, I had to dig deeper into their needs, expectations, and negative experiences to understand the dissonance in our perception. Eventually, I realized that some of the strategies that this healthcare provider seemed to have adopted to improve the uptake of deinfibulation (e.g., scheduling deinfibulation on the day of the first consultation) largely contributed to the participants' negative impression (e.g., they felt pressured to undergo deinfibulation).

3.1.3 Analysis of data

Thematic analysis is an ongoing process of identifying, analyzing, and reporting patterns within the data [272]. I adopted this thematic analysis approach in analyzing the qualitative data. Although I had already started identifying patterns during data collection, what I am presenting in this section is the analytical process corresponding to the six phases of thematic analysis described by Braun and Clarke [272]: familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

First, I entered all audio files into NVivo 12 and separated each data source (i.e., interviews, FGDs, and participant observations). Then, instead of transcribing the audio files, I listened to each interview twice in its entirety before assigning codes to the various audio segments. The generated codes at this stage were largely data-driven, i.e., not consciously influenced by specific theories or literature. Still, my approach was not inductive per se, as the research questions had influenced my decisions in identifying and selecting codes and relevant audio segments. Once I had identified and assigned initial codes, I then used insights from the participant observations, third round of interviews, and discussions with my supervisor to review (e.g., merge and re-define) these codes. For example, following a discussion with my supervisor, I joined five of the initial codes related to potential FGC-related health problems (normalization, contradicting information, consistent information, contradicting observations and experiences, and consistent observations and experiences) into one code (identifying FGC-related health problems). I also revised the description text of the new code to accommodate the meaning dimensions in the five initial codes. I then identified, compared, refined, and named themes and sub-themes in the subsequent phases, collated all corresponding data extracts under these initial themes/sub-themes, and translated them to English when applicable. I retained a few codes as sub-themes (e.g., identifying FGC-related health problems) and collated others into themes and sub-themes during this process. For example, I grouped codes related to the perceived signs of virginity (tightness, resistance, snapping sound, and bleeding) and virginal behavior (shyness, sexual ignorance, and reluctance) into the sub-theme proof of virginity. Then, I reviewed and wrote detailed interpretations of all identified themes and sub-themes and validated these interpretations through the FGDs. Furthermore, notes from the FGDs and participant observation also helped guide the revised analysis.

Finally, I identified and grouped themes and sub-themes addressing the different research questions in the two qualitative papers (Papers I and II). Then with the help of the candidacy theory [239] (paper I), planned behavior [273], and sexual script [274] (paper II) as additional analytical lenses, I consolidated the analytical content of the themes and sub-themes into detailed and coherent accounts. Please see papers I and II for more details regarding why and how I used these exact theories.

3.2 The quantitative study

The hypothesis of the quantitative study stemmed from the literature review and the KAP framework [275], i.e., healthcare providers need proper training to acquire the knowledge and attitude necessary to provide quality healthcare to girls and women with FGC [2].

In Norway, GPs' role in managing FGC-related health problems is primarily limited to assessing whether the health problems could be related to FGC and eventually referral to the FGC-specialized clinics. Therefore, to identify factors influencing the attitudes and practices of GPs in Norway concerning assessing FGC as a potential cause of health problems (paper III), I used national survey data from a substudy in the Kjønslemlestelse-HelseVel. The substudy employed a cross-sectional design conducted between June and July 2019 using the University of Oslo's web-questionnaire system "Nettskjema."

3.2.1 Recruitment and participants

The project leader engaged the IQVIA Institute for Human Data Science (IQVIA) to help recruit the study participants. IQVIA had an e-mail list of 4100 GPs in Norway (out of 4774 registered GPs in 2019 [276]). Since these 4100 GPs had not reserved themselves against being contacted by the company, IQVIA sent them participation requests, including information about the study and a link to the online survey. Unfortunately, out of the 4100 e-mail addresses administered by IQVIA, 306 were no longer valid; hence, only 3794 GPs received a request to participate. To increase the response rate, IQVIA sent a reminder. Furthermore, the project leader and the study coordinator emailed the chief medical officers in all Norwegian municipalities requesting a further distribution of the study information and participation requests to local GPs. They also published information about the study in the Journal of the Norwegian Medical Association, three relevant websites, and relevant Facebook groups.

Nevertheless, only 223 completed the questionnaire, which constitutes a response rate of 5.8%. Furthermore, one respondent had missing data on all sociodemographic variables; hence was excluded from the analyses. Table 2. depicts the sociodemographic characteristics of the participants.

Table 2. Sociodemographic characteristics of participants in the cross-sectional survey among GPs in Norway

Variable		N =222 n	Percent (%)
Gender	**Female**	121	54,5
	Male	101	45,5
Age (years)	**< 30**	2	0,9
	30-39	61	27,5
	40-49	68	30,6
	50-59	41	18,5
	≥ 60	50	22,5
Location of practice	**Urban**	131	59,0
	Rural	91	41,0
Length of experience (years)	**≤ 5**	20	9,0
	6-15	81	36,5
	16-25	45	20,3
	26-35	51	23,0
	≥ 36	25	11,3
Country of medical training	**Norway**	160	72,1
	Abroad	62	27,9

3.2.2 Instruments

At the time of the study, no instruments (validated or otherwise) to assess the GPs' clinical practices in managing girls and women with FGC-related health problems were available. Therefore, based on an extensive literature review, the project leader and the coordinator of the substudy designed an online self-administered questionnaire (Appendix) with contributions from the project leader of the Kjønslemlestelse-HelseVel study, my supervisor, and me. Then, they piloted the questionnaire among seven GPs for clarity, adequacy, and relevance of questions and response alternatives, which resulted in minor adjustments to some questions and response alternatives.

In paper III, I have used data from the first two sections of this questionnaire that addressed the explanatory and outcome variables relevant to my study.

3.2.2.1 Outcome variables

The questionnaire did not include direct questions on the GPs' attitude or practices in assessing FGC as a potential cause of relevant health problems among girls and women living with FGC. Nevertheless, it included another essential question on affect, i.e., whether they feel discomfort talking to patients about FGC. The response alternatives for this question were yes, somewhat, and no. Therefore, I used this question as one of the outcome variables and dichotomized the response alternatives to yes (yes and somewhat) and no. The other outcome variables I included were four questions on the GPs' practices concerning whether they ask girls and women from FGC-practicing countries about their FGC status when they present with: 1) genitourinary problems, 2) during pregnancy, 3) with mental health problems, and 4) with sexual health problems. Again, I dichotomized the original response alternatives of yes, sometimes, and no to yes (yes and sometimes) and no.

3.2.2.2 Explanatory variables

From the literature review, I have identified four categories of variables (sociodemographic characteristics, training, knowledge, and experiences) that can explain variations in the GPs' attitudes (comfort/discomfort) and practices in assessing FGC as a potential cause of relevant health problems.

Sociodemographic variables

The sociodemographic variables included gender, age, length of experience, location of practice, and country of basic medical training (see table 2).

Training on FGC

I included three questions that assessed received training on FGC 1) whether they received any training on FGC during basic medical studies (hereafter undergraduate), 2) whether they received any training on FGC after completion of medical studies including specialization and continuous medical training (hereafter post-graduate), and 3) whether they received training on FGC-related health problems. These questions had the response alternatives yes, partly, and no, which I dichotomized to yes (yes and partly) and no.

Knowledge on FGC

I included four questions assessing knowledge on FGC 1) “are you in need of more knowledge on the WHO classification of the different types of FGM?,” 2) “are you familiar with the medical codes for FGM (ICD-10, or NCMP-NCPS-NCPR)?,” 3, “do you need to know more about the legislation related to FGM?,” and 4) “do you think you have adequate knowledge concerning the traditional and cultural meaning of FGM for affected women?.” These questions also had the response alternatives yes, partly, and no, which I again dichotomized to yes (yes and partly) and no.

Experience with patients with FGC-related health problems

The question assessing this variable was, “have you ever been consulted by women who had health problems related to FGM?” with the response alternative of yes and no.

3.2.3 Statistical analysis

I conducted descriptive analyses for the explanatory and outcome variables and presented the frequency and percentage results. To identify potential confounders of demographic characteristics, I compared each category of the explanatory variables by each demographic variable using the Chi-square test and binary logistic regression. Then, I examined the association between the outcome and explanatory variables through binary logistic regression analyses, adjusted for possible confounders, and looked for interactions between the explanatory variables. I also excluded missing data from these analyses.

Finally, I summarized the results from the binary logistic regression analyses using crude odds ratio (OR), adjusted odds ratio (aOR), p-value, and confidence interval (CI). Results with a p-value < 0.05 were considered statistically significant. All tests were two-tailed. I conducted all analyses using IBM SPSS statistics version 26.

4 Ethical considerations

Research projects' scientific and social value is the fundamental ethical justification for conducting any research project with human participants [277]. In other words, ethically justifiable research projects must contribute scientifically sound new information relevant to either the promoting of individuals or public health or the understanding or intervening on a significant health problem. Nevertheless, scientific and social values cannot justify violating the research participants' dignity or autonomy [277, 278]. Minimizing potential harm to the research participants, ensuring that their consent to participate is voluntary and well informed, and allowing them to withdraw from the study at any time are underlined as safeguards for the participants' dignity and rights in international [277, 279] and national regulatory documents [278].

In Norway, only medical and health research aiming to acquire new knowledge about health and disease falls under the mandate of the national regulatory document (the Health Research Act) [278]; and hence requires prior approval from a Regional Ethical Committee (REK). Still, the Norwegian Social Science Data Services (NSD) assesses health research that falls outside the Health Research Act. Accordingly, the project teams needed ethical approval from NSD for the pilot project [266] and REK for the Kjønslemlestelse-HelseVel project. Hence, before commencing both projects, we sent NSD and REK the research protocols and application forms highlighting the ethical considerations and safeguard measures. Subsequently, both applications were approved with a few modifications (see the Appendix); and I endeavored to address all ethical considerations per the approved and recommended safeguarding measures while conducting the pilot and Ph.D. studies.

I strived to enhance scientific quality (see section 6.1) and minimize potential harm so that the projects' scientific and social value outweighed possible risks [277]. The social value of the projects is to contribute knowledge that could potentially improve the offer and quality of FGC-specialized healthcare. On the other hand, as the qualitative study, in particular, posed potential risks to the participants, I paid special attention to mitigating these risks.

The qualitative study

The ethical considerations related to the qualitative study were ensuring informed consent, secure storage and handlings of data, and minimizing any potential risks.

With few exceptions, researchers are obliged to provide potential research participants with the information and the opportunity to make voluntary and informed decisions regarding whether to accept or decline to participate [277-279]. Furthermore, researchers should approach informed consent as a process and ensure that participants have the right to withdraw at any point in the study. Thus, keeping these ethical guidelines in mind, I prepared information letters and consent forms (see Appendix) for the pilot and Ph.D. studies in English, Norwegian, and Arabic. The information letters included the study objectives and social value, that participation was voluntary, they could choose where and when to meet, my intention to meet several times, and that they could withdraw from the study at any time. I also highlighted the types of research questions I would address and their autonomy in deciding what to share. Furthermore, I explained that I would request to take notes and audio-record the interviews, replace their names with codes, and store them in a locked cabinet for a maximum of five years before deleting the recordings and any non-anonymized information. Finally, following REK's recommendation, I also included information about Norwegian law and my legal obligation to report any information related to an imminent risk of FGC to the authorities.

Key persons at local immigrant organizations and networks, minority counselors, and other participants shared these information letters with potential participants. Still, once I established direct contact with the potential participants, I repeated this information verbally. I particularly emphasized that participation was voluntary, that they could withdraw from the study anytime, that the duty to avert supersedes the confidentiality code, assured them about the confidentiality of other information, and explained what confidentiality means and entails. Then, after I was sure that they fully understood the provided information, I asked for their written or verbal consent. Furthermore, I asked those who opted for verbal consent for permission to record their consent. Finally, since the Norwegian Health Research Act allows independent consent from 16 years, I did not need parental consent for participants aged 16-18 years.

The other ethical consideration I addressed in the qualitative study was minimizing potential risks for the participants, such as emotional distress, financial loss (e.g., fees to transportation or babysitters), and stigmatization. Using terminologies that the participants themselves used during the interviews and the FGDs was one of the measures I used to reduce potential emotional distress and internalized stigma. Nevertheless, as recalling and talking about FGC experiences could also cause the participants severe emotional distress, the Kjønslemlestelse-HelseVel project leader ensured access to a private psychologist free of charge for the participants whenever required. Fortunately, none of the participants were overly distressed during the interviews. Still, a few teared up, and I interrupted several interviews to confirm that the participants were alright, inform them about the free access to a psychologist, remind and assure them that we could take a break, stop or abandon the interview altogether if wished or needed. Nevertheless, these participants only opted for a 15-30 minutes break. Then, they consistently asked to resume the interview, and a few even said that they experienced the interviews as therapeutic.

To compensate for financial loss to the participants (e.g., transportation or babysitters fees and daily wages), I provided gift cards (the equivalent of 30 USD). Lastly, I addressed the risk of stigmatization that was highly relevant because, in the public debate on immigration and integration in Norway and other Western countries, anti-immigration participants often use research findings to justify or perpetuate their political agendas [280]. Therefore, consulting and incorporating stakeholders’ perspectives during the planning, implementation, and dissemination phases was one of the safeguards measures. Furthermore, I paid particular attention to respectful dissemination of the findings, including using the morally-neutral term FGC in the papers and this extended summary.

The quantitative study

The original plan for the quantitative study that REK had initially approved was to send the GPs the information letters, consent forms, and questionnaires via post. However, the project leader had modified this plan (due to logistical issues) and submitted a change request to REK, which was approved (see the Appendix). The modifications included an anonymous online survey (see the Appendix), where no identifiable information about the participants or their patients was requested nor stored. The approved changes also included hiring IQVIA to recruit potential participants by sending emails to the 4100 GPs who had not reserved against being contacted by the company. Accordingly, IQVIA emailed these GPs the background information and purpose of the study, informed them that the survey was anonymous, and invited them to participate via the included link to the online survey. Subsequent filling and submission of the survey indicated voluntary and informed consent.

5 Summary of the papers

5.1 Paper I - Barriers and facilitators to the access to specialized female genital cutting healthcare services: Experiences of Somali and Sudanese women in Norway

This paper aims to identify factors that hinder or facilitate access to the FGC-specialized services among Somali and Sudanese in Norway beyond the maternity context. Therefore, I explored and compared the perceptions and experiences of those who received FGC-specialized healthcare and those who did not. In particular, I explored their motivations, navigation decisions, and experiences of seeking medical attention for health problems potentially associated with FGC.

I adopted a definition of access in line with the candidacy theory [239], i.e., a dynamic process of negotiations between individuals and the healthcare system from the initial perception of need until reception of appropriate healthcare.

The participants were motivated to seek healthcare for problems that persisted despite self-management attempts, interfered with their ability to perform expected duties and roles, and caused severe pain. However, lack of knowledge on FGC-related health problems or a conflict between information and experiences, observations, and messages from doctors and peers hindered their identification of these problems as FGC-related; and hence whether to seek help at FGC-specialized clinics.

Instead, the participants booked appointments with their regular GPs, expecting the GPs to assess whether their health problems were FGC-related and provide appropriate assurance, treatment, or referral. However, most participants and their GPs mutually missed the opportunity to properly evaluate whether their health problems were related to FGC. For example, hindered by feelings of shame, embarrassment, and fear of judgment, only a few participants, had disclosed their FGC status to their GPs. Similarly, the GPs typically did not address FGC or link the health problems to FGC. Consequently, most participants concluded that the GPs lacked knowledge of FGC or that their health problems were not FGC-related. Still, the GPs often referred participants to gynecologists, who in turn referred them to FGC-specialized clinics.

At the FGC-specialized clinics, participants received offers of deinfibulation. Typically, sexual norms determined whether the participants accepted or declined these offers (paper II). Still, despite finding deinfibulation acceptable, some participants refused the procedure because of negative experiences with healthcare providers at these clinics. Overall, participants characterized their experiences as negative when they felt the healthcare providers disrespected them and did not appropriately address their fears and concerns regarding esthetics, retraumatization, and pain. In addition, negative experiences negatively affected the overall satisfaction with the FGC-specialized services also among those who accepted the deinfibulation offers.

In contrast, when the healthcare providers met them with respect, provided them with sufficient information about their health problems and deinfibulation, and involved them in the decision-making, the participants felt satisfied and had readily accepted offers of deinfibulation.

5.2 Paper II – Sexual norms and the intention to use healthcare services related to female genital cutting: A qualitative study among Somali and Sudanese women in Norway

This paper also contributes to specific objective 1, i.e., identifying factors influencing access to the FGC-specialized services among Somali and Sudanese in Norway beyond the maternity context. As almost all participants explained their intentions to use or not to use FGC-related healthcare interventions through different sets of social norms and expectations related to premarital and marital sexual conduct, this paper focuses on these sexual norms.

I identified four sexual scripts (distinct sets of sexual norms) influencing the intentions to use various FGC-related healthcare interventions. These scripts are 1) the virgin scenario, 2) the passive sexual partner scenario, 3) the conditioned active sexual partner scenario, and 4) the equal sexual partner scenario. These sexual norms seem to result from an interplay between norms in countries of origin, norms in Norway, and the expectations and attitudes of husbands and partners. In turn, this interplay seems to have led to a gradual change in sexual norms among the Sudanese participants from traditional norms (e.g., premarital chastity, marital sexual availability, and passive sexual behavior) to transitional ones (e.g., premarital chastity, marital sexual availability, yet active sexual behavior) and finally to gender equality norms (e.g., the irrelevance of premarital chastity and taking control over own sexuality). In contrast, the sexual norms among the Somali were more dichotomous with the total support of the traditional norms among older participants, yet the complete rejection of these norms and adoption of gender equality among many of the younger participants.

I further found that the sexual norms in the virgin and passive sexual partner scenarios negatively affect the intention to use all FGC-related healthcare interventions except for martial deinfibulation. In contrast, the equal sexual partner scenario positively influences the intention to use all these healthcare interventions. On the other hand, whereas the conditioned active sexual partner scenario positively influences the intention to use interventions that help to improve marital sexual lives, it negatively impacts the intention to use premarital interventions.

5.3 Paper III - Factors associated with general practitioners' routines and comfortability with assessing female genital cutting: A cross-sectional survey

This paper aims to identify factors influencing comfort/discomfort and routines of GPs in Norway concerning FGC assessment as a potential cause of health problems. It used survey data from 222 GPs in Norway and adopted a KAP theoretical framework. Thus, it first examined the distribution of the explanatory variables, i.e., sociodemographic characteristics, levels of received training, self-assessed knowledge, and experiences with patients suffering from FGC-related health problems. Similarly, it examined the distribution levels of the two outcome variables, i.e., comfort/discomfort and the routines of asking relevant patient groups about their FGC status when they present during pregnancy or with potential FGC-related health problems. Then it investigated the association between the explanatory and outcome variables.

Over half of the respondents were females, 30-49 years old, and had 6-25 years of experience after undergraduate training. Although two-thirds of the respondents had received training on FGC during undergraduate or postgraduate training, or both, only over half received training on FGC-related health problems. Around four-fifth claimed adequate knowledge on cultural aspects of FGC but inadequate knowledge on FGC medical codes and a need for more knowledge on FGC typology and legislation. Furthermore, one-third had experiences with patients with FGC-related health problems, and slightly over half felt discomfort talking about FGC. Finally, around one-fifth never asked relevant patient groups about FGC when presenting during pregnancy or with genitourinary and sexual health problems, and slightly less than half never asked when patients presented with mental health problems.

Female respondents were more likely than male respondents to have FGC training and experience with patients with FGC-related health problems. Similarly, they were more likely to ask relevant patients groups about their FGC status during consultations concerning pregnancy and genitourinary and sexual health problems. Length of experience and age were positively associated with asking relevant patient groups about their FGC status when presenting with mental health problems. Moreover, any postgraduate FGC training and training on FGC health problems, knowledge of FGC medical codes, and experience with FGC-related health problems were positively associated with asking about FGC status during pregnancy and consultations for genitourinary, sexual, and mental health problems.

After adjusting for other explanatory factors, female GPs were less likely than their male counterparts to ask about FGC status when the patients presented with mental health problems. Feeling discomfort talking to patients about FGC was significantly higher among GPs reporting a need for more knowledge on FGC typology and significantly lower among those with knowledge of FGC medical codes. Furthermore, experience with FGC-related health problems and knowledge of FGC medical codes were positively associated with GPs asking relevant patient groups about their FGC status during consultations concerning genitourinary, mental, and sexual health problems.

6 Discussion

6.1 Methodological discussion

This doctoral dissertation is mixed-methods research that combines a qualitative and a quantitative study to expand the research inquiry and investigates the different components necessary to better understand factors influencing access to FGC-related healthcare services in Norway beyond the maternity context. Nevertheless, since I analyzed both studies independently, it is not a given conclusion this constitutes a mixed-methods design. For example, some researchers accept a lack of integration between a qualitative and a quantitative study during data analysis when mixing the methods aims to expand the scope and range of the research inquiry [281] (e.g., this doctoral thesis). On the other hand, other researchers require integration between the qualitative and quantitative components at the level of data analysis in a mixed-methods design [264]. Whether the mixed-methods research fits into the currently available typologies of mixed-methods designs or not, pragmatic scholars suggest using methods-specific quality criteria to evaluate the overall research [265]. That is because while pragmatism approaches knowledge as a construct based on the reality of the world we experience and live in [264], it acknowledges that some accounts are more authentic than others [264, 265].

6.1.1 Trustworthiness of the qualitative data

Guba's trustworthiness criteria [282] are probably the most influential criteria for evaluating the quality of qualitative research. For example, checklists such as the Consolidated criteria for reporting qualitative research (COREQ) [283], developed to ensure qualitative research reporting quality, seem to have incorporated Guba's trustworthiness criteria.

Guba (1981) [282] proposes four criteria: credibility, transferability, dependability, and confirmability. These four criteria correspond to established standards within the quantitative methods, such as internal validity, external validity (generalizability), reliability, and objectivity. Nevertheless, Guba adapts his proposed criteria to different epistemological assumptions than those underpinning their quantitative counterparts. For example, instead of assuming that researchers can maintain an objective distance from the research 'objects,' Guba asserts an unavoidable interrelation between the researcher and the participants. Similarly, instead of assuming that knowledge/research findings are context-free and generalizable, he approaches them as working hypotheses bound to contexts. He also disregards the notion that researchers could eliminate all confounders, ensuring that the findings truly represent the phenomenon/research focus.

Instead, he proposes taking certain actions to reach a credible representation. These actions include prolonging the engagement with the participants (e.g., repeat interviews and participant observations) and discussing initial analysis with other researchers, cross-checking data and interpretations using different data sources (e.g., interviews, participant observations, etc.), and theoretical perspectives. Still, the most crucial action to enhance credibility is checking the initial and near-final interpretations with other source group members (i.e., members of the group from which the participants were selected).

In the qualitative study, I took most of these actions to enhance the study's credibility. For example, I established trust and better understood the research topic by prolonging my engagement with the participants through repeat interviews and participant observations. Although not included in the recommended actions, I argue that I also gained the participants' trust by carefully explaining the concepts of confidentiality and anonymity, as most were unfamiliar with these concepts or had experiences in home countries with doctors breaching patients' confidentiality. Moreover, I repeatedly discussed codes and themes with my supervisor, used insights from the participant observations to inform the data analysis, and member-checked my interpretations with the participants and members of the source group during the data collection (repeat interviews) and afterward (validation focus groups). Finally, I repeatedly checked for contradicting opinions and experiences in both the data and my interpretations until I reached an interpretation that could explain these contradictions (e.g., the conditioned active sexual partner scenario in paper-I).

Acknowledging that the findings are context-bound [282], I provided a thick description of the Norwegian health policies, healthcare system, and FGC-specialized services, enabling others to decide whether my findings are transferable to their settings. I also used purposeful sampling [282, 284] to maximize the data's range of perspectives and experiences. Nevertheless, all Somali participants were fluent in either English, Norwegian, or Arabic, i.e., I did not interview participants who only spoke Somali, and their perspectives and experiences are therefore absent in this dissertation.

Unlike reliability, dependability is not concerned with data stability [282]. Instead, it accounts for the instability linked to the researcher as the research instrument through triangulation of methods, letting two separate research teams develop and cross-check the developing insights, and providing a comprehensive record of the methodology. However, while I have used both repeat-semi-structure interviews and participant observations, my purpose with the latter was not to collect comparable data but rather to inform the interview guide and the analysis. Furthermore, although I have discussed the coding strategy and early interpretations with my supervisor, she did not code or analyze any of the interviews. Nevertheless, I have provided in section 3.1 a detailed record of the methodology.

Finally, confirmability accounts for the researcher's influence on the generation and interpretations of the data [282]. In qualitative research, it is inherent that the researcher's background and position influence each step of the study process, from selecting the study scope and methods up to the framing and communication of conclusions [285]. Therefore, attempting to attain objectivity would be unrealistic and unachievable, i.e., eliminating the researchers' influence on the findings. Instead, researchers should incorporate different perspectives (e.g., purposeful sampling and theoretical triangulation). More importantly, researchers should provide a detailed account of their epistemological assumptions, personal characteristics, preunderstandings, and relationship with the participants (i.e., reflexivity). As I have already clarified my ontological and epistemological positions in this dissertation, I focus on the rest in the following subsection.

6.1.1.1 Reflexivity

Personal characteristics and preunderstanding

I am a female Sudanese doctor who migrated to Norway in 2007 to join a master's program in international community health at the University of Oslo. During my childhood and early adolescence in Sudan, a country with a high prevalence of FGC, my knowledge of FGC was surprisingly limited. It stemmed mainly from the stories of schoolmates bragging about their cutting ceremonies and mothers threatening their daughters or other females, whenever angry, with circumcision, regardless of whether these girls or women were circumcised or not. I remember that I was puzzled at the time by such contradictions. Was circumcision a punishment or a celebration? Still, I did not care enough then to pursue an answer.

Only at medical school have I started to grasp the extent of cutting involved and the health complications. Further discussions with other female medical students (from various social classes, ethnicities, and regions) also helped me understand the different motivations behind FGC. We often concluded such discussions, conceding that infibulation was gruesome, but the sunna type was harmless (referring to type 1a). After graduation and during my rotation in the obstetrics department, my firsthand experiences of the challenges/complications faced by infibulated women consolidated my theoretical knowledge and anti-infibulation moral stand. Nevertheless, in the next nine years, my research interests were in a different field, including the first four years after I have moved to Norway. The heated discussion in Norway on FGC eventually got me re-engaged. Still, despite being firmly against subjecting minors to any form of FGC, I was not convinced by experts/activists' explanations of how type 1a could cause many of the health complications often listed in scientific and non-scientific lectures and seminars. However, I have since changed my opinion.

Meeting women with type 1a with potential FGC-related health problems during various seminars on FGC in Oslo had triggered my curiosity. Thus, I spent considerable time examining the literature on health complications related to type I following these encounters. Even though the quality of the scientific evidence was suboptimal, the medical explanation of how such complications (e.g., obstetrical complications or dyspareunia) could be associated with this type was pretty plausible (e.g., adhesions, large cysts and keloids, entrapment of nerves, etc.).

Consequently, health complications and healthcare were my primary research interests when I joined the FGC research team at NKVTS in 2014. Since then, my knowledge of the topic has tremendously expanded. Furthermore, my understanding of knowledge gradually shifted from objectivism towards constructionism, probably influenced by my medical anthropologist supervisor and mentor.

My relationship with the participants

Researchers' position during the research process largely influences how and what they can capture and understand [270]. Thus the concept of 'productive distance' describes an ideal researcher's position where the researcher is not too close to the research participant to the degree of fusion, nor too distant to the level of alienation.

Keeping the concept of 'productive distance' [270] in mind, I have strived to establish a relationship of mutual respect and trust. Further, I have anticipated that both the Sudanese and Somali participants would perceive me as an "insider" [286] and thus find it easy to communicate their perceptions and experiences. Further, as the interviews with the Somali participants were either conducted in Arabic, English, or Norwegian rather than Somali, I thought attaining a productive distance position would be easier with the Somali participants. However, I was concerned that Sudanese participants might be reluctant to freely share their opinions and experiences in fear of gossip and judgment. Moreover, most participants were either unfamiliar with or skeptical of the concepts of confidentiality. Hence, I repeatedly clarified these concepts and what data I would share with others, emphasizing the punitive repercussions I could face if I breached confidentiality.

Subsequently, my experience with both the Sudanese and Somali was that my position as an insider/outsider was not static but somewhat fluid. Both Sudanese and Somali participants seemed to perceive me as someone who shared experiences and understanding of cultural nuances and knowledge of FGC. Still, the Somali participants seemed to view me as an outsider, to the degree that they could share sensitive data about conflicts with their family members without being afraid of gossip. Moreover, a few young Somali participants seemed to see me as a 'safe' counselor/confidant who could guide them through their non-FGC-related conflicts with their parents. Finding the right balance between providing the necessary help to these young and vulnerable girls while keeping a professional distance has been a continuous struggle.

Similarly, I realized that the Sudanese had regarded me as partly an outsider because of my lifestyle choices (e.g., the way I dress and that I was married to a Norwegian). Further, my clarifications regarding confidentiality helped create what I experienced as a good balance between distance and closeness. Finally, my medical background further facilitated trust and openness around health problems and intimate sexual experiences that the participants said they had not previously shared with anyone because of shame and embarrassment.

6.1.2 Validity and reliability of the quantitative data

As mentioned above, the criteria researchers use to evaluate the rigor of quantitative studies stems from realist ontology and objectivism theoretical assumptions. These criteria are internal and external validity and reliability.

Internal validity and reliability

Internal validity addresses whether the study has established a trustworthy cause-and-effect relationship between the explanatory and outcome variables, i.e., the researchers have ruled out all alternative explanations of the findings [183, 184, 287]. Thus, researchers must first use a suitable research design to establish a cause-effect relationship, such as randomized clinical trials and prospective cohort studies. For example, the best design to test my hypothesis for the quantitative study would have been an intervention study with two groups of GPs randomly allocated to intervention (training on FGC) or a control group (no training). Then tested at baseline and over time, measuring their knowledge, attitudes, and practices relevant to the care of women with FGC-related health problems. Nevertheless, as mentioned in section 1.2.1, such studies are expensive and time-consuming, which was essentially why a cross-section design was employed instead. This trade-off between resources and a research design suitable for establishing cause-effect meant that I could only establish associations and not conclude causal relationships.

Other considerations relevant to the internal validity of the quantitative study include measurement error, self-reported variables (information and social desirability bias), and controlling for other explanatory variables (confounding).

Measurement error occurs when the measuring instrument (e.g., a questionnaire) could not accurately measure the variables [184]. To safeguard against such an error, researchers must validate or use a validated instrument. Typically, researchers need to assess the validity (i.e., to which degree the instrument could measure what the researchers intend to measure) and reliability (i.e., the instrument's ability to produce the same results under the same conditions). As no relevant, validated instruments were available at the time, the project leader and the project coordinator of the quantitative study developed the questionnaire. They then tested its content validity among seven GPs. Nevertheless, they did not test the questionnaire a second time among the same seven GPs to assess its ability to produce similar measures at both time points (i.e., test-retest reliability).

The second set of considerations relevant to the study's internal validity is information and social desirability bias associated with self-reported measures. Information bias is particularly relevant to self-assessed knowledge as healthcare providers do not always assess their knowledge accurately [38, 288]. On the other hand, using a self-administered online questionnaire could have mitigated the social desirability bias.

The last internal validity consideration is confounding. I have adjusted for all alternative explanatory variables (e.g., sociodemographic characteristics and experience with women with FGC-related health problems) that I identified in the literature. Nevertheless, I cannot rule out the possibility of residual confounding.

External validity

External validity refers to the generalizability of the findings to the target population [183, 184, 287]. Sample selection, response rate, and selection bias can affect external validity.

The sample was selected from a nationwide source population of 4100 GPs in Norway who allowed a certain company (IQVIA) to contact them by email. This source population constituted 79.5% of all GPs in Norway in 2019 [276]. Nevertheless, despite various attempts to increase the response rate, only 5.6% completed the questionnaire. This low response rate challenges the external validity of the findings. Moreover, although the participants' gender and age distribution were close to that of the target population [276], I cannot rule out the possibility of selection bias. Self-selection bias of GPs with experience with FGC-related health problems being more interested in participating is possible. Nevertheless, as the questionnaire was self-administered online, the participants were completely anonymous and could not be contacted to ask about reasons for non-participation. However, it is most likely that the low response rate was partly due to collecting the data during the summer holiday.

6.2 Discussion of the findings

This doctoral thesis aims to better understand factors influencing access to FGC-related healthcare services in Norway beyond the maternity context. Hence, paper-I provided an overview of barriers and facilitators to access to FGC-specialized healthcare as perceived and experienced by Somali and Sudanese participants. Paper-II zoomed in on the role of sexual norms in identifying health needs and seeking and accepting healthcare. Finally, Paper-III picked up on the mutual silence on FGC during participants' GPs consultations in paper-I. Thus, it investigated factors associated with GPs' comfort/discomfort and routines of asking about patients' FGC status when relevant patients groups present with potential FGC-related health problems. As I have individually discussed the main findings in each paper, this section presents a holistic discussion of major themes.

6.2.1 Health problems as a negotiated construct

The qualitative study highlighted how health problems for the participants were not objective identification of suffering but rather a construct of effect on daily life. For example, some participants only perceived not experiencing orgasm as a sexual health problem when it intervened with their roles as good wives (conditioned active sexual partner scenario). Moreover, researchers found predominant discourses in Western countries on FGC, gender, and sexuality to strongly influence women's perceptions of their genitals and sexuality, leading to a sense of inferiority and insufficiency [56, 261]. In turn, internalized stigma and low self-esteem contribute to an increased risk of psychological and sexual health problems among girls and women with FGC in these countries [23-27, 178, 179].

In Norway, the main aim of health information on FGC-related health problems is FGC prevention [241-243]; hence the provided information encompasses all possible health problems indiscriminate of FGC types or available healthcare interventions. In particular, participants repeatedly received information on FGC-related sexual health problems in the absence of sexual healthcare interventions (e.g., counseling), which frustrated them immensely. My findings partly confirm that many internalized the health information on FGC-related sexual health problems but still showed that was not necessarily typical for all (e.g., the passive sexual partner scenario).

Overall, participants did not identify their health problems as FGC-related unless their acquired knowledge on FGC-related health problems resonated with their understanding and experiences of suffering, shaped mainly by sexual norms. For example, despite receiving information on genital cysts as FGC-related health problems, only participants with personal experiences and interpretations of these cysts as medical problems seemed to internalize this information and endorse the possible link to FGC. Therefore, health information-based intervention to help individuals make appropriate healthcare decisions [289] might not be sufficient for some women with FGC-related health problems. To secure adequate healthcare for these women, healthcare providers need to take an active role in assessing the health problems and enabling the women to make informed healthcare decisions.

However, Norwegian health policies [244] and the organization and delivery of services for girls and women with FGC [66] seem to assume and expect health information on FGC-related health problems and healthcare services would help these girls and women to identify their problems and FGC as a cause, and seek the proper healthcare. Thus, there seems to be a mismatch between available services, the expectations and assumptions underpinning the Norwegian FGC-related healthcare policy and services, and the factors influencing the women's identification of health problems and their motivation and decisions in seeking healthcare.

6.2.2 GPs: the lost opportunity

The qualitative study indicated that a mutual silence on FGC during consultations between women and their GPs resulted in losing an early opportunity to assess whether their health problems were related to FGC. It also explained the women's silence as a product of embarrassment, shame, and fear of judgment. It depicted that the women preferred and expected the GPs to raise the topic if medically relevant. Similar patterns of mutual silence, shame and fear of judgment, and preference for the healthcare providers to ask about FGC have been reported in various studies [51, 56, 63, 67, 263, 290-292]. However, only a few were from non-maternity settings [263, 291, 292]. I could identify only one other paper addressing silence on FGC from the perspective of GPs [293]. This paper was based on qualitative data highlighting various concerns GPs in the UK had related to how, when, and with whom to talk about FGC. They were afraid of offending women, breaching cultural sensitivities, or triggering traumatizing memories. Hence, they preferred to ask women about their FGC status only in the context of potentially FGC-related health problems. However, the quantitative study in this doctoral thesis has shown that many GPs also do not ask the women about their FGC status in the context of potentially related health problems. Knowledge of the different types of FGC and relevant medical codes and experience with patients with FGC-related health problems were the main factors influencing whether the GPs felt comfortable talking about FGC or had asked the women about their FGC status when medically relevant.

In Norway, several FGC-specialized clinics exempt women with FGC from the otherwise required referrals from GPs, which could explain the apparent marginalized role of GPs in the care for women with FGC. However, this doctoral thesis has shown that women still contact their GPs rather than FGC-specialized clinics for potential FGC-related health problems. Furthermore, the silence on FGC had resulted in referrals to gynecologists rather than FGC-specialized clinics. Unfortunately, this meant that the women had to wait for several months for the specialists' appointments and endure negative encounters during vaginal examinations from gynecologists not familiar with FGC.

6.2.3 A non-informed consent?

After surpassing the silence on FGC during consultations with the GPs and shock and judgment with the gynecologists, some women were satisfied to meet compassionate healthcare providers at the FGC-specialized clinics who showed extensive knowledge and competence in FGC and addressed their deinfibulation-related fear and concerns.

Although per sexual norms, these women found deinfibulation acceptable, they wanted reassurance that it would alleviate their health problems, i.e., avoid unnecessarily deinfibulation. Furthermore, they were afraid the healthcare providers might judge them, and that deinfibulation would make their vulva “a gaping hole” and be as traumatic as their childhood circumcision. The latter concern stemmed primarily from perceiving deinfibulation as another extremely painful cutting of their genitalia that would bring back memories of extreme helplessness, fear, and painful urination. Several studies found similar concerns also within the maternity context [56]. Similarly, a previous Norwegian study [64] found that whereas healthcare providers viewed deinfibulation as “just a little incision,” women perceived deinfibulation as a more profound procedure. In addition, a few of the participants satisfied with the FGC-specialized clinics were first hesitant about deinfibulation, fearing it would compromise their virginity/proof of virginity, but had undergone deinfibulation following adequate clarifications and reassurances. In contrast, some women had refused to undergo deinfibulation primarily because the healthcare providers failed to address their fears and concerns. These findings highlight that women could not make informed decisions about their healthcare without comprehensive information that addresses their fears and concerns.

Besides the negative experiences concerning this lack of sufficient information, some women were dissatisfied with not getting enough time to decide whether to undergo deinfibulation. They felt pressured to undergo deinfibulation during what they had thought was an initial consultation. The healthcare providers' arrangement of deinfibulation on first-time consultations could be explained by their fear that the women would not return for deinfibulation if they postponed the procedure for a later appointment [294].

Furthermore, some participants felt deprived of the opportunity of joint decision-making concerning pain management. For example, women who feared emotional distress and pain expressed a desire for general anesthesia. Hence, they felt disempowered and disrespected when the healthcare providers dismissed their fears and referred to deinfibulation as a minor procedure only requiring local anesthesia. Similar disempowering experiences from different Western countries were also identified in a systematic qualitative review [56].

Regardless of negative experiences concerning lack of information and autonomy, women who underwent deinfibulation at the FGC-specialized clinics for non-maternity purposes were satisfied with the positive effects on the problems that had motivated their health-seeking, such as sexual and menstrual pain and cysts. In addition, they were happy to experience unexpected improvements regarding urination, vulvar itching, and sores, as well as increased sexual pleasure. Women who underwent deinfibulation in an FGC-specialized clinic in the US for non-maternity purposes were similarly satisfied with the effect of deinfibulation on their symptoms and sexual function [295].

Nevertheless, there is still a need to prevent such negative experiences as the healthcare providers' lack of addressing the women's fears, and concerns had hindered their access to proper care. Equally important, they undermined women's right to autonomy, informed consent, and involvement in decision-making related to their healthcare anchored in the Norwegian Patients' Rights Act [255] and recommended in the WHO's and national gynecological guidelines [2, 3, 258].

6.2.4 Specialized or mainstreamed services?

Whether to organize the healthcare delivery services for immigrants as separate or mainstream services is an ongoing debate in Europe [234]. On the one hand, separate services empower immigrants and provide more targeted healthcare but can cause or accentuate anti-immigrant sentiments. Furthermore, separate services are vulnerable to political prioritizations regarding funding. On the other hand, mainstream services would strengthen social solidarity and ensure a unified national healthcare system. Nevertheless, FGC is exclusive to minority groups, and healthcare providers mostly lack knowledge and competence in FGC. Thus, one could argue that mainstreaming FGC-related healthcare services would not be cost-effective.

In Norway, FGC-related healthcare services are a separate specialized offer for girls and women with FGC. Furthermore, this offer is provided at the women's outpatient clinics in seven major hospitals, i.e., integrated into the national healthcare system. Hence not as vulnerable to political agendas as other separate services. However, these FGC-specialized clinics do not treat mental or sexual health problems other than sexual problems related to penetration difficulty among infibulated women [29, 258]. Yet, the qualitative study showed that many participants had numerous potential FGC-related health problems, including sexual and mental health problems.

Therefore, women with sexual health problems or mental health complaints associated with FGC would have to seek help at mainstream services lacking competence in FGC [28]. Furthermore, evidence indicates that the Norwegian mainstream mental healthcare services are hard to access for women from SSA countries, particularly those with FGC [65]. In addition, the mainstream services are unlikely to have the right competence to provide the pre-and postoperative counseling that the WHO's guidelines recommend for women undergoing deinfibulation [3]. In other words, women with FGC in Norway have unmet psychological and sexual healthcare needs.

Unfortunately, neither are such services commonly available in other Western countries [28]. Still, several Western countries provide psychological and sexual counseling for women with FGC primarily as a part of a multidisciplinary approach for women considering clitoral reconstruction after FGC [28, 296-298]. Exceptions for providing such services beyond the context of clitoral reconstruction include FGC-specialized clinics in the UK dedicated to non-pregnant women [298]. These clinics adopt a model of women-centered care and offer psychological counseling not only for women undergoing deinfibulation but also for women with other FGC types. Findings from a retrospective service review at one of these clinics indicate a high demand for psychological counseling, particularly among women with FGC types I and II.

7 Conclusion: implications and recommendations

This doctoral dissertation has identified several factors influencing women’s access to appropriate FGC-related healthcare.

First, it highlighted how the women were uncertain whether their problems were caused by FGC, which is understandable since many other possible medical explanations exist. Therefore, I suggest that the GPs, the per facto gatekeepers to the FGC-specialized services, should be responsible for the diagnosis and not the women. Furthermore, as knowledge on FGC health problems, typology, and medical codes were the main factors influencing practice and comfortability with assessing FGC as a differential diagnosis whenever relevant, it is crucial to provide them with comprehensive training prioritizing such knowledge.

The doctoral dissertation has also shown how sexual norms are both drivers and hindrances of seeking and accepting FGC healthcare interventions. Furthermore, it showed that Somali and Sudanese women had unmet needs for psychosexual counseling. Therefore, it is commendable that the primary measure in the current action plan is to evaluate the national healthcare offer on FGC. Similarly, it is a good sign that the action plan finally highlighted psychosexual problems in the context of healthcare. Thus, instead of recommending offering psychosexual healthcare to girls and women with FGC, I limit my recommendation to the organization of these services once provided. Based on the current evidence, a holistic healthcare offer at the FGC-specialized clinics would be the best alternative.

Other factors influencing women’s access to appropriate FGC-related healthcare included positive and negative healthcare experiences with the FGC-specialized clinics. Many healthcare providers at the FGC-specialized clinics are key contributors to the national gynecological guidelines on FGC, which recommend measures to address most of my findings regarding participants' concerns and fears. Thus, it is unlikely that the negative experiences that the participants had described are due to insufficient knowledge and competence in FGC. Nevertheless, ensuring a systematic implementation of the guidelines would help grant women their autonomy and informed consent rights and improve their healthcare experiences.

Since this dissertation focused on access to the FGC-specialized services with deinfibulation as the primary intervention, future research should explore the healthcare needs of girls and women with other types of FGC.

A final recommendation is a call for quantitative researchers to let findings from qualitative studies, including this dissertation, inform the development or validation of instruments measuring health complications on FGC. For example, as demonstrated in this doctoral thesis, sexual norms viewing sexual intercourse as husbands’ right render some women unable to say no. Thus, instruments that include questions about the frequency of intercourse as a proxy for desire would be invalid among these women. Another example is menstrual pain. Several qualitative studies, including mine, suggest that FGC-related menstrual pain is experienced as severe pressure pain at the vulva. Therefore, assessing the association between FGC and menstrual pain without taking account of such specifications would affect the findings.

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Part II – papers I –III

I

PLOS ONE

RESEARCH ARTICLE

Barriers and facilitators to the access to specialized female genital cutting healthcare services: Experiences of Somali and Sudanese women in Norway

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Abstract

Background

Girls and women subjected to female genital cutting (FGC) risk experiencing obstetrical, gynecological, sexual, and psychological health problems. Therefore, Norway has established low-threshold specialized healthcare services where girls and women with FGC-related health problems can directly seek medical attention. Nevertheless, we lack data about access to these services, especially for non-maternity-related purposes. In this article, we explore experiences of seeking medical attention for health problems that are potentially FGC-related, aiming to identify factors that hinder or facilitate access to FGC-specialized services.

Methods

We conducted a qualitative study in three Norwegian cities employing semi-structured repeat interviews with 26 girls and women subjected to FGC, participant observation, and three validation focus group discussions with 17 additional participants. We thematically analyzed the data and approached access as a dynamic process of interactions between individuals and the healthcare system that lasts from an initial perception of need until reception of healthcare appropriate to that need.

Findings

We identified several barriers to healthcare, including 1) uncertainty about FGC as a cause of experienced health problems, 2) unfamiliarity with FGC-specialized services, 3) lack of assessment by general practitioners of FGC as a potential cause of health problems, and 4) negative interactions with healthcare providers. In contrast, factors facilitating healthcare included: 1) receiving information on FGC-related health problems and FGC-specialized services from a non-profit immigrant organization, 2) referral to gynecologists with good knowledge of FGC, and 3) positive interactions with healthcare providers.

Citation: Ziyada MM, Johansen REB (2021) Barriers and facilitators to the access to specialized female genital cutting healthcare services: Experiences of Somali and Sudanese women in Norway. PLoS ONE 16(9): e0257588. https://doi.org/10.1371/journal.pone.0257588

Editor: Nülüfer Erbil, Ordu University, TURKEY

Received: April 7, 2021

Accepted: September 5, 2021

Published: September 17, 2021

Data Availability Statement: All relevant data are within the manuscript.

Funding: MMZ received funding from the research council of Norway (https://www.forskningsradet.no/en/) for the project number 262757. REBJ received no specific funding for this work. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests: The authors have declared that no competing interests exist.

Conclusion

Assessing whether FGC is the cause for experienced health problems requires diagnostic competency and should not be left entirely to the patients. We recommend that Norwegian policymakers acknowledge the central role of GPs in the clinical management of patients with FGC-related health problems and provide them with comprehensive training on FGC.

1 Introduction

Migrant health and equitable access to healthcare for migrants are gaining importance in many European countries [1,2]. In this article, we explore healthcare-seeking experiences in Norway related to female genital cutting (FGC).

The World Health Organization (WHO) defines FGC, also known as female circumcision and female genital mutilation (FGM), as all procedures that involve the partial or total removal of the external female genitalia or other injuries to the female genital organs for non-medical reasons [3]. The WHO further classifies FGC into four types. The first three increase in severity from the partial or total removal of the clitoris in type I to the sealing of the vulva except for a small hole for passing both urine and menstrual blood in type III (infibulation). On the other hand, the fourth type (IV) includes all other harmful procedures to the female genitalia, including practices such as pricking and piercing.

FGC is prevalent in 30 countries in Africa, Asia, and the Middle East, with over 200 million girls and women estimated to have undergone the practice [4]. Migration from these countries to other parts of the world has resulted in a minority population affected by FGC in Europe [5–8], the USA [9], Australia [10], and Canada [11]. In Europe, over half a million immigrant girls and women had undergone FGC, of which around 17,000 live in Norway [5,7].

FGC exposes affected girls and women to a series of physical and psychological health problems throughout their lives [12–16]. The frequency and severity of these problems vary according to FGC type and specific conditions under the procedure, including hygiene, anesthesia, anatomical knowledge of the circumciser, etc. [17]. Both the clitoris and its surrounding genital tissues have a dense nerve and blood supply [18]; hence injury or damage to these tissues could cause immediate complications such as severe pain, urinary retention, bleeding (hemorrhage), and hemorrhagic shock [3,12]. In the long-term, the injury to either the clitoris, the surrounding tissues, or both could lead to the formation of inelastic scar tissue, keloids, cysts, and neuromas [12,16]. These conditions, together with the obstruction of the vaginal and urethral opening in type III, causes a series of physical health problems, including increased risk of cesarean section, episiotomy, perineal tears, postpartum hemorrhage, stillbirths, urinary- and reproductive- tract infections, prolonged and painful urination, menstrual problems, difficult and painful sexual intercourse, and reduced sexual desire and satisfaction [12–14,19–23]. Furthermore, pain and trauma could lead to psychological health problems, including mental health problems (e.g., irritability, sadness, anger, distress, flashbacks and nightmares, low self-esteem, and relationship problems) and mental health disorders such as depression, anxiety disorders, and post-traumatic stress disorder (PTSD) [14,24–27]. In addition, recent evidence indicates a possible association between stigma and low self-esteem and an increased risk of psychological and sexual health problems among girls and women with FGC living in countries of migration where the majority population has negative attitudes towards FGC [19,28–31].

Consequently, girls and women subjected to FGC might need specialized healthcare such as sexual and psychological counseling, removal of cysts, and deinfibulation [16]. Deinfibulation is a minor surgical procedure whereby healthcare providers release the infibulation seal to expose the vaginal and urethral openings [32–35]. Although healthcare providers mostly perform deinfibulation during pregnancy or childbirth, they can also conduct it for non-obstetrical reasons such as easing the urinary and menstrual flow, facilitating penetrative vaginal intercourse, and reducing sexual pain.

In Norway, specialized healthcare services for FGC-related health problems are primarily deinfibulation and removal of cysts [36,37], available at the specialist healthcare level at all central women's outpatient departments.

Typically, access to Norwegian specialist healthcare would require a referral from healthcare providers at the primary healthcare level, primarily general practitioners (GPs) [38]. GPs characteristically provide regular, emergency, or acute healthcare services at their medical practices (within office hours) or urgent care centers (after hours). Therefore, all residents are entitled and encouraged to register with a regular GP to ensure both primary care and referrals whenever necessary. In addition, specialists could issue referrals to other specialist healthcare services. Patients commonly pay a subsidized consultation fee when visiting their GP, the urgent care centers, and outpatient healthcare specialists. Co-payments vary between 18 USD per visit for regular GP and 40 USD for outpatient healthcare specialists.

To increase the accessibility of the FGC-specialized services, some hospitals have exempted girls and women with FGC-related health problems from the otherwise required referral and allowed them to contact their women's outpatient departments directly. Nevertheless, two recent studies [39,40] at two of these outpatient departments identified only 358 girls and women as patients attending FGC-related services during a 10–12 years period. It is noteworthy that these two outpatient departments are located in two large cities (Oslo and Trondheim) that accommodate a high number of immigrants originating from FGC practicing countries [41]. Furthermore, the vast majority of these 358 girls and women did not take direct contact but were referred by other healthcare providers [39,40]. Besides the complaints given as reasons for referral, many of these girls and women were found to have numerous genitourinary and sexual problems that they did not seek help for previously. Therefore, it does not seem that exemption from referral had increased the accessibility of FGC-specialized services for the target group. Unfortunately, we do not know enough about factors that hinder or facilitate their journey while seeking medical attention at the FGC-specialized services, especially for non-maternity-related purposes. We realize that some women prefer deinfibulation during childbirth rather than in the second trimester [40]. We also know that some girls find premarital deinfibulation unacceptable because it contradicted some sexual and cultural norms [42–44]. A very recent study [45] gave new insights on other barriers to help-seeking and access to healthcare that 13 girls and women subjected to FGC had experienced in Norway. Identified barriers included lack of information on both FGC-related health complications and healthcare services, avoidance of disclosing FGC-related health problems to healthcare providers because of shyness and shame, insufficient knowledge of FGC among healthcare providers, and healthcare providers being more concerned about the criminal aspects of FGC than the women's healthcare needs. Still, we need to know more about the experiences of girls and women who managed to receive medical attention at the FGC-specialized services in Norway: *What motivated these girls and women to seek medical attention*? *Why did they not contact the FGC-specialized services directly*? *Where did they seek medical attention before referral to FGC-specialized services*? *What barriers, facilitators, or both did they encounter while seeking medical attention for FGC-related health problems*? *How did their experiences differ from those who did not receive medical attention at the FGC-specialized services*?

Understanding the barriers and facilitators encountered by the target group to access FGC-specialized services could guide healthcare providers and health authorities to improve the current services and ensure equitable healthcare for this minority group. This article aims to identify factors that hinder or facilitate access to the FGC-specialized services among Somali and Sudanese subjected to FGC. We explore the experiences of those who did and those who did not receive medical attention at the FGC-specialized services. As most research on access to healthcare has been on maternity-related issues, we limit our focus to our participants' non-maternity-related healthcare experiences.

1.1 Theoretical framework

Access to healthcare is an essential yet ambiguous concept with wide variations in its interpretation and conceptualization in existing literature [46]. Two recent and popular conceptualizations on access to healthcare are Levesque et al. (2013) conceptual framework [46] and Dixon-Wood et al.'s (2005) candidacy theory [47]. Both conceptualizations approach access as a dynamic process of interactions between individuals and healthcare systems, starting with the individuals' perceptions of a need and culminating with healthcare responding appropriately to this need. Levesque et al. (2013) frame access as the result of the interaction between five characteristics of the population and five characteristics of the healthcare system. The five characteristics of the population include the ability to: perceive healthcare needs, seek healthcare, reach, pay, and engage with healthcare services. Correspondingly, the healthcare system characteristics include approachability, acceptability, availability and accommodation, affordability, and appropriateness of the healthcare services. They suggest that health literacy and beliefs about health and sickness influence the ability to perceive healthcare needs. Hence, providing individuals with proper health knowledge will improve their perceptions of healthcare needs eligible for medical attention and ultimately enhance their access to appropriate healthcare. An underlying assumption is that health problems suitable for medical attention are static, and patients' limited health literacy hinders their access to proper healthcare. However, Dixon-Wood et al. (2005) challenge this underlying assumption and claim that eligibility for medical attention is negotiated between individuals and healthcare services. They argue that in the same way individuals continually strive to constitute and define what they perceive to be appropriate objects for medical attention, healthcare services are constantly forming and defining the "proper objects" of medical attention. Dixon-Wood et al. (2005) emphasize that the various healthcare services often are organized around an *"ideal user"* with a particular set of competencies and resources required for precisely using the services in a specific manner and for intended health problems.

Hence, for patients to successfully enter and use the healthcare services, their health knowledge and other necessary competencies (usually patterned by age, gender, social class, or ethnicity) need to align with the professional and organizational cultures of the healthcare services. To accommodate the duality of healthcare, Dixon-Wood et al. (2005) propose a concept of candidacy that describes eligibility for medical attention as a dynamic negotiation between individuals and healthcare services. They highlight different stages along the journey for medical attention where such negotiations typically occur. These stages include identification of candidacy, navigation of the healthcare system, claim of candidacy, adjudication of candidacy, and responses to offers of healthcare services. At each stage, candidacy is influenced by a different set of factors. In the first three stages, these factors include individuals' abilities to: identify health problems that need medical attention, navigate the healthcare services, and claim their candidacy. In the subsequent stages, candidacy is influenced by the permeability of the healthcare services, the healthcare providers' perceptions of the availability and suitability of resources needed to address the patients' claims to candidacy, the dynamics of the interactions between patients and healthcare providers, and the acceptability of offered services to the patients.

While we initially used the conceptualizations of both Levesque et al. (2013) and Dixon-Wood et al. (2005) in analyzing the data for this article, as the analysis progressed, we found Dixon-Wood et al. (2005) concept of candidacy to best capture the complexities of our findings. For example, we found that receiving information on FGC-related health problems had helped the participants suspect that their health problems were FGC-related. Nevertheless, they had only accessed the FGC-specialized services when the healthcare providers had authorized these health problems as FGC-related. Thus, while both conceptualizations fitted the first of these two findings, only the candidacy theory remained a good fit for the second. Hence, we chose to use the candidacy theory to inform the organization and interpretation of our findings.

2 Methods

This article draws on data from an explorative qualitative study examining the perceptions and experiences of Somali and Sudanese participants in Norway on healthcare needs and healthcare services related to FGC. We conducted this study in 2016–2018 utilizing semi-structured repeat interviews with 26 participants, participant observation, and three validation focus group discussions (FGD) with 17 additional participants. In this article, we explore the experiences with seeking medical attention for potential FGC-related health problems to identify factors that hinder or facilitate access to non-maternity-related FGC-specialized services.

2.1 Setting, recruitment, ethics, and participants

Somali and Sudanese are among the largest FGC-affected groups in Norway [7]. Therefore, we recruited the study participants from three Norwegian cities (Oslo, Drammen, and Trondheim) that accommodate large numbers of girls and women with origins from both countries.

We recruited the study participants through different starting points using purposeful sampling, as described in Patten (2015) [48], to ensure a varied sample in terms of age, marital status, education, type of FGC, and length of stay in Norway. In addition, we purposefully recruited participants in the age group 16–25 years as young women have been underrepresented in previous studies.

We informed all potential participants about the study's aim and ethical and practical issues relevant to them if they agreed to participate. In addition, we oriented them about the voluntary nature of participation and our plan for data storage and management. To include potential participants who might have difficulties giving written consent, we asked the ethical committee to permit oral consent. Permission was granted. Therefore, per the ethical clearance for this study, both verbal and written consent from potential participants who had professed to understand the provided information and had agreed to participate are accepted as informed consent. Hence, we asked all who consented to join for oral or written consent, including those aged 16–18 years. The Norwegian Health Research Act allows minors to give independent consent from 16 years, except for clinical drug trials or other research projects involving bodily interventions. Although the ethical committee did not stipulate any form of documentation for oral consent, we voice-recorded the verbal consent of all participants who had granted recording. We stopped recruitment once we ceased to observe new information. Table 1 outline the general characteristics of the participants.

This study was initially approved in 2016 by the Norwegian Social Science Data Services. In 2017, the Norwegian Regional Committee for Medical and Health Research Ethics approved the study as a sub-study (Ph.D.) within a large project. Consistent with the ethical clearance, we did not pay the participants for their participation but compensated many with a gift card (the equivalent of 30 USD) for transport, wages lost, or both.

Table 1. Overview of participants' characteristics.

Characteristic	Participants	
	Semi-structured repeat interviews (n = 26)	**Focus group discussions (n = 17)**
Background		
Somalia	11	11
Sudan	15	6
Age (years)		
16–21	9	1
22–27	8	5
28–33	1	4
34–39	2	4
40–45	3	2
$\geq$ 46	3	1
Marital status		
Married	10	7
Divorced	5	4
Single	11	6
Education		
$\leq$ Middle school	2	1
High school	9	11
College	10	4
Graduate school	5	1
Type of FGC		
Type I	3	0
Type II	4	5
Type III	19	12
Length of stay		
$<$ 1 year	1	0
1–5 years	6	4
6–10 years	5	5
$>$10 years	14	8

https://doi.org/10.1371/journal.pone.0257588.t001

2.2 Interviews, participant observation, and focus group discussions

The first author conducted all semi-structured repeat interviews, participant observations, and two FGDs, while the second author conducted the third FGD. We performed all interviews in participant-selected locations, such as cafés and homes of either the first author or the participants. In contrast, we carried out the FGDs on the premises of local immigrant organizations. The first author is a native Arabic speaker, fluent in English, and has moderate competence in Norwegian. Hence, she conducted the interviews and FGD with the Sudanese participants in Arabic and the Somali participants in English, Arabic, or a mixture of English and Norwegian.

The first author conducted 61 semi-structured interviews with 26 participants, of whom she interviewed 17 twice and 9 three times. All 26 participants we invited had agreed to a second interview, whereas only nine out of 10 invited participants had agreed to a third interview. The first-time interviews aimed to build trust and encourage the participants to narrate experiences related to their FGC. In the second time interviews, the participants were encouraged to elaborate further on their FGC experiences by revisiting the narrations from the first interviews, with the first author probing for confirmations, corrections, and elaborations. Using a semi-structured interview guide [44], the first author asked the participants to narrate what they could remember and wanted to share concerning their circumcision experiences, experiences of health problems they attributed to the circumcision, and how they managed these health problems and why. The first-time interviews lasted between 30–90 minutes and the second 60–180 minutes. In both interviews, the participants' narrations went mostly uninterrupted and with minor probing. Although the first-time interviews were unrecorded, the first author had tried to minimize any recall bias by recording her recollections and interpretations immediately after each interview. However, all of the second-and third-time interviews were audio-recorded.

The purpose of the third time interview was to member-check our preliminary analysis. Here, we presented our initial interpretations of emerging patterns and themes to each of the nine participants for further discussion and clarification. These interviews lasted between 60–90 minutes. Finally, we sought to validate our preliminary interpretations of emerging patterns from the three rounds of interviews through three validation FGDs with 17 Somali and Sudanese participants. We presented our overall findings for discussion and probed for confirmations, disagreements, modifications, and elaborations. We recorded our notes from the FGDs and saved them as audio files.

Moreover, the first author participated in over 20 seminars wherein girls and women subjected to FGC shared their experiences with FGC and the healthcare system in Norway. Following each seminar, the first author recorded her observation as audio field notes and used them to inform the semi-structured interview guide and the data analysis.

2.3 Analysis

The first author analyzed the data in close discussion with the second author. We entered all audio files into NVivo 12 and separated each data source (i.e., interviews, FGD, and participant observations). We identified recurrent themes and patterns in all interviews following the thematic analysis approach described by Braun and Clarke [49]. The only difference is that we did not transcribe the audio files first. Instead, the first author listened to each interview twice in its entirety before assigning codes to relevant audio segments. She kept adding to- and refining- initial codes while coding all of the participants' two first interviews. She then used insights from all third interviews and discussions with the second author to refine the codebook. Next, we sorted the codes into potential themes and collated all corresponding data extracts under these initial themes. We reviewed and refined these themes repeatedly until we developed well-identified themes and sub-themes. The first author transcribed and translated the collated audio segments directly to English whenever necessary. Notes from the FGDs and participant observation added further insights and weight to the findings. Using the candidacy theory [47] as an additional lens, we refined the themes and sub-themes addressing our objective and combined them into a coherent description. To minimize the risk of recognizing the participants, we have used pseudonyms and slightly altered- or kept- the participants' characteristics vague and ambiguous. Finally, we followed the checklist of consolidated criteria for reporting qualitative research (COREQ) [50] to facilitate peer assessment of the article's trustworthiness criteria (i.e., credibility, transferability, dependability, and confirmability).

2.4 Reflexivity

The first author probably gained the trust of both the Sudanese and Somali participants by striking a good balance between her roles as insider and outsider, as described by Kusow [51]. As a Sudanese female doctor born and raised in Sudan, we expected both Somali and Sudanese participants to perceive her as someone who shared experiences and understanding of cultural subtleties and knowledge of FGC and thus find it easy to communicate their perceptions and experiences. Still, we were concerned that by sharing the same background as the researcher, some Sudanese participants could be afraid of gossip and judgment and consequently reluctant to share opinions or experiences that deviated from the community's socio-cultural norm. Therefore, the first author repeatedly explained confidentiality issues, de-identification, and possible repercussions of any deviation from these ethical principles. We also think that the first author's departure from the local Sudanese norms, demonstrated by her marriage to a Westerner, led some participants to regard her as partly an outsider. Furthermore, the first author's medical background seemed to have further facilitated trust and openness. Some women provided it as a reason for finding it easy to share information they had not previously shared.

3 Findings

We explored the participants' experiences with seeking healthcare for potential FGC-related health problems along a spectrum that starts with the initial perception of health problems and culminates with the reception of appropriate healthcare. We found that most participants had experienced a series of health problems that could have been related to FGC at one or more points across their lifespan. During childhood, the most common complaints described by participants were burning micturition, recurrent itching, and sores on their genitals. Post-puberty, the most common complaints were mental and sexual health problems, severe menstrual pain, and recurrent painful vulvar lumps.

Nevertheless, we identified different factors (see Table 2 for a summary of these factors) that influenced whether these participants had received appropriate healthcare for these problems.

3.1 Identification of candidacy

We identified two barriers that have deterred the participants from seeking medical attention at the FGC-specialized services. Firstly, we found that despite the magnitude of experienced health problems, not all participants had identified these problems, and consequently neither themselves, as candidates for medical attention. Typically, the participants had first tried home remedies before considering other options. For example, the participants took over-the-counter painkillers, drank warm herbal tea, and placed hot bottles on their bellies for severe menstrual pain. They had also carefully attended vulvar lumps and gently squeezed out the pus until it was empty and no longer painful. Only when they could not tolerate the pain, could no longer self-manage these health problems, or were concerned that the vulvar lump could be a cancerous tumor had they consulted others or sought medical attention. One such participant was Aaraan, a 23 years old Somali woman who had suffered for several years from repeated vulvar lumps that the gynecologist eventually diagnosed as benign cysts. Aaraan described her reason for finally seeking medical attention after many years of self-management as follow:

> *"I remember from my late childhood . . . until I was twenty, I always had cysts [forming] down there . . . I remember that sometimes I will open them [the cysts] by myself . . . to take out what is inside. But, this last time, I could not take it out [the content of the cyst] because it was excruciating. . . it [the cyst] was closed completely. Previously, they [the cysts] used to have little openings . . . on the top . . . there was also a . . . a crust? But, the last cyst, I could not open that one. So I just left it. I avoided touching and was very careful when I washed my down parts. Then, I went to the gynecologist to know what it could be. I was terrified that I have cancer or something similar."*

Table 2. Barriers and facilitators to the access to FGC-specialized services in Norway.

Theme	Barriers	Facilitators
Identification of candidacy	• Uncertainty regarding whether genitourinary problems were FGC-related: ○ Conflicting opinions from healthcare providers, and ○ Conflicting views from people of trust.	• Experiencing health problems that: ○ Caused severe pain, ○ Persisted despite attempts of self-management, ○ Were lumps that raised the participants' concern over malignancy, and ○ Interfered with their ability to perform expected duties and roles. • Receiving information on FGC-related health problems, and • Linking experienced sexual and mental health problems to FGC: ○ Consistent endorsement of the link between sexual and mental health problems and FGC by healthcare providers and trusted others.
Navigating the healthcare system	• Language barriers and limited knowledge of the Norwegian healthcare system as newcomers, • Limited knowledge of FGC-specialized services: ○ Not accessing available information on official websites, and ○ Lack of information on sexual and psychological counselors familiar with FGC. • Practical issues with appointments: ○ Language, ○ Invalid numbers or switchboard operators not familiar with FGC-specialized services, and ○ Co-payment fees being high for students.	• Having a social network with good language competence and knowledge of the Norwegian system, • Residing in municipalities that assisted during settling, and • Receiving information on FGC-specialized services from local immigrant organizations.
Permeability and adjudication of candidacy	• Seeking healthcare at regular GPs and not FGC-specialized services, • FGC not assessed as a possible cause of health problems: ○ Not disclosing FGC status for shame and fear of judgment, ○ GPs not asking about FGC/ not linking health issues to FGC, and ○ Complaints of severe menstrual pain not taken seriously. • Long gynecologists' waiting lists, and • Feeling judged and disrespected.	• Informing the GPs that they suspected FGC to cause the health problem, and • Being referred to gynecologists with good knowledge of FGC.
Response to offers and satisfaction with FGC-specialized services	• Sexual norms rendering deinfibulation unacceptable, • The healthcare providers did not address needs for: ○ Respect, ○ Proper consultations and enough time to deliberate over decisions, ○ Assurances on: ▪ The aesthetic effect of deinfibulation on the vulva, ▪ Making deinfibulation a less traumatic and painful experience, and ▪ Involving them in decisions about pain management. • Psychosexual counseling was not part of the offered FGC-specialized services.	• Sexual norms rendering deinfibulation acceptable/desirable, • The healthcare providers accommodated needs for: ○ Respect. ○ Proper consultations and enough time to deliberate over decisions, ○ Assurances on: ▪ The aesthetic effect of deinfibulation on the vulva, ▪ Making deinfibulation a less traumatic and painful experience, and ▪ Involving them in decisions about pain management, • Experiencing a positive impact of deinfibulation on health problems.

https://doi.org/10.1371/journal.pone.0257588.t002

Similarly, not all participants who had experienced mental and sexual health problems perceived themselves to need medical attention. Typically, participants were motivated to seek medical attention only if they perceived that the mental and sexual health problems harmed their intimate relationship, other significant aspects of their lives, or both. More details on the interrelationship between different sets of perceived sexual roles and duties and the participants' decisions on whether or not to seek medical attention for potential FGC-related health problems are provided in a separate article [44].

Secondly, we found that most participants were uncertain whether their genitourinary problems were related to FGC and thus did not identify themselves as candidates for FGC-specialized services. Most participants had received information on FGC-related health problems at seminars. This information, especially pictures of keloids and cysts, had made them aware of a possible link between their health problems and FGC. However, they had encountered conflicting opinions on some FGC-related genitourinary health problems, particularly menstrual pain, from healthcare providers in Norway and home countries. While some healthcare providers had attributed severe menstrual pain to FGC, others had disagreed and instead attributed such pain to uterine muscle contractions. The participants also claimed to have received equally conflicting messages regarding these health problems from trusted peers. Such contradicting opinions left most participants uncertain whether their menstrual pain and other health problems such as vulvar lumps and urinary infections were related to FGC and thus whether they were candidates for FGC-specialized services.

Only after deinfibulation and experiencing a remarkable improvement in their health problems, some participants had become sure that these health problems had been FGC-related. For example, the before- and after- deinfibulation experiences of menstrual pain had helped them differentiate between “normal” menstrual pain and menstrual pain in “tightly” infibulated girls and women. They explained that pre-deinfibulation, the opening was insufficient for the menstrual blood to flow freely, thus allowing clots to form, accumulate, and add a new dimension to pain in the form of extreme pressure. The following quote from Hadiya, a Sudanese participant in her early-40s, depicts what the participants understood as FGC-related menstrual pain:

> *“Initially, I did not relate my menstrual pain to circumcision, but then I felt this immediate difference after deinfibulation. You see, I still get menstrual pain, but it is different. The heaviness is gone. Now, I feel the pain in my belly, in the area around the bladder and uterus. Before, I also had severe pain way down, around the [vaginal] opening. . . a pressure pain . . . it was as if you have a three or four kilos weight of something pressing on you. It was the blood not finding a way to come out. It was as if you are giving birth! Severe pressure and pain, and then you suddenly feel a huge clot passing out. You feel this instant relief but then feel the pressure building up again! I do not want to be gross, but I will tell you anyway, the pressure would sometimes be so intolerable that I would insert my fingers and pull the clots out!”*

Similarly, once the participants noticed that their recurring experiences of vulvar itching and burning micturition had stopped after deinfibulation, they became sure these problems were FGC-related. For example, Khalda, a Sudanese participant in her 40s, described her long experience with itching and burning micturition and explained that it was only after deinfibulation that she knew it was FGC-related:

> *“[. . .] since I was a child, I had this problem . . . repeated itchiness down there. I would scratch and scratch until it bleeds. I could not help myself. So when I go to the bathroom, peeing would be very painful. It was like adding salt to an open wound! So, I would try to hold the urine as long as I could. [. . .] since the surgery [deinfibulation], it is over ten years now . . . during all this time, I haven’t experienced these problems not even once! So, I know for sure they were related to the circumcision.”*

Some urinary problems, such as delayed- and slow- relief, were mostly normalized and not recognized as problems until after deinfibulation. For example, the following quote from Omayma, a Sudanese participant in her mid-20s, was typical:

> *"I only realized that I had problems when I felt a difference in everything after deinfibulation. Previously, whenever I was peeing, I had to wait for some time and squeeze hard to get relieved, but now I get immediate relief."*

In contrast to genitourinary problems, certainty about the link between FGC and sexual and mental health problems had helped the participants identify their candidacy to FGC-specialized services. Participants claimed that their own experiences, the interpretations of healthcare providers, and trusted peers had consistently endorsed the information they had received in seminars linking mental and sexual health problems such as panic attacks and painful sexual intercourse to FGC. They were, therefore, sure that these health problems were FGC-related. Many participants reported experiencing panic attacks in situations that reminded them of the powerlessness and pain they had felt during their circumcision. They explained that certain smells and activities (e.g., disinfectants and the mere act of lying down during childbirth or examination at the gynecologist) would transfer them to when they were held tightly by one or more women as little girls while another cut their private parts. Some participants also professed to have experienced panic attacks during sexual intercourse. Several participants, mainly in the age group 16–25 years, expressed mixed feelings of anger, deep sadness, and shame over being circumcised, as they believed circumcision has rendered them "mutilated" and "unattractive."

Many sexually active participants described their sexual debuts as painful and enduring experiences where full vaginal penetration had only been possible after repeated agonizing attempts over periods varying from several days to several months. A few of these participants claimed to continue experiencing severe pain during sexual intercourse even years later. They also claimed that their enduring experiences of sexual debut had left them continuously struggling with feelings of shame and self-doubt. One of these participants was Ilham, a 27 years old Sudanese participant, who eloquently narrated her experience of sexual debut and its lasting effect:

> *"It was like a nightmare! The wedding party was over, and we went to the hotel. And there we were, the two of us alone. Like any other bride, I was shy yet excited. It started well, but suddenly in the middle of it all, he stopped. He got up and got dressed. I was confused! He sat next to me and covered me with the bedsheet. He then asked me: 'you are infibulated, right? Why didn't you tell me? I never wanted to marry a girl that was circumcised, let alone infibulated! Still, if I knew you were infibulated, we could have arranged for it to be opened'! I was mortified. I wished the ground would open and swallow me up! I told him it wasn't too late; he could still divorce me and find someone not circumcised to marry. He hugged me and reassured me that was not what he meant. He said he loved me and hence didn't want to cause me any pain, and that would have been impossible with infibulation. So, if I had told him beforehand, he could have arranged for it [infibulation] to be opened. I eventually calmed down and agreed to go and have it opened by a doctor. But, you know what? Something inside me broke that night! I feel disgusted with myself! He tries to reassure me and tell me that now I am normal down there, but I won't let him look. I always turn the light off when we make love."*

Furthermore, many participants said they were either not getting much sexual pleasure or could not reach sexual climax. The professed reduced sexual pleasure left some participants feeling dissatisfied and frustrated and had eventually led to marital problems. They explained that their sexual dissatisfaction, often combined with pain and triggered memories of their circumcisions, had reduced their sexual desire and led them to avoid intimacy with their partners. Consequently, their partners accused them of being “cold” and “frigid,” an accusation that made them feel hurt and anxious.

3.2 Navigating the healthcare system

The first barrier that the participants encountered while navigating the healthcare system in Norway was their limited knowledge of the system and the Norwegian language. Many participants explained that before migrating to Norway, the healthcare systems they were familiar with were quite different from the Norwegian system, especially GPs as gatekeepers to specialized services. Therefore, several of these participants depended on their social network to get familiar with the Norwegian healthcare system during the first years after migration. They discussed their health problems with people they trusted and asked where and how to seek help. Consequently, their knowledge about the healthcare system varied according to the knowledge levels among their social network. The participants, whose social network was knowledgeable, were quickly acquainted with the Norwegian healthcare system and had promptly registered with a GP. A few participants had also received considerable help from their municipalities upon settling. In contrast, participants with a less knowledgeable social network took a long time getting familiar with the system and registering with a GP. As a result, these participants sought healthcare primarily at urgent care centers until they finally enrolled with a GP.

The second barrier was their limited knowledge of FGC-specialized services. Even though several official Norwegian websites provide information on FGC-related services in various languages, only two participants had searched for and found relevant information on these sites. Instead, the primary source of health information for both the participants and their social networks was seminars arranged by non-profit immigrant organizations. Still, the participants were frustrated that they had received information on FGC-related health problems but not FGC-specialized services. For some, getting information on health problems but not healthcare had left them angry, sad, and hopeless. For example, *Reem*, a 22 years old Sudanese girl, described her feelings during- and after- such FGC seminars as follow:

> *“[. . .] when she mentioned menstrual pain . . . I was so angry! I was so angry with my mother for doing this to me! I suffer every month! I miss school and lie in bed for three days. I am in such pain I cannot tolerate being touched. I was already suspecting it was because of the pharaonic circumcision [. . .]. Then, they told us about deinfibulation, after a year, I think, and I was angry with that woman, the one who gave the seminar on health complications. Why did she not tell us that we could get help? Why did she tell us about all those problems and just left us feeling miserable?”*

Nevertheless, the participants were happy that non-profit immigrant organizations had recently started providing information on FGC-specialized services for non-maternity-related health problems. The participants mostly received information on FGC-specialized services from seminars arranged by such organizations, either directly or through their social network. Still, the participants complained over lacking information on sexual and psychological counselors familiar with FGC, especially after knowing psychological and sexual counseling was not part of the offered FGC-specialized services. Several participants claimed that they did not seek professional counseling because of not knowing where to find FGC-competent counselors.

The third barrier participants had faced while navigating the healthcare system was practical issues concerning appointments with either the GP or the FGC-specialized services. Several participants experienced that they needed better command of the Norwegian language to book appointments and adequately communicate their needs for medical attention. They had also found the provided contact numbers for the FGC-specialized services were either invalid or belonged to hospitals' switchboards where the operators were not familiar with the services. Finally, a few participants found the co-payment fees for FGC-related consultations high for students and the less affluent. Hence, they suggested waiving such fees to encourage these two groups to seek medical attention.

3.3 Permeability, claims, and adjudications of candidacy

Limited knowledge of FGC-specialized services and uncertainty of whether some gynecological health problems were FGC-related had deterred participants from seeking medical attention at the FGC-specialized services. Instead, many participants had sought medical attention for potential FGC-related health problems with their regular GPs. Nevertheless, participants encountered three main barriers in their encounters with the GPs that had hampered a proper assessment of whether their health problems were FGC-related and subsequently prevented or delayed their referral to FGC-Specialized services. The first barrier was feelings of shame and embarrassment over undergoing FGC, and fear of being judged had discouraged participants from disclosing their FGC status to their GPs. Consequently, the participants had either reluctantly revealed their FGC status while relaying their potential FGC-related health problems or withheld it but expected the GPs to ask them about their FGC status if relevant. The second barrier was that when the GPs did not ask them about their FGC status or indicated a link between their health problems and FGC, participants concluded that the GPs lacked knowledge on FGC or their health problems were not FGC-related. The following quote from a Somali participant in her late teens illustrates some of these experiences:

> *"After I told her [the GP] about my problem [itching, sores, and recurrent lumps in the vulva], I waited to see if she would ask me about circumcision . . . everyone knows that Somalis are circumcised! So, when she did not ask me about circumcision, I knew that it [the health problem] has nothing to do with circumcision."*

The GPs had only adjudicated candidacy to FGC-specialized services for participants who proactively claimed their candidacy and told their GP that they suspected infibulation as a cause of their sexual health problems. These participants had typically linked their health problems to FGC but had not known about either the FGC-specialized services or the exemption from referral. Still, the GPs had referred most participants with sexual health complaints and vulvar lumps to outpatient gynecologists at their private practices or the hospitals' outpatient departments.

The third and last barrier participants encountered in their meetings with GPs mainly concerned severe menstrual pain. These participants claimed that their regular GPs did not take their complaints of severe menstrual pain seriously. Instead, the GPs had only prescribed contraceptive pills, advised them to use over-the-counter painkillers, and had refused to issue more effective painkillers or sick leave. Subsequently, when severe menstrual pain persisted even after months of using the prescribed contraceptive pills and over-the-counter painkillers, these participants had decided to seek help at the urgent care centers. There, they claimed to have received adequate pain management. Also, the doctors at the urgent care centers had linked the severe menstrual pain in two participants to FGC, herewith adjudicating their candidacy to FGC-specialized services and referring them for deinfibulation. The participants thought that this difference in the medical assessment of their menstrual pain was because advanced bookings had prevented their regular GPs from observing the pain intensity and consequently grasping their suffering. Contrastingly, the doctors at the urgent care centers could comprehend their struggle since they could drop in whenever they were in acute pain.

Referral to outpatient gynecologists had also resulted in the adjudication of candidacy. The participants were mostly satisfied with the gynecologists' knowledge of FGC and their ability to assess whether their health problems were FGC-related before referring them to the FGC-specialized services. Nevertheless, the participants had to overcome also two barriers here. The first was the long waiting list for appointments that left them suffering for several months before their health problems were eventually assessed and diagnosed. The second was negative encounters with the gynecologists. Several participants recalled feeling judged, humiliated, and disrespected by gynecologists who had displayed their shock and disgust and used an aggressive tone to ask them never to subject their daughters to such "inhuman" tradition while examining their genitalia. Following such experiences, participants had avoided undergoing vaginal examinations and disclosing their FGC status to other healthcare providers for a long time. The following quote from Najwa, a Sudanese participant in her early-20s, depicts an early experience with a female gynecologist:

> *"She started to examine me and made this face . . . as if she was disgusted. I told her, 'by the way, I did not do this to myself. I did not even have a choice.' She then said, 'I am sorry, but this is very terrible. I hope you would not do this to your daughters in the future.' I almost answered back that I will!"*

After such encounters, Najwa and a few other participants had refused further referrals until their GPs ensured that the referrals were to gynecologists with vast experience with FGC.

3.4 Responses to offers and satisfaction with FGC-specialized services

At the FGC-specialized services, almost all participants had received offers for deinfibulation, sometimes also removal of cysts, to address their various genitourinary and sexual problems. The participants' responses to these offers were influenced primarily by their perceived sexual norms and secondarily by the dynamics of their interactions with the healthcare providers. Typically, cultural norms related to accepted sexual behavior had determined the acceptability of deinfibulation for the participants and their final decisions to accept or decline the offers. As we have discussed the influence of sexual norms on the acceptability of the various FGC-specialized healthcare offers in a separate article [44], we will only present our findings on the dynamics between the participants and the FGC-specialized healthcare providers.

We found that the interactions' dynamics had influenced some participants to decline deinfibulation though they found the procedure acceptable/desirable. Also, the interaction dynamics with the healthcare providers had significantly influenced the participants' satisfaction with the FGC-specialized services.

Overall, the participants were afraid that the healthcare providers could judge them and that deinfibulation could be as painful and traumatic as their initial experiences of circumcision, lead to painful urination, and leave their vulva wide open like a "gaping hole." Consequently, they were satisfied and had readily accepted offers of deinfibulation when the healthcare providers had addressed each of these concerns and helped them overcome their fear, and vice versa.

Firstly, participants were concerned that the healthcare providers would not meet them with respect. They were sensitive to having several people inspecting their vulva and characterized such experiences as humiliating and disrespectful. The following quote from Sahra, a Somali girl in her early-20s, illustrates the participants' reactions to such experience:

> *"I would never forget how small I felt at the time. [The gynecologist] had students in the room. She did not ask me if it was okay. I never agreed to have them staring at my private parts! It was a very uncomfortable situation. I felt violated [and] disrespected."*

In contrast, participants appreciated and highlighted occasions when the gynecologist had asked medical students to leave the room as positive examples of compassion and respect. Najwa was particularly appreciative of the positive dynamics since she had a previous unfortunate experience with one gynecologist:

> *"This gynecologist was very good . . . really considerate. She had students in the room [but] she understood without me saying anything that would be problematic for me. She did not even ask me if I would mind having [the students] there. [Instead,] she politely asked them to step out for a bit. I appreciated that [as]I felt well respected. She gained my trust 100% by doing just that."*

Secondly, participants wanted proper consultations where the healthcare providers had assessed their health problems, explained why deinfibulation was offered, and gave them enough time to consider these offers. Several participants had repeatedly declined offers of deinfibulation from healthcare providers, assuming it was a routine offer for all infibulated girls and women. Only when the gynecologists had explained how deinfibulation would alleviate their health problems had they considered and accepted the offer. Participants also appreciated being offered more than one consultation to discuss their concerns. Reversibly, the participants were dissatisfied with the FGC-specialized services at one particular women's outpatient department and claimed they were misinformed about their appointments and pressured to undergo deinfibulation. They described their astonishment to find that their expected consultations were instead appointments for deinfibulation. They were also frustrated over what they described as the "take-it or leave-it" attitude the gynecologists seemed to have adopted. They felt pressured to decide whether to undergo deinfibulation or not at their first appointment. In the following quote, a Somali participant in her late-20s describes her frustration with such attitude:

> *"She [the gynecologist] had never told me that I had to have surgery . . . just a consultation. Also, the letter I got said consultation and not surgery [. . .]. So, when I went to [the FGC-specialize services], I thought the gynecologist would talk to me about my problem . . . what are my options. . . a regular consultation! But, she was ready to do a surgery [deinfibulation and cyst removal]; she was not polite or kind. I told her I was not ready for surgery and that I came for a consultation. I knew a lot about the Norwegian health system, I am a nurse, so I knew a lot about patients' rights, that the patients should receive prior information. [That] there must be a consultation first! I could have had cancer as far as I knew [since] until that point, I did not know what [the cyst] was. So, when she told me that she was ready to do the surgery, I told her I was not ready and came for a consultation and was not prepared to have surgery. She said to me, 'you have to go through with the surgery now. Otherwise, you have to go home'. . . So, I told her, 'okay, then I want to go home.' So, I left and went home."*

Still, a few participants appreciated that the gynecologists had adopted a prompt and matter-of-fact attitude and perceived it as a positive display of professionalism that had helped them see deinfibulation as a simple procedure. They had also appreciated not getting time to dwell on their fears.

Finally, participants wanted the healthcare providers to assure them that their vulva would not be "wide and ugly" after deinfibulation and try to make deinfibulation a less traumatic and painful experience and involve them in decisions about pain management. Participants who recalled that the healthcare providers had discussed pain management during- and after-deinfibulation and presented various pictures of vulva before- and after- deinfibulation had praised these healthcare providers for helping them overcome their fears. They recounted these consultations as positive experiences and the healthcare providers as competent, kind, and compassionate. Many participants also singled out one particular midwife who originated from an infibulation-practicing country and used to work at one of the FGC-specialized services as exceptionally competent, compassionate, and helpful. Oppositely, participants who had not experienced that the healthcare providers had addressed these concerns had felt angry and frustrated that they could have spared unnecessary anxiety and wasted time. The following quote from Maryan, a Somali woman in her early-30s, was typical:

> *"After going through with the surgery, I found it was not bad as I heard or expected. I think [the gynecologist] could have given me better information about the surgery, but she had many things going on at the same time . . . many women waiting for their surgeries. Then there were the students and the interpreters. She did not have the time to give me a good explanation about the surgery. She was also not, umm, kind? Listening to her, I thought it would be as a big deal as giving birth! However, it was nothing like that. She could have told me how I would look or feel after the surgery. I was so afraid that I would look like I gave birth to eight kids! I did not want that."*

Terrified that deinfibulation could be as traumatic as their initial FGC experiences, several participants felt frustrated and powerless when the outpatient gynecologists readily dismissed their requests for general anesthesia. They recalled that they could not stop their bodies from shaking and had even fainted during the procedure. In hindsight, they did not consider general anesthesia necessary, but they wished that the outpatient gynecologists had been compassionate and spent some time addressing their fears. The following quote demonstrates how one of these participants, a Sudanese woman in her early-30s, described such experience:

> *"Just the thought of someone cutting me down there again sent me to full panic. I needed it done, but I did not want to be awake. So, I asked [the gynecologist at the FGC-specialized services] to knock me out. I told her how I felt and that the gynecologist who referred me there assured me that I did not need to be awake, but she said that was impossible. She gave me ten minutes to make up my mind [as] she had other patients waiting. So, I had ten minutes to decide whether to do it with local anesthesia or go home. I had spent a long time ensuring I had this day free from work, so I finally agreed. I then asked her to give me strong painkillers at least, but again she refused! She said it was not necessary. She was [acting] cold, and as a matter of fact, she was not kind at all . . . I do not think I felt any pain, but I was shaking and sweating the whole time."*

Many participants had also wished that counseling was part of the FGC-related offered services to better deal with the low self-esteem, flashbacks, and panic attacks that many struggled to overcome. Nevertheless, such negative experiences with the operating gynecologists did not affect the participants' satisfaction with the effect of the services they had received. All participants who had undergone deinfibulation, removal of cysts, or both stated that these procedures had considerably helped their health problems. They had noticed immediate improvement regarding menstrual pain, painful sexual intercourse, and reduced sexual pleasure. A few participants attributed the improvement in sexual pleasure to their clitorises being found intact under the infibulation seal. Still, participants whose clitorises were said not to be intact also claimed a noticeable improvement in sexual pleasure and eventually also in sexual desire. Several participants had also noticed that painful urination and recurrent itching, sores, and painful lumps in their vulva had stopped after deinfibulation. Many were also positively surprised by the improved urinary flow.

4 Discussion

We explored the experiences of 26 Somali and Sudanese girls and women subjected to FGC to identify factors that had hindered or facilitated their access to non-maternity-related FGC-specialized services in Norway. We approached access as a dynamic process of interactions between individuals and the healthcare system that lasts from an initial perception of need until reception of healthcare appropriate to that need. As a result, we identified several hindering and facilitating factors at four different stages of their healthcare-seeking journeys (Table 2). To lift our findings and enhance their transferability [52] to other contexts, we have initially used both Levesque et al. (2013) conceptual framework [46] and Dixon-Wood et al.'s (2005) candidacy theory [47] to analyze the data for this article. However, as the analysis progressed, only the candidacy theory remained a good fit for the findings. Thus, we have organized and interpreted our results only in line with the candidacy theory.

We found that in the first stage of their healthcare-seeking journey, the participants' health problems they identified as candidates for medical attention were: lumps and other genitourinary, sexual, and mental health problems that persisted, interfered with their ability to perform expected duties and roles, or caused severe pain. Dissimilar to participants in a former study [45], most of our participants had received information on FGC-related problems and thus suspected their health problems could be FGC-related. A possible explanation for this difference could be that other immigrant groups included in the before mentioned study are less targeted with such information than Somali and Sudanese [53], who were the only groups we included in our study. Still, conflicting messages from healthcare providers and trusted peers had left our participants unsure whether their genitourinary health problems were FGC-related. Recent results [54] illustrating conflicting opinions and approaches concerning menstrual pain and FGC among Swedish healthcare providers support this latter finding. Such conflicting messages hindered most participants from identifying their candidacy for the FGC-specialized services. This finding highlights the difficulty facing girls and women with FGC in identifying health problems as FGC-related, even after receiving relevant information. It also highlights the limitation of focusing on health literacy and exemption from the referral requirement as crucial initiatives for improving access to the FGC-specialized services in Norway. Instead, we think primary healthcare providers with diagnostic competency and FGC knowledge should be responsible for determining the real cause of potential FGC-related problems, particularly as other conditions [18,55,56] could also cause many of these problems.

In the second stage, social networks and some municipalities had helped the participants upon settling in Norway to overcome the language barrier and unfamiliarity with the Norwegian health system, whereas non-profit immigrant organizations were their primary sources of health information on FGC. Former findings [57] have emphasized the role of social networks and immigrant organizations as bridge-builders between immigrants and the healthcare system in Norway. For many years, the Norwegian government has financially supported- and engaged non-profit immigrant organizations in the preventive work on FGC [53]. This preventive framework could be one of the reasons these organizations have focused more on providing information on FGC-related health problems rather than FGC-specialized services as experienced by our study participants. Participants had pondered over lacking knowledge on FGC-competent counselors and claimed it as a reason for not seeking psychosexual counseling. A recent systematic review had also identified the lack of knowledge about FGC-specialized services beyond maternity contexts [58] as a barrier to accessing healthcare in Western countries for women subjected to FGC.

In the third stage, unfamiliarity with FGC-specialized services and uncertainty about FGC as a cause of experienced health problems left the participants un-*ideal users* [47] of these services. Therefore, they chose to book appointments with their regular GPs rather than the FGC-specialized services hoping that the GPs would assess whether their health problems were FGC-related and advise them on the next steps. Nevertheless, feelings of shame, embarrassment, and fear of judgment had discouraged participants from disclosing their FGC status to their GPs and ultimately hindered a proper assessment of FGC as a potential cause for their problems. This finding confirms the hypothesis that ethnic minorities are sensitized to the possibility that some aspects of their cultural practices are prone to judgments [47]. Consistent with a Dutch study [59], our participants had either reluctantly revealed their FGC status while relaying their potential FGC-related health problems or withheld it but expected the GPs to ask them about their FGC status if relevant. When the GPs did not ask them about- or link their health problems to- FGC, participants mostly concluded that the GPs lacked knowledge of FGC or that their health problems were not FGC-related. We do not know the GPs' exact reasons for not asking about FGC, but former findings [60–62] suggest that perceiving FGC as a taboo and having insufficient knowledge may play a key role. In several Western countries, GPs score low on both the clinical and cultural aspects of FGC [63–65]. In contrast, gynecologists score higher than other healthcare providers [65,66]. Hence, explaining why gynecologists were the ones mostly adjudicating the candidacy to FGC-specialized services among our participants.

In the final stage, sexual norms [44] determined the acceptability of deinfibulation and the participants' final decision to accept or decline surgery offers. Still, negative dynamics in their interactions with healthcare providers had led some participants to reject deinfibulation offers despite their positive attitudes towards the procedure. The dynamics of interactions with healthcare providers had also influenced participants' eventual satisfaction with the FGC-specialized services. Participants reported many concerns related to fear of judgment and the process of deinfibulation per se. However, when the healthcare providers met them with respect, provided them with sufficient information about their health problems and deinfibulation, and involved them in the decision-making, the participants felt satisfied and had readily accepted offers of deinfibulation. As patients in Norway are entitled to the information necessary for understanding their condition and treatment options and participate in healthcare decisions [38], it is a surprise that participants had not experienced healthcare providers to accommodate these needs more often. Unfortunately, such negative experiences with healthcare providers also seem widespread among migrants with FGC in other Western countries. In a recent systematic review [58], the authors identified over 30 studies on healthcare experiences where girls and women subjected to FGC had reported feeling exposed and humiliated, judged and stereotyped, and lacking choice, power, and control over their healthcare.

4.1 Implication for policy and clinical practice

Our findings suggest that health authorities and healthcare providers in Norway, and possibly other Western countries, need to address several issues to ensure that girls and women subjected to FGC have access to healthcare appropriate to their needs.

Firstly, as girls and women subjected to FGC seem to rely on non-profit immigrant organizations for health information, these organizations could also be encouraged to provide information on FGC-specialized services. Secondly, girls and women subjected to FGC seem to have an unmet need for psychosexual counseling. As a start, psychosexual counseling could be part of the offered FGC-specialized services. Eventually, continuous and comprehensive training of psychosexual counselors on FGC could help to mainstream these services. Thirdly, as GPs are per facto gatekeepers to the FGC-specialized services and whether FGC is the cause for the health problems requires medical knowledge of other possible causes and diagnostic competency, the onus should not be left entirely to the women. Finally, our findings suggest a need for healthcare providers to treat patients, including those subjected to FGC, with respect and compassion, provide sufficient time and information for the patients to make informed decisions, and involve them in the decision-making about their healthcare.

5 Conclusion

This article identified a series of barriers and facilitators facing girls and women while accessing FGC-specialized healthcare in Norway.

A key finding is that although girls and women with FGC do not always need referrals to access the Norwegian FGC-specialized healthcare services, none of the participants with potential FGC-related health problems had directly booked appointments with these services. That was mainly due to the participants' difficulty assessing whether their health problems were FGC-related and unfamiliarity with the FGC-specialized healthcare services. Thus, most participants had first sought medical attention at their GPs. However, when the GPs did not inquire about their FGC status or suggested a link between their health problems and FGC, participants mostly concluded that the GPs lacked knowledge of FGC or that their health problems were not FGC-related. Consequently, the GPs' inadequate assessment of FGC as a potential cause of health problems delayed the participants' access to appropriate healthcare. This finding suggests that Norwegian policymakers need to acknowledge the central role of GPs in the clinical management of patients with potential FGC-related health problems and provide them with comprehensive training on FGC. Another key finding is that the interaction dynamics with healthcare providers also influenced the participants' access to appropriate healthcare. For example, many participants had at one or more points refused offers of deinfibulation because of perceived disrespect, aesthetic concerns, and fear of retraumatization and pain during and after genital surgery. However, positive dynamics where the healthcare providers met the participants with respect and addressed their fears and concerns had facilitated the participants' acceptance of offers of deinfibulation. Therefore, regardless of their moral stand on FGC, we would urge healthcare providers to meet patients with FGC with respect and consistently provide sufficient information necessary for healthcare decision-making.

Acknowledgments

We want to thank our participants for their generosity in sharing their stories and insightful reflections. We are also grateful to Inger-Lise Lien for leading the project that included the first author's Ph.D. as a subproject.

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II

PLOS ONE

RESEARCH ARTICLE

Sexual norms and the intention to use healthcare services related to female genital cutting: A qualitative study among Somali and Sudanese women in Norway

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Citation: Ziyada MM, Lien I-L, Johansen REB (2020) Sexual norms and the intention to use healthcare services related to female genital cutting: A qualitative study among Somali and Sudanese women in Norway. PLoS ONE 15(5): e0233440. https://doi.org/10.1371/journal.pone.0233440

Editor: Nülüfer Erbil, Ordu University, TURKEY

Received: October 28, 2019

Accepted: May 5, 2020

Published: May 18, 2020

Peer Review History: PLOS recognizes the benefits of transparency in the peer review process; therefore, we enable the publication of all of the content of peer review and author responses alongside final, published articles. The editorial history of this article is available here: https://doi.org/10.1371/journal.pone.0233440

Data Availability Statement: All relevant data are within the manuscript.

Funding: ILL and MMZ received funding from the research council of Norway (https://www.

Abstract

Background

Female Genital Cutting (FGC) is a traditionally meaningful practice in Africa, the Middle East, and Asia. It is associated with a high risk of long-term physical and psychosexual health problems. Girls and women with FGC-related health problems need specialized healthcare services such as psychosexual counseling, deinfibulation, and clitoral reconstruction. Moreover, the need for psychosexual counseling increases in countries of immigration where FGC is not accepted and possibly stigmatized. In these countries, the practice loses its cultural meaning and girls and women with FGC are more likely to report psychosexual problems. In Norway, a country of immigration, psychosexual counseling is lacking. To decide whether to provide this and/or other services, it is important to explore the intention of the target population to use FGC-related healthcare services. That is as deinfibulation, an already available service, is underutilized. In this article, we explore whether girls and women with FGC intend to use FGC-related healthcare services, regardless of their availability in Norway.

Methods

We conducted 61 in-depth interviews with 26 Somali and Sudanese participants with FGC in Norway. We then validated our findings in three focus group discussions with additional 17 participants.

Findings

We found that most of our participants were positive towards psychosexual counseling and would use it if available. We also identified four cultural scenarios with different sets of sexual norms that centered on getting and/or staying married, and which largely influenced the participants' intention to use FGC-related services. These cultural scenarios are the virgin, the passive-, the conditioned active-, and the equal- sexual partner scenarios. Participants

forskningsradet.no/en/) for the project number 262757. REBJ received no specific funding for this work. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Competing interests: The authors have declared that no competing interests exist.

with negative attitudes towards the use of almost all of the FGC-related healthcare services were influenced by a set of norms pertaining to virginity and passive sexual behavior. In contrast, participants with positive attitudes towards the use of all of these same services were influenced by another set of norms pertaining to sexual and gender equality. On the other hand, participants with positive attitudes towards the use of services that can help to improve their marital sexual lives, yet negative towards the use of premarital services were influenced by a third set of norms that combined norms from the two aforementioned sets of norms.

Conclusion

The intention to use FGC-related healthcare services varies between and within the different ethnic groups. Moreover, the same girl or woman can have different attitudes towards the use of the different FGC-related healthcare services or even towards the same services at the different stages of her life. These insights could prove valuable for Norwegian and other policy-makers and healthcare professionals during the planning and/or delivery of FGC-related healthcare services.

Introduction

In the last decade, migrant health and migrants' equitable access to healthcare has received increased attention in Europe [1–4]. This attention is reflected in the significant increase in the body of literature on the provision and utilization of healthcare services related to Female Genital Cutting (FGC) in the European context [5–12]. FGC is mostly prevalent in 30 countries in Africa, Asia and the Middle East [13], but over half a million immigrant women and girls living in Europe are estimated to have undergone FGC [14]. In Norway, around 17,300 girls and women are estimated to have undergone FGC prior to arrival in the country; half of them are of Somali origin [15].

The World Health Organization (WHO) classifies FGC into four types, where the most extensive form is type III (infibulation) [16]. Infibulation is characterized by the sealing of the vulva (leaving a small hole for passing both urine and menstrual blood) through the cutting and apposition of the labia majora and/or minora, with or without excision of the clitoris [16]. Women and girls who underwent FGC have a higher risk of experiencing a series of long-term genitourinary, obstetrical, and psychosexual health problems than those who did not [17–19]. The occurrence and severity of these health problems increase with the extensiveness of FGC. Genitourinary problems include clitoral inclusion cysts, keloids, dysmenorrhea, hematometra, hematocolpos, urinary tract infections, dribbling, poor urinary flow, and prolonged micturition [12, 17, 20–22]. The obstetrical problems include increased risk of cesarean section, episiotomy, perineal tears, postpartum hemorrhage, and stillbirths [18, 23]. Psychosexual health problems include symptoms of anxiety, depression, dyspareunia, lack of sexual desire and reduced sexual satisfaction [19, 24–30]. Nevertheless, there is increasing evidence that the association between FGC and adverse psychosexual health outcomes is context- dependent [12, 27, 31–35]. In contexts where FGC is positively regarded, as it is often the case in FGC high prevalent countries, women and girls who underwent FGC are less likely to complain of psychosexual health problems. In contrast, women and girls who underwent FGC and then migrated to Western countries, where FGC is negatively regarded, are more likely to report psychosexual problems [27, 31–35].

Therefore, many European countries, including Norway, have established specialized clinics to meet the healthcare needs of immigrant women and girls who underwent FGC and to provide them with appropriate and sensitive healthcare [36]. The FGC-related healthcare services generally provided in these clinics are deinfibulation, removal of keloids and cysts, clitoral reconstruction, and psychosexual counseling.

Deinfibulation is a minor surgical procedure performed before or after marriage (premarital or marital) on infibulated women and girls who underwent FGC to expose both the vaginal and urethral openings [37–40]. It is typically performed for obstetrical reasons (e.g. to enable childbirth), but can also be performed for gynecological and genitourinary reasons (e.g. to ease urinary and/or menstrual flow, enable sexual intercourse and reduce sexual pain). Removal of keloids and cysts is often conducted in conjunction with deinfibulation.

Clitoral reconstruction is a surgical procedure developed to reduce vulvar and clitoral pain, as well as to improve sexual function and body image in women and girls who underwent any type of FGC involving the removal of the clitoris [41–46]. The idea behind clitoral reconstruction is that the clitoral glans is the part of the clitoris that is removed during FGC, while other parts such as the crura and the body are left intact underneath the ensuing scar tissue. Therefore, it is possible to reconstruct/replace the cut part of the clitoris through the removal of the scar tissue, the exposure of the clitoral stump, and the creation of neo-prepuce. Nevertheless, independent evidence on the safety of clitoral reconstruction is scarce [39, 41].

Psychosexual counseling, on the other hand, is deemed both safe and effective in enhancing the body image, self-confidence, and subsequently the sexual function of women and girls who underwent FGC. Therefore, the WHO guidelines on the management of FGC-related health problems recommend psychosexual instead of clitoral reconstruction for the enhancement of sexual function [39, 41, 45].

In Norway, out of the aforementioned FGC-related health services, only deinfibulation and removal of genital cysts and keloids are available [36]. Neither clitoral reconstruction nor psychosexual counseling with special competence on FGC is available. Considering that psychosexual problems associated with FGC are more relevant in countries of migration, the unavailability of such services in Norway could be a cause for major concern. Nevertheless, already available FGC-related services in Norway are underutilized [47], possibly because of sociocultural beliefs pertaining to premarital sexual behavior [9, 48]. Therefore, prior to the development of any new services, it is important to explore whether women and girls in Norway who underwent FGC have a need for such services, and whether they intend to use such services were it to be available. In this article, we aspire to answer the following questions: *What are the attitudes of women and girls, who underwent FGC and who lives in Norway, towards the utilization of FGC-related healthcare services, regardless of their availability in Norway? What are the perceived norms pertaining to these services? Would these women and girls use psychosexual counseling and/or clitoral reconstruction were they to be offered?*

Theoretical perspectives

The analysis in this article is primarily informed by the theory of planned behavior and to a lesser extent by the theory of sexual script. As clitoral reconstruction and psychosexual counseling are unavailable in Norway, it is unlikely that our participants have ever used these services. By focusing on the "intention" to use rather than the actual use, the theory of planned behavior [49] accommodates the exploration of attitudes and norms related to the utilization of unavailable services.

In the theory of planned behavior [49], the *intention* to perform a certain behavior is postulated to be the most important determinant of that behavior. Also, the person's *intention* to perform the behavior is determined by that person's *attitude* towards performing the behavior, the *subjective norm* associated with the behavior, and the person's *perceived control* over the performance of the behavior. A person is considered to have a *positive attitude* towards a behavior when that person holds strong beliefs pertaining to the positive value of performing that behavior, and vice versa. Similarly, the *subjective norm* is considered positive when the person believes that important referents such as parents, spouses, etc. expect him/her to perform the behavior and he/she is motivated to meet the expectations of these referents. Still, *perceived control*, the degree to which the person believes he/she can exercise control over the performance of the behavior, is considered the most important determinant for the *intention* to perform the behavior.

In this study, we found that the attitudes and norms pertaining to the intention to utilize deinfibulation, clitoral reconstruction and psychosexual counseling were predominantly related to sexual norms. This led us to the sexual script theory.

In the sexual script theory [50], sexuality is understood as scripts learned from available *cultural scenarios*. These *cultural scenarios* are described as values and principles that are collectively developed and held, and which act as the reference for what to count as sex and sexual situation, as well as for what to consider as acceptable sexual behaviors. In interpersonal relationships, these *cultural scenarios* can be individually adapted as *interpersonal scripts* and possibly internalized as *intrapsychic scripts*.

How these two theories helped to inform our analysis is described in the methods and together with the findings.

Methods

This article is based on data from a larger explorative qualitative study examining the perceptions and experiences of Norwegian Somali and Sudanese pertaining to their FGC-related healthcare needs and healthcare services. The data was collected in the period 2016–2018 utilizing participant observation and semi-structured repeat interviews with 26 participants.

The study participants were recruited from one of three Norwegian cities (Oslo, Drammen, and Trondheim) that accommodate a high number of girls and women with origins from one or more of the four largest groups in Norway subjected to FGC, and in particular infibulation, i.e. Somali, Sudanese, Eritreans, and Ethiopians. To facilitate between-groups comparisons, we decided to focus on only two groups: 1) the Somali, as they constituted the largest group in Norway subjected to FGC and 2) the Sudanese, because of the similarities between them and the Somali in terms of prevalent types of FGC, religion, and cultural values such as chastity and marriageability [9].

Participants, recruitment and data collection

The 26 participants we interviewed were between 16–63 years old (see Table 1). Six of these participants were initially recruited as key informants, but their interviews thereafter expanded and also included personal FGC-related experiences. They were purposefully recruited based on their extensive knowledge of Somali and Sudanese immigrants in Norway gained through their work experiences in the educational and healthcare systems, as well as local non-governmental organizations. The remaining 20 participants were recruited through different starting points and with purposeful diversity in a select number of characteristics (see Table 1). We also made special efforts to recruit participants in the age group 16–25 years since they were mostly underrepresented in previous FGC research in Norway.

Potential participants were informed about the aim of the study, the voluntary nature of participation, and further process if they were to agree to participate. They were also oriented

Table 1. Overview of participants' characteristics.

Characteristic	Participants	
	Other participants (n = 20)	Key informants (n = 6)
Background		Withheld for anonymity
Somalia	9	
Sudan	11	
Age (years)		
16–21	8	1
22–27	7	1
28–33	1	0
34–39	2	0
40–45	1	2
46–51	1	0
52–57	0	1
58–63	0	1
Marital status		
Single	9	Withheld for anonymity
Married	7	
Divorced	4	
Have children		
Yes	8	Withheld for anonymity
No	12	
Education		
≤ Middle school	2	0
High school	8	1
College	7	3
Graduate school	3	2
Type of FGC		
Type I	2	Withheld for anonymity
Type II	4	
Type III	14	
Length of stay		
< 1 year	1	0
1–5 years	6	0
6–10 years	5	0
>10 years	8	6

https://doi.org/10.1371/journal.pone.0233440.t001

about the plan for data storage and management. All those who agreed to participate were asked for their consent. According to the Norwegian Health Research Act, the general rule is that minors can give independent consent from the age of 16. The only exceptions to this rule are when minors in the age group 16–18 years are to participate in clinical drug trials, or when bodily interventions are to be performed. Parental consent is only required in connection with these two exceptions. Therefore, we directly obtained informed consents from all participants, including those in the age group 16–18 years. In accordance with the ethical clearance for this study, we state to have obtained informed consent from a potential participant only when this participant has professed to understand the above-listed information and clearly stated her consent to participate. In our application for the ethical clearance, we have asked to allow oral consent alongside the written one to include illiterate participants and/or those having difficulties in giving written consent. The ethical committee approved our application without stipulation for any form of documentation for the oral consent. Still, we voice-recorded the oral consents of all participants who agreed to that. None of the participants were paid for participation, but many were compensated for transport and/or wages lost in the form of a gift card (the equivalent of 30 USD).

The study was first approved in 2016 by the Norwegian Social Science Data Services as a pilot project, and then by the Norwegian Regional Committee for Medical and Health Research Ethics in 2017 as a Ph.D. project.

Recruitment was stopped once we ceased to observe new information in the collected data. 61 interviews were conducted with the 26 participants, as 17 participants were interviewed twice and nine participants three times. All interviews were conducted by the first author (MMZ) in participant-selected locations, such as cafés and homes of either MMZ or the participants themselves. The interviews with Sudanese participants were conducted in Arabic, while Somali participants were interviewed in either English or Arabic or a mixture of English and Norwegian.

The first interviews served two purposes: building trust, and inviting and encouraging the participants' own narrations of FGC related experiences. These interviews lasted between 30–90 minutes, during which neither voice-recording nor hand notes were taken. However, immediately after each interview, MMZ recorded her recollections, as well as her interpretations of the interview. In these interviews, MMZ asked the participants to narrate what they could remember and wanted to share concerning their circumcision experiences (See S1 Appendix. Semi-structured interview guide). They were also asked to focus during these narrations, wherever possible or applicable, on experiences of health problems they attributed to the circumcision, and how these health problems were dealt with and why. The participants' narrations went mostly uninterrupted and with a little probing. At the end of these first interviews, all participants were invited to second interviews. All of the 26 participants accepted the invitations and the time and location of the second interviews were agreed upon.

The second interviews were also flexible and lasted between 60–180 minutes. In these interviews, MMZ's interpretations and recollections of information given in the first interviews were individually discussed with the participants, probing for confirmations, corrections, and elaborations. Still, the need for probing was often minimal since the participants were mostly forthcoming with their views and experiences. All of the second interviews were voice-recorded with participants' permission.

Thereafter, the author's preliminary interpretations of patterns and emerging themes were individually discussed and expanded upon during additional third interviews with nine participants. These interviews were also voice-recorded and lasted between 60–90 minutes.

In addition, observations from MMZ's participation in over 20 workshops and seminars on FGC, as well as validation group discussions carried out at the end of data analysis with additional 17 Sudanese and Somali participants, added further insight and weight to the findings.

Analysis

All voice-recordings, including those of MMZ's recollections and reflections after the interviews, were entered into NVivo 12. Recurrent themes and patterns were identified following the thematic analysis approach described by Braun and Clarke [51]. Still, rather than transcribing the voice-recordings, MMZ listened twice to each interview in its entirety before starting to assign codes to the different extracts of the audio. The initial codes were then refined in the light of new insights gained from the third interviews, as well as discussions with the last author (REBJ). Codes were then sorted into potential themes and all corresponding data extracts were collated under these initial themes. These themes were repeatedly reviewed and refined until clearly identified themes and sub-themes were developed. The collated audio extracts under these refined themes and sub-themes were transcribed and translated directly to English by MMZ. Finally, using the theories of planned behavior and sexual script as additional lenses, the content of themes and sub-themes relevant to the research questions addressed in this article were consolidated into a rich and coherent description. To protect the participants' identity, and to minimize the risk of recognition, we have intentionally withheld and/or kept the participants' characteristics vague and ambiguous. We have also assigned more than one pseudonym to a few participants.

Reflexivity

To build trust, the information given to the participants during recruitment was repeated in the first interviews, reemphasizing issues of confidentiality, de-identification, and possible repercussions for the researcher if she were to deviate from these ethical principles. Furthermore, we think MMZ's position and personality had helped to achieve a good balance between MMZ's roles as insider and outsider, as described by Kusow (2003), and had thus played a major role in gaining the trust of both the Sudanese and Somali participants. As a Sudanese female born and raised in Sudan, both Somali and Sudanese participants probably perceived MMZ as an insider i.e. someone who shared experiences and understanding of cultural subtleties and knowledge of FGC. Still, sharing the same background as the researcher could have the disadvantage of making some of the Sudanese participants afraid of gossip and judgment were they to share opinions or experiences that deviate from the community's socio-cultural norm. Fortunately, this did not seem to be the case. A likely explanation could be that MMZ's own deviations from the local Sudanese norms, demonstrated by her western style of dressing and her marriage to a Westerner, had led the participants to also regard her partly as an outsider. Furthermore, MMZ's medical background seemed to have further facilitated trust and openness. Some women said that MMZ's medical and cultural backgrounds made it easy to share information that they had not previously shared with anyone.

Findings

Almost all participants explained their intention to use or not to use FGC-related healthcare services through references to different sets of social norms and expectations pertaining to premarital and marital sexual conduct. These social norms and expectations were often described by the participants as well-known, but mostly non-verbalized, sets of values that they were expected to conform to. All study participants described how they had learned, from early on, that marriage and motherhood were the measuring stick against which their future value would be assessed. They explained how an unmarried, divorced, and/or childless woman with an impressive repertoire of academic and/or professional achievements would commonly be referred to as "unfortunate", "unlucky", or even "a failure" by her family, friends and the local community. Therefore, women would generally be motivated to adhere to the norms that would increase their chances of getting and/or staying married. Nevertheless, it soon became evident that there were considerable variations among the participants regarding these latter norms, mainly those pertaining to staying married. These variations were evident between Somali and Sudanese, old and young participants, and within these groups. For example, a few Sudanese participants strongly believed that not displaying interest or pleasure in the sexual act was the sexual norm for married Sudanese women. Yet, this strong belief was intensely contradicted by other Sudanese participants. Hence, we found the term *subjective norms* as described in the theory of planned behavior [49] to best describe the varying perceptions among our participants on what they believed to be the societal sexual norms. Therefore, we grouped similar subjective norms together, which eventually resulted in the formation of four different *cultural scenarios*. These scenarios included one premarital scenario (the virgin scenario) and three marital ones (the passive sexual partner scenario, the conditioned active sexual partner scenario, and the equal sexual partner scenario). Each of these cultural scenarios had implications for the acceptability of the various FGC-related healthcare options (See Table 2), mainly deinfibulation, clitoral reconstruction, and psychosexual counseling.

Although one could expect it to be easy to distinguish between the subjective norms forming the various cultural scenarios and the participants' own attitudes, we found that such distinction was only evident when there was a conflict or discrepancy between one's attitude and the subjective norm. Similarly, agency or perceived control was most evident in the narratives of those who rejected the subjective norms.

The virgin scenario

All of the participants referred to virginity as the most important prerequisite for marriageability, both in their countries of origin and in their local communities in Norway. Also, almost all of the participants talked about sex or sexual intercourse in terms of penetrative vaginal intercourse, and of virginity in terms of the absence of such penetration. Virginity was claimed to be verifiable by the presence of an intact hymen. As long as girls were to avoid penetrative vaginal intercourse and consequently preserved their hymens, almost all of the participants believed that these girls would be considered virgins. On the other hand, girls were said to be considered as "open" and "non-virgins", even in the absence of any sexual activity, if their hymens were deemed not intact. It was also a widespread strong belief among the participants that during the first vaginal intercourse, a man could tell whether the girl's hymen was intact or not. A man would be expected to notice a number of physical signs that would either confirm or negate its intactness. These signs were described in relation to different stages of vaginal intercourse. The first sign would be a very tight vaginal opening sufficient to make the girl or woman scream out of pain upon the first attempts of penetration. The second was claimed to be a noticeable resistance from the hymen, which would temporarily prevent full vaginal penetration. The third and last sign was described as a snapping sound that would indicate the break of the hymen. Once the act was over, the ultimate proof would be the presence of blood, whether on the bedsheet, in-betweens the girl's or woman's thighs, or as droplets on the floor on her way to the bathroom. Many of the participants explained how these signs would be repeatedly emphasized in stories shared among friends about wedding nights. A few participants said that even though they had never engaged in premarital sexual activity, they were still very scared of failing to prove their virginity. They were aware of an ongoing discussion on the presence of different types of the hymen and that not all women would bleed at the first vaginal intercourse. One of them was Suha, a Sudanese participant in her early-20s who said:

> *"My married friends scared me. They told me that I will experience severe pain, will bleed and hear a pop sound . . . they really scared the hell out of me. . . In general, whether you bleed or not is a source of stress for both men and women. For the man, he will be very suspicious if the wife did not bleed. For the woman, if she did not bleed, she will be afraid that her husband will think that she was not a virgin. She will be really scared."*

Nevertheless, these physical signs (tightness, pain, and bleeding) were claimed not to always be sufficient. Almost all participants claimed that also women's behavior during first marital intercourse would be scrutinized for signs of virginity. Typically, a virgin should be shy, sexually ignorant, and very reluctant. Any deviation from these expectations was deemed sufficient

Table 2. Summary description of themes and their implications for the intention to use FGC-related healthcare services and the care and prevention work on FGC.

Theme	**Summary description***	**Implications**	
		Intention to use FGC-related healthcare services	**Care and prevention work on FGC**
The virgin scenario	• Both Sudanese and Somali participants. • As a sexual partner, a virgin: ○ Is shy, reluctant, and sexually ignorant. ○ Experiences severe pain upon her husband's first attempts of penetration, ○ Demonstrates that she is in pain (e.g. screaming), ○ Bleeds profusely once penetration is achieved (full vaginal penetration varies from few days up to several months).	Reluctance to undergo premarital deinfibulation.	• Concerns over safeguarding and proving virginity are central to the continued practice of FGC and the reluctance to seek healthcare. Activists and healthcare professionals should aptly address these concerns.
The passive sexual partner scenario	• Mainly Somali participants. • Sexual intercourse is the husband's "legal right". Hence, it is the woman's duty to have sexual intercourse with her husband whenever he wants, as long as it is not anal sex, neither during her period. • In addition, a good wife should: ○ Not show interest in sex (must not initiate), ○ Be passive (lie down like a log) and never show that she is enjoying sex even if that is the case.	Reluctance to use FGC-related healthcare services that focus on improving the women's sexual experiences such as psychosexual counselling and clitoral reconstruction. In contrast, deinfibulation in the context of pregnancy and childbirth is very acceptable.	• While assessing the sexual function of girls and women with FGC, health professionals need to remember that: ○ High frequency of sexual intercourse is not necessarily a reflection of the women's desire. ○ Not initiating sexual encounters is not necessarily a reflection of lack of desire.
The conditioned active sexual partner scenario	• Only Sudanese participants. • Sexual intercourse is the husband's "legal right". Hence, it is the woman's duty to have sexual intercourse with her husband whenever he wants, as long as it is not anal sex, neither during her period. • However, a good wife in this scenario is an active sexual partner. She: ○ Initiates (traditional or other signals: smoke bath, traditional perfume, sandal incense, sexy lingerie, and candle light). ○ Reciprocates and enjoys sexual intercourse with her husband–up to a limit (she should not exceed her husband's sexual stamina). ○ Demonstrates sexual desire and pleasure even when that is not the case.	FGC-related healthcare services that can improve the married women's sexual experiences such as psychosexual counselling and clitoral reconstruction are commonly accepted.	• While assessing the sexual function of girls and women with FGC, health professionals need to remember that: ○ High frequency of sexual intercourse is not necessarily a reflection of the women's desire. ○ Initiation is not necessarily a reflection of sexual desire.
The equal sexual partner scenario	• Mainly younger Somali and Sudanese participants in the age group 16–25 years. • Virginity is irrelevant. • Women's sexual pleasure have equal importance to that of men: ○ A girl or a woman can initiate, reciprocate and fully enjoy sexual intercourse. ○ She can also refuse her husband's/partner's sexual advances. • Strongly believe that FGC is associated with sexual health complications. These beliefs were attributed to either first- hand knowledge from the girls' first experiences of sexual intercourse or to the media. This resulted in: ○ Feelings of shame and inadequacy. ○ Need to dissociate from the media image of circumcised girls as weak and sexually mutilated victims.	All FGC-related healthcare services that can improve the girls and women's psychosexual wellbeing such as deinfibulation, psychosexual counselling and clitoral reconstruction are strongly accepted.	• A need for critical reflections by activists and the media over the unintended repercussions of their choices of words and the contents of the messages they use in anti-FGC campaigns.

*This summary description does not reflect the variations within each theme.

https://doi.org/10.1371/journal.pone.0233440.t002

to raise the man's suspicion regarding the bride's virginity. Asha, a Somali participant in her mid-20s, explained why she pretended to be reluctant and sexually ignorant on her wedding night as follow:

> *"A friend of mine, her husband accused her of being sexually experienced. He told her he can see that she was excited. And that was just because . . . since she was educated and well-informed, she knew what was going to happen! So people tell you to pretend to know nothing, even if you do. You have to act stupid and naive and make him think that he is doing all the teaching."*

Many participants shared numerous stories about a few girls that they personally knew, and many that they did not, who were divorced immediately after the wedding nights because the husbands had declared them "used", "open" and "non-virgin". Such an outcome, to be declared as a non-virgin on the wedding night, was considered to be amongst the worst mishappenings that could transpire a Sudanese or a Somali girl and her family. It was described as "scandalous" and "bound to tarnish the family reputation once and for all". Most of the participants were hence of the opinion that Sudanese and Somali girls and women would feel tremendous responsibility towards preserving family honor.

The virgin scenario had a strong influence on girls' and women's perceptions of the acceptability of premarital deinfibulation. Regardless of the magnitude of health problems that unmarried girls and women might encounter because of infibulation, many of the participants claimed that they would be very skeptical of undergoing premarital deinfibulation. Many participants explained that the term *opening surgery*, the English translation of deinfibulation in Norwegian, would equate the procedure to "deflowering" and "compromising virginity". Since many participants considered it probable that future husbands would expect them to be virgins, they had felt it necessary to avoid such procedure. Sara, a Sudanese participant in her early-20s, who despite spending considerable time during the interview to describe how infibulation had adversely affected her health and school attendance, explained why she had decided to forgo premarital deinfibulation:

> *"I would say to myself 'what if I were to have the surgery now and then met a man and got married?' I won't be able to discuss this with him beforehand, you know . . . so if he found that it is not as he expected down there, he might say to himself 'this girl had slept with other men for sure!' Even if I explained, he might not believe me . . . he might even tell my parents and others that I was not a virgin! It would be a scandal! Just imagine that [uneasy giggles] after all my parents had done for me! . . . no, believe me, I am better off this way."*

Furthermore, many participants considered preserving the integrity of the infibulation seal to be a sure measure to pass as virgin. To enable penetrative vaginal intercourse in an infibulated girl or a woman, the seal of skin, ensuing from the narrowing of the vaginal opening during infibulation, would first have to be torn or cut open. This would commonly be done by the husband, using his penis, finger, or other tools over a period of time varying from few days up to several months. This process would cause the girl or woman to bleed and scream from pain. Thus, it would seem that the typical response of an infibulated girl or woman to her first experiences of penetrative vaginal intercourse had become an overarching expectation of how virginity should manifest. Also, this overarching expectation would appear to have become the social script for virginity for all women, irrespective of FGC. Sure enough, many participants considered it important to avoid premarital deinfibulation so as to conform to the social expectations of a virgin. However, some of the participants had different attitudes towards virginity than the subjective norms. These participants were very critical towards the virginity expectation and refused to be measured by it. Two of these participants argued that virginity was meaningless since a girl could engage in a wide variety of sexual activity, including anal intercourse, and still be considered a virgin. Other participants argued that since virginity in Islam was a requirement for both the husband and the wife, and since husbands could not physically prove their virginity, women should similarly not be asked to prove it. The rest described how they, early in life, had decided whether they intended to marry a fellow countryman, and how such a decision had subsequently influenced how they valued their virginity. This quote from Khadija, a Somali participant in her early-40s who had undergone premarital deinfibulation as a 19-years-old, would be a good example:

> *"I was never concerned about virginity. Since I was a child, I kept telling my mum that I will never marry a Somalian man. It did not even have anything to do with virginity or circumcision at the time. I just did not have anything in common with them. My way of thinking and their way of thinking was totally different. I always said that. . . and because I said it many times it did not come as a shock when I decided to marry a Norwegian. But even if I were to marry a Somalian, I believe that there are modern Somalian men who do not care whether you are open or not."*

The perceived control over the decision of not to marry a fellow countryman, unless he was modern, would seem to have influenced Khadija and a few other participants to no longer care about preserving the proof of their virginity. Such perceived control would also appear to have made it simpler for them to undergo or to consider undergoing premarital deinfibulation.

The passive sexual partner scenario

In the first of the three cultural scenarios pertaining to marital sexual conduct, a good wife was described as one who should be sexually available, yet passive. The subjective norms that informed this scenario were shared more by the Somali participants than the Sudanese. Many participants, adhering to both this scenario and the next one, stressed the husband's "legal right" to sexual intercourse. Hence, they considered it to be the woman's duty to let her husband "do his thing" according to his wishes and regardless of hers. However, there were a few exceptions. Many participants cited the husbands' wishes for anal intercourse or sexual intercourse during menstruation as legitimate reasons for the women to not obey the husbands, as both acts were claimed to be forbidden in Islam (*haram*). A few also considered severe illnesses a legitimate reason, but other participants strongly disagreed. Except for these reasons, these participants alleged that it was a wife's duty to patiently await and never reject her husband's advances. Many of the participants believed that if a wife were to deny her husband, she would be cursed by the angels. The notion of marital rape was absent from the descriptions of all but one of the participants. This participant shared the story of a Sudanese friend who claimed to be raped by her husband during their honeymoon, even though the marriage was the result of a two-years-long love story. After tolerating the husband's initial attempts at deinfibulation for several days, the excruciating pain suffered during these attempts had eventually led her to refuse further attempts. The husband had thus become impatient and tied her up and forced himself on her. This led the friend to ask for a divorce and to disclose the reason for this decision to close family members and friends. However, instead of being met with understanding, she was told that this was not rape, but rather a justifiable means for the husband to exercise his legal right. Subsequently, she was pressured to return to the husband with strong instructions to never deny him again. This story would seem to indicate that sexual gratification was largely considered a man's prerogative. An indication that was further strengthened by the acceptance of many participants that women should refrain from initiating sexual intercourse as this would imply that women have sexual desire. The latter was believed to scare the husbands as they would think that their wives had "excessive" sexual urges that might make them more inclined to cheat. Hawa, a Somali participant in her mid-20s, described how the husband of a friend had tried to solve what he allegedly considered problematic behavior:

> *"Men do not like women to take the initiative. They ask the women what is wrong with them. I know someone who was told by her husband not to eat chocolate ever again . . . he thought that chocolate was what made her ask for sex!"*

Many participants explained that out of fear of raising the husband's mistrust, they would refrain from initiating sexual intercourse. For the same reason, if the women who adhered to this sexual scenario were to feel sexual enjoyment during the sexual act, they would make sure to hide it. They generally portrayed sexual intercourse as something not to be enjoyed by the women but rather endured. Still, almost all of these participants said that the prospect of having children made sexual intercourse worth the trouble. The following quote from Fathia, a Somali participant in her mid-30s, was typical:

> *"Sex is not something to enjoy. It is to have babies. The man will come, do his thing and then leave you alone. He does not care that you did not enjoy it. Some men will not trust you if they think you like sex."*

Overall, almost all of those who identified with this scenario said that healthcare services aiming to improve sexual health, specifically sexual counseling and clitoral reconstruction, were totally unsuitable for them. A typical response to inquiries regarding why they have not sought help for their reported experiences of sexual pain or lack of sexual gratification, was giggles that were eventually replaced by serious facial expressions and comments similar to the following by Halima, a Somali participants in her late-20s:

> *"Wouldn't it have been great to finally experience it [orgasm]? [Giggles] But seriously, no, I am happy that it [sexual intercourse] finishes quickly. I am usually so tired and just want to sleep . . .you know . . . after shopping for groceries, cooking, cleaning, doing laundry, looking after the children . . . I am the one who has to do everything around here, you know . . . I just want to be left alone . . . honestly, I would be happy if he found someone else to give him sex [Giggles] No way I would consider changing anything . . . even now [when I am] not enjoying sex, my husband is often suspicious! Are you crazy? Of course, I wouldn't!"*

Thus, healthcare services to improve sexual pleasure for the women such as clitoral reconstruction and psychosexual counseling were considered inherently incompatible with the requirements of their roles as wives. Also, many of the participants described relationships characterized by emotional detachment and painful sexual encounters that made them shy away from intimacy and/or sexual intercourse. Marital deinfibulation, on the other hand, was viewed more positively by these participants but only in the context of pregnancy and childbirth. In other words, unlike improved sexual life, childbirth was considered as an acceptable reason to undergo deinfibulation.

The conditioned active sexual partner scenario

Akin to the previous cultural scenario, this second marital scenario, described only by Sudanese participants, considered sexual intercourse and sexual gratification as the husband's legal right and prerogative. However, expectations to the wives' sexual behaviors differed in that they had to be actively engaged. Almost all participants adhering to this scenario agreed that once virginity was proven, a good wife should initiate, reciprocate, and display enjoyment during the sexual intercourse. Yet, there seemed to be a ceiling to this active engagement, which was mostly explained in terms of not exceeding or overtaxing the husband's sexual drive.

Overall, sexual intercourse was talked about as a cornerstone for marriage that if neglected, marriage would crumble. Wives would be warned that if they did not cater to their husbands' sexual needs, their husbands would most probably cheat, take a second wife and/or divorce them. This perception was expressed in many ways. For example, a woman complaining of an unfaithful husband would be told that it was her fault as she did not please him sexually. Also, if a wife complained about her husband's negligence, stinginess, or aloofness, she would be told that sexual enticement would be her trump card and the way to go. This sexual enticement was described by the participants, adhering to this scenario, in terms of a variety of in- and out- of bed methods. Out-of-bed methods included: wearing sexy lingerie, creating a romantic environment at home, wearing a henna tattoo, waxing, and using traditional sauna (*dukhan*), incense (*bakhoor*), perfumes (*khumra*), and scrubs (*dilka*). In-bed methods included: being attentive and accommodative to the husband's sexual needs and fantasies, as well as displaying sexual pleasure through body movements and sounds of pleasure. Most of these participants professed to find the out-of-bed methods easy to adopt. In contrast, several had problems with methods pertaining to the in-bed enticement. These latter participants mostly attributed the sexual problems they were facing, such as lack of desire and sexual excitement, pain, and inability to reach orgasm, to circumcision. Some claimed that their ability to enjoy sexual intercourse was cut away together with their clitorises. A few also said that the narrow vaginal opening, ensuing from infibulation, meant that sexual intercourse was a continuous source of pain even after years of marriage. Thus, to still be expected to experience and display sexual pleasure seemed for many of them unfair and a clear double standard. They further explained that the reason they had been subjected to FGC, in the first place, was the perceived need of meeting the Sudanese men's requirement of virginity. Subsequently, they blamed the men for all sexual challenges they were experiencing and felt "betrayed" and "disappointed" when their spouses' accused them of being "frigid" and "cold". To avoid being called such names, as well as to sexually please their husbands, several participants claimed that brides would be advised by other married friends or relatives to use lubricants and local analgesics, hide their difficulties, and fake desire and orgasm. The following quote from Nagla, a Sudanese participant in her early-20s, depicted some of the aforementioned expectations of a good wife according to this cultural scenario:

> *"The intimate relation is essentially an interaction where the two melt into each other. Sudanese men, unless they are cold, do not like cold women. So, as a wife, I should show my interest and make myself ready. As you know, once you have the dukhan, henna, khumra, or dilka, your man will know you are ready. . . Of course, some women do that out of duty and then lie down there like a log. This is so bad! Interaction and reciprocation make the marriage stronger. If I was cold and he met a beautiful woman in the street, he will be seduced by her. So, if I was cold, I will have to fake it to keep my home and marriage intact."*

Almost all of the participants, adhering to this scenario, claimed that sexual interest and desire were easy to fake. Yet, faking orgasm was found by some participants unfamiliar and difficult to the extent that a few had actually received detailed instructions from close friends and relatives on how to do that. A typical example of such instructions was given by Nada, a Sudanese participant in her 40s:

> *"She told me to move, increase the rhythm of my breathing and make it louder . . . also . . . to grunt and to contract my vagina . . . it was very graphic! I was shocked."*

Although almost all of the participants believed faking to be a good strategy, those who professed to do that were a bit skeptical. Some felt that it often made their spouses spend a long time experimenting with new sexual positions, which meant they had to endure for a longer time than if they were not pretending. Many also experienced faking sexual excitement as emotionally draining. They confessed to feelings that resembled grief and longing, grief over the cut clitoris, and longing for these sexual feelings that they were faking. The following quote from an interview with Munira, a Sudanese participant in her 30s, would illustrate how these participants typically talked about the clitoris and sexual pleasure:

> *"I was thinking about it [the clitoris] all the time. I will be in the cinema and suddenly I am looking around wondering if I am the only one there without a clitoris. . . the only one who doesn't fully enjoy sex. So, I was very excited when I first heard of clitoral reconstruction. It was on a TV documentary I think. . . I am not sure. . . anyway, for months I couldn't think of anything else! I asked all my friends if they knew anything about it. I even called a doctor friend in Sudan. . . he is actually a man! Imagine how shameless I was [Laugh] it shows you how desperate I was then [Giggles]. He told me he didn't know about the operation. He wasn't a gynecologist, that's why. He thought it might be useful, but he thought what I really needed was counseling. . . he thought the real problem was in my head. . . he was probably right. . . anyway, I was very disappointed when I found out that it [clitoral reconstruction] wasn't available in Norway."*

The majority of our Sudanese participants seemed to be very interested in improving their sexual lives and, thus, in healthcare help in the form of psychosexual counseling and clitoral reconstruction. This finding was also emphasized by all of our six key informants, who worked closely with a much larger number of Somali and Sudanese women than the one we have interviewed. The following quote by Sara, one of these key informants, was typical:

> *"You know, I worked for a long time with the Somali [before also started working with the Sudanese] and was used to the fact that they won't discuss sex in front of others. So I was in a way unprepared for the Sudanese! [Giggles] The way they openly talked about sex. . . it was refreshing! [. . .] They told me many times that they needed to talk to a professional who can teach them about sex and sexual pleasure."*

Still, the participants' apparent interest in improving their sexual lives had not translated into an unequivocal interest in marital deinfibulation. Instead, the participants' attitudes towards marital deinfibulation were primarily influenced by their husbands' preferences rather than the subjective societal norms. A few considered, in agreement with their spouses, their experiences with marital deinfibulation to be very positive. These deinfibulations had commonly been undertaken to facilitate vaginal penetration and/or childbirth. They said to feel a noticeable improvement in their sexual lives, both in terms of reduced pain and increased sexual pleasure after deinfibulation. In contrast, other participants had negative attitudes towards marital deinfibulation. These participants were unhappy with the outcome of their deinfibulation experiences, which had been performed in connection to pregnancy and childbirth. These participants insisted that the doctors had opened them more than what they believed to be necessary and appropriate. A major concern was their spouses' negative reaction. They complained about how their spouses were repeatedly telling them that they had become "too wide", using idiomatic expressions to equate vaginal penetration after deinfibulation to driving in "the highway". Subsequently, these participants were seriously contemplating options that would make them “tight” once again such as using the special herbal mix “*Afsa”* or even traveling abroad to undergo reinfibulation. On the other hand, three participants had gone against their husbands’ wishes for marital deinfibulation. These participants revealed that they had strongly resisted their husbands’ pleas to seek deinfibulation during their honeymoons. Fear of reliving their childhood experiences of infibulation, motivated them to take control and refuse to conform to their spouses’ wishes, even at the high expense of getting divorced.

The equal sexual partner scenario

In this last scenario, women’s sexual pleasure was believed to have equal importance to that of men. It was mainly younger Somali and Sudanese participants in the age group 16–25 years who helped to inform this scenario, but a few were much older. These participants seemed to identify with subjective norms that centered on the ideals of gender equality. They expected their boyfriends or husbands to contribute equally to household chores and the raising of children, and in return that they (the participants) would contribute financially. Also, that they would be free to initiate, reciprocate and fully enjoy and express their sexuality. The following quote from Aminah, a 21 years old Somali participant was typical:

> *“We are in Norway*! *This is not Somalia*, *where the woman has to do everything . . . in and out of the house*. *Even in the most conservative countries . . . like Saudi Arabia . . . it is expected that men share some of the responsibilities*. *They take care of money and heavy work*, *while the women stay at home to clean*, *cook*, *and take care of the kids*. *But in Somalia*, *the women will do everything and the men nothing*! *Luckily we are in Norway now*. *We do everything equally [smile]*.*”*

Almost all of the participants identifying with the subjective norms on gender and sexual equality attributed these norms to the prevailing values in the larger Norwegian society. The exception was a couple of participants who attributed these values to what they claimed were the correct Islamic teachings. They clarified that according to the correct Islamic teachings, sexual gratification was an equal legal right of the wife as it was of the husband. Therefore, it was also a husband’s duty to sexually please his wife.

Furthermore, most of the participants identifying with this scenario anticipated full autonomy in all personal decisions, including the right to reject unwanted sexual advances, even those made by boyfriends and husbands. Thus, these participants strongly considered it rape if they were to be subjected to forced sexual advances by a boyfriend or a husband, and found it unforeseeable that family members or friends would try to convince them otherwise. A few of these participants also seemed to have strained relationships with their families. They confessed to harbor strong feelings of anger towards their parents, particularly their mothers, for failing to protect them from FGC. They believed FGC to be a “barbaric” and “cruel” tradition that negatively affected their health and wellbeing. Still, they chose to suppress this anger instead of talking it over with either their parents or professionals. They found talking to their parents about such feelings to be extremely difficult. Similarly, they were afraid that talking to professionals would exacerbate prejudices towards parents of non-Western backgrounds. The rest of participants had equally negative attitudes towards FGC, but they claimed to have forgiven their parents for subjecting/ letting them be subjected to FGC. They generally excused their mothers for “not knowing better” or “being really young” at the time. Also, common to the participants represented by this scenario was their strong beliefs concerning sexual health complications of FGC and their positive attitudes towards healthcare services geared towards improved sexual health. Five of the participants explained that their strong beliefs on sexual complications stemmed from first-hand knowledge gained during their first experiences of sexual intercourse. These five participants clarified that they had found it difficult to disclose, beforehand, their FGC status to their boyfriends/husbands. Therefore, they ended up in awkward situations when, amid their first sexual encounters, it was suddenly revealed that they were infibulated. Two of them had dealt pragmatically with the situation, while the other three professed to still struggle with residual feelings of shame. One of the two participants who took a pragmatic approach was Jawaahir, a Somali participant, who was 19 years old at the time:

> *"We tried to have sex. He tried and tried but could not get it in . . . On top of that, it was extremely painful. So I went to my general practitioner and told him what has happened. He referred me to the women clinic to get the surgery [deinfibulation]. We tried again sometime after the surgery and it worked perfectly this time. Mission accomplished, case closed!"*

For Jawaahir and another participant, the awkward and difficult first sexual encounters did not result in residual feelings of inadequacy or shame. Both claimed that deinfibulation was all they needed to move forward with their sexual and social lives. In contrast, Ilham, a 27 years old Sudanese participant, was one of those who professed to continue to struggle with residual feelings of shame and poor self-image many years afterward:

> *"It was like a nightmare! The wedding party was over and we went to the hotel. And there we were . . . the two of us alone. Like any other bride, I was shy, yet excited. It started well . . . but suddenly in the middle of it all, he stopped . . . he got up . . . and got dressed . . . I was confused. He sat next to me and covered me with the bedsheet. He then said to me 'you are infibulated, right? Why didn't you tell me? I never wanted to marry a girl that was circumcised, let alone infibulated! Still, if I knew you were infibulated, we could have arranged for it to be opened'! I was mortified. I wished the ground would open and swallow me up! I told him that it wasn't too late; he can still divorce me and find another one who is not circumcised to marry. He hugged me and reassured me that was not what he meant . . . he said he loved me, and because he loved me he didn't want to cause me any pain . . . and that would have been impossible with infibulation. So if I had told him beforehand, he could have arranged for it [infibulation] to be opened. I eventually calmed down and agreed to go and have it opened by a doctor. But you know what? Something inside me was broken that night! I feel so disgusted with myself! He tries to reassure me and tell me that now I am normal down there, but I won't let him look. I always turn the light off when we make love".*

For Ilham and the other two participants, deinfibulation was not sufficient on its own. All three believed that they would benefit from psychosexual counseling. One of them also contemplated traveling to Sweden to reconstruct her clitoris to "completely reverse the circumcision".

The remaining participants who adhered to this scenario said to have first acquired their knowledge of FGC-related sexual complications from the media. All of these participants expressed deep feelings of shame and a pressing need to dissociate from the image presented in the media of circumcised girls as weak and sexually mutilated victims. One of these participants kept her FGC status a top-secret and decided to avoid any situation that could expose her as "mutilated". She claimed that she was unaware of any FGC-related healthcare services. Hence, she had reluctantly accepted the idea of a lonely and childless future. The other participants also kept their FGC status as a secret but decided to act proactively to minimize the risk of being exposed as "mutilated". These participants underwent deinfibulation a long time before they were sexually active. Two of them found that they had their clitorises intact underneath the infibulation, which made it very easy to pretend that they had never been circumcised. Nevertheless, the other two participants, of whom one was married to a Norwegian, said that even after deinfibulation they were still unable to hide their FGC status. Therefore, when they started to have problems reaching orgasm, they decided to fake it rather than risk drawing attention to their original FGC status. Yet, they were unhappy with the toll faking orgasm had taken on both their health and relationships. They professed to find it frustrating that psychosexual counseling was not offered alongside deinfibulation in the specialized FGC-healthcare clinics.

Discussion

With the help of the theory of planned behavior as well as the sexual script theory as additional analytical lenses, we explored the intention of Somali and Sudanese immigrants in Norway to use a number of FGC-related healthcare services.

We found that almost all of the subjective norms that our participants identified with, and which pertained to the intention to use FGC-related services centered on getting and/or staying married. These subjective norms represented different outcomes of the interplay between norms in countries of origin, norms in Norway and the expectations and attitudes of the husbands and partners. The latter was typically gleaned through interpersonal interactions. The different outcomes of this interplay seemed to have changed gradually among the Sudanese participants from traditional subjective norms, to in-between or transitional ones, and finally to subjective norms of gender equality. Contrary to earlier findings from Sudan [52, 53], only small numbers of our Sudanese participants exclusively identified with the traditional norms of virginity and passive sexual behavior. The majority of our Sudanese participants related to transitional subjective norms that combined traditional norms of chastity and virginity with norms of active sexual behavior. A few rejected all traditional subjective norms and fully adopted those of sexual and gender equality. While no other study did describe these transitional subjective norms, other studies in Norway [9, 48], Canada and Australia [54] similarly identified virginity as an important sexual norm for their Sudanese participants. For our Somali participants, the outcomes of the interplay between the different norms varied between total support of traditional subjective norms such as virginity and passive sexual behavior among older participants to complete rejection of the same norms among many of the younger participants. These findings were in accordance with other findings from Norway [9, 48], the United States [55], Canada and Australia [54]. While the concept of sexual intercourse as a duty and obligation was linked to traditional norms in our participants' countries of origins, this concept, together with other sexual challenges such as faking orgasm, were also documented among ethnic Norwegians [56] and American women [57] who did not practice FGC, but suffered from decreased sexual desire, sexual pain, and anorgasmia.

Our second finding was that each of the traditional and transitional subjective norms, as well as the subjective norms of gender equality, had specific implications for the intention to use FGC-related healthcare services. Similar to previous findings [9, 48], we found traditional subjective norms, which we grouped under the virgin and passive sexual partner scenarios, to have negative implications for the intention to use almost all of the FGC-related healthcare services. In contrast, subjective norms of gender equality had positive implications for the intention to use all of the same services. The picture was more complex though for the transitional subjective norms that we grouped in the conditioned active sexual partner scenario. We found the transitional subjective norms to have mostly positive implications for the intention to use services that help to improve marital sexual lives, yet negative implications for the intention to use premarital services.

We further found that attitudes and subjective norms pertaining to the intention to use FGC-related services were unsurprisingly inseparable when the participants found these norms agreeable or unavoidable. However, it was possible to distinguish between the two when there was a discrepancy between the participants' attitudes and the subjective norms. Finally, we established that agency/control was exercised to both reject and conform to negative subjective norms pertaining to the intention to use FGC-related services. Some participants had undergone premarital deinfibulation and risked dishonoring their families by rejecting the negative subjective norms towards the procedure, while others refrained from undergoing marital deinfibulation and risked divorce by rejecting the positive subjective norms towards this later procedure. Hence, reluctance to utilize FGC-related healthcare services should not be equated with a lack of agency.

Conclusion

In this article, we explored the intention of Somali and Sudanese immigrants in Norway to use a number of FGC-related healthcare services. We found that the intention to use these healthcare services varies between and within our two groups of Somali and Sudanese participants. We also found that the intention to use different services, or even the same service but at different points of time, could vary in the same individual. Nonetheless, many of our participants have positive attitudes towards psychosexual counseling and would most probably use the service were it to be offered as part of the Norwegian FGC-specialized healthcare services. These findings indicate that the underutilization of some FGC-related healthcare services does not necessarily mean that other FGC-related services would also be underutilized. An insight that could prove valuable not only for Norwegian but also for other policy-makers and healthcare professionals during the planning and/or delivery of FGC-related healthcare services. In addition, our findings give deeper insights into the meaning of FGC for immigrant women. One of these insights is that infibulation acts as a safeguard and/or evidence of virginity for girls with FGC, hence many of these girls are reluctant to seek and/or accept healthcare. These concerns over safeguarding and/or providing proof of virginity could also contribute to the continued practice of FGC. Therefore, both activists and healthcare professionals should aptly address these concerns. Furthermore, as evident in this article, sexuality and FGC are closely related. Hence, in their meeting with girls and women with FGC, healthcare professionals should not avoid talking about sexuality. They should also remember that many girls and women with FGC perceive sexual intercourse with their husbands as a religious duty that they cannot refuse. Therefore, while assessing the sexual function of these girls and women, healthcare professionals should not equate the high frequency of sexual intercourse with these women's desire. Similarly, initiation or lack of initiation of sexual intercourse by these girls and women is commonly governed by sexual norms and should not be equated with either desire or lack of desire. These latter insights could also be valuable for the validation of instruments used to assess the female sexual function. Finally, our findings indicate an urgent need for critical reflections by activists, the media and healthcare professionals over the use of terminology and messages that can contribute to feelings of shame and inadequacy in young girls. Many young participants in the age group 16–25 years harbored feelings of shame and inadequacy and a need to dissociate from the prevailing image of circumcised girls as weak and sexually mutilated victims.

Supporting information

S1 Appendix. Semi-structured interview guide.
(PDF)

Acknowledgments

We would like to thank our key informants for their insightful reflections and valuable help with the recruitment of participants.

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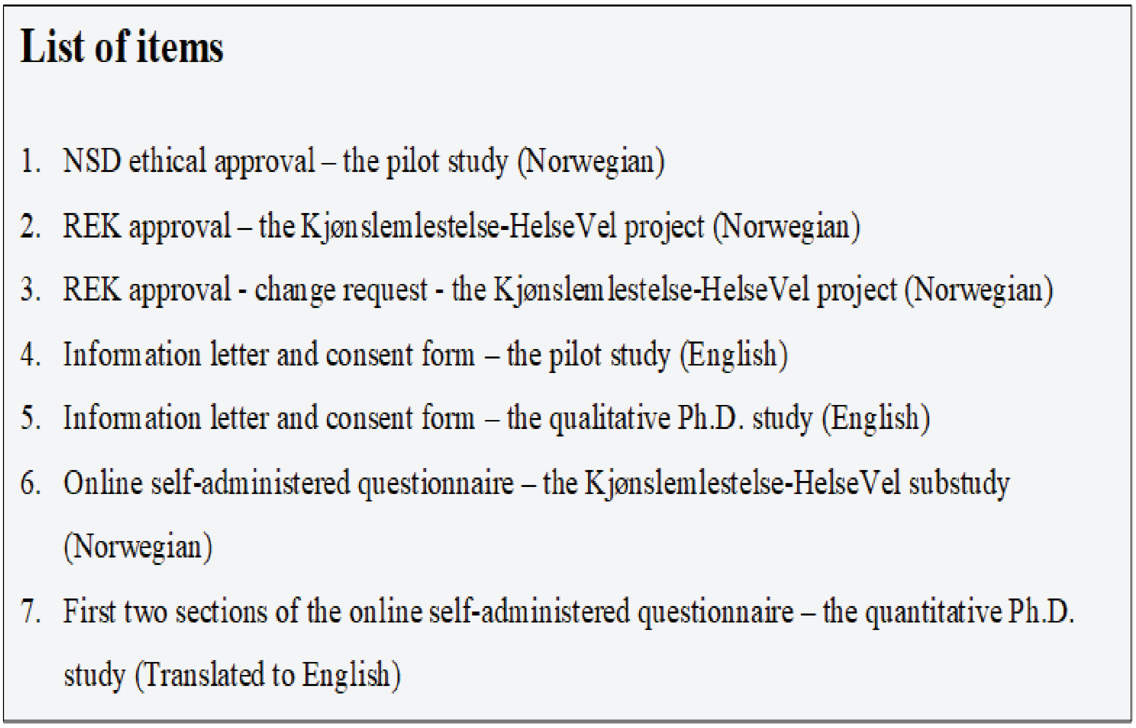
Part III - Appendix



List of items

1. NSD ethical approval – the pilot study (Norwegian)
2. REK approval – the Kjønslemlestelse-HelseVel project (Norwegian)
3. REK approval - change request - the Kjønslemlestelse-HelseVel project (Norwegian)
4. Information letter and consent form – the pilot study (English)
5. Information letter and consent form – the qualitative Ph.D. study (English)
6. Online self-administered questionnaire – the Kjønslemlestelse-HelseVel substudy (Norwegian)
7. First two sections of the online self-administered questionnaire – the quantitative Ph.D. study (Translated to English)

Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

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Ragnhild Elise Brinchmann Johansen
Nasjonalt kunnskapssenter om vold og traumatisk stress (NKVTS)
Postboks 181 Nydalen
0409 OSLO

Vår dato: 07.04.2016 Vår ref: 48121 / 3 / AH Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 30.03.2016. Meldingen gjelder prosjektet:

48121	*Health care for women with female genital cutting living in Norway -A study about knowledge, considerations and experiences from FGC-reparative surgeries*
Behandlingsansvarlig	*Unirand AS, ved institusjonens øverste leder*
Daglig ansvarlig	*Ragnhild Elise Brinchmann Johansen*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, ombudets kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/meldeplikt/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 11.04.2021, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Kjersti Haugstvedt

Åsne Halskau

Kontaktperson: Åsne Halskau tlf: 55 58 21 88

Vedlegg: Prosjektvurdering

Personvernombudet for forskning

Prosjektvurdering - Kommentar

Prosjektnr: 48121

Formålet til prosjektet er å se på helseomsorg for omskårede kvinner og barn i Norge.

Utvalget består av helsepersonell som jobber med feltet, samt kvinner, menn og ungdommer over 16 år fra områder som praktiserer omskjæring.

Utvalget rekrutteres gjennom snøballmetoden, og via helseinstitusjoner. Personvernombudet legger til grunn at frivilligheten understrekes ved rekrutteringen. Vi legger også til grunn at taushetsplikten ikke er til hinder for førstegangskontakt og rekruttering der det skjer via sykehus/klinikker. Vi anbefaler at helsepersonell distribuerer informasjonsskriv til aktuelle pasienter, slik beskrevet i meldeskjemaet. Videre bør pasienter som er interesserte, få tilbud om å ta direkte kontakt med forsker dersom de er interessert i å delta. Denne framgangsmåten ivaretar både taushetsplikten og frivilligheten.

Utvalget informeres skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet som er godt utformet, men vi anbefaler at
- det antydes noe om hvor lenge råmaterialet (transkripsjoner og lydopptak skal lagres) og når det er planlagt å anonymisere/slette råmaterialet (måned/år)
- at utsagnet om at rådata lagres anonymt byttes ut med en forklaring på at rådata lagres konfidensielt og uten navn, men knyttet til en kode. Det kan også forklares at det vil innhentes noen brakgrunnsopplysninger, slik at informanten er forberedt på at det i noen grad vil behandles personopplysninger om dem under prosjektperioden.

Vi ber videre om at utsagnet "Studien er godkjent av Norsk Samfunnsvitenskapelige datatjeneste (NSD). Dette betyr at de er trygge på at studien blir gjennomført på en ordentlig måte, som ikke risikerer ubehag hos de som deltar og at data lagres og presenteres slik at anonymitet sikres" endres til "Studien er godkjent av NSD - Norsk senter for forskningsdata. Prosjektleder legger også vekt på at studien blir gjennomført på en ordentlig måte, som ikke risikerer ubehag hos de som deltar og at data lagres og presenteres slik at anonymitet sikres".

Vi legger til grunn at alle informantgrupper mottar tilsvarende informasjon i studien. Når det gjelder helsepersonell anbefaler vi at de minnes om at de har taushetsplikt ovenfor forsker og således ikke kan oppgi informasjon om enkeltpasienter/pårørende under intervjuene, men kun omtale dem i anonymisert form.

Det behandles sensitive personopplysninger om etnisk bakgrunn eller politisk/filosofisk/religiøs oppfatning og helseforhold.

Personvernombudet legger til grunn at forsker etterfølger Unirand AS sine interne rutiner for datasikkerhet.

Forventet prosjektslutt er 11.04.2021. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres.

Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
- slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette/anonymisere eventuelle lydopptak

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK sør-øst	Camilla Bø Standal	22845821	12.09.2017	2017/977 REK sør-øst D
			Deres dato:	**Deres referanse:**
			18.07.2017	

Vår referanse må oppgis ved alle henvendelser

Inger-Lise Lien
Nasjonalt kunnskapssenter om vold og traumatisk stress

2017/977 Fysisk og psykisk helsehjelp for jenter og kvinner utsatt for kjønnslemlestelse

Forskningsansvarlig: Nasjonalt kunnskapssenter om vold og traumatisk stress
Prosjektleder: Inger-Lise Lien

Vi viser til tilbakemelding mottatt 18.07.2017. Tilbakemeldingen ble behandlet på komiteens møte 16.08.2017.

Prosjektleders prosjektbeskrivelse

Prosjektet undersøker behovet for fysisk og mental helsehjelp som skyldes kjønnslemlestelse samt organisering, terskler, tilgjengelighet og bruk av helsetjenestene på primær- og spesialisert nivå. Studien vil fokusere på ulike former for sosial og symbolsk kapital som kan kreves for å få tilgang til de ulike helsesystemene. Prosjektet vil også bidra med ny kunnskap om forventinger og tro på systemet. Problemstillingene vil bli undersøkt ut fra perspektivet til minoritetsmiljøer og det profesjonelle helsesystem ved hjelp av kvalitative metoder som dybdeintervjuer, fokusgrupper og deltagende observasjon. Studien vil også via kvantitative metoder 1) sammenligne psykisk helse hos jenter i Gambia som har vært kjønnslemlestet og en kontrollgruppe, samt 2) å kartlegge kompetanse hos helsepersonell i Norge.

Saksgang

Søknaden ble første gang behandlet i møte den 07.06.2017, og komiteen fant da at den foreliggende informasjonen ikke var tilstrekkelig til at det kunne fattes vedtak. Komiteen besluttet å utsette videre behandling av søknaden, til prosjektleder hadde kommet med en tilbakemelding på komiteens merknader.

Følgende inngikk i komiteens vurdering, jf. brev av 27.06.2017:

"Prosjektet skal undersøke behovet for fysisk og mental helsehjelp som skyldes kjønnslemlestelse samt organisering, terskler, tilgjengelighet og bruk av helsetjenestene på primær- og spesialisert nivå. I Norge skal anslagsvis 200 fra berørte miljøer (jenter 16-18 år og foreldre/foresatte) og 80 helsepersonell rekrutteres. I Gambia skal det rekrutteres skolejenter i alderen 12-16 år med bakgrunn fra de etniske gruppene mandinka og wolof i ulike skoler og klasser og de vil bli tilfeldig valgt.

Den foreliggende informasjonen er ikke tilstrekkelig til at det kan fattes et endelig vedtak. Følgende merknader ønskes besvart før det kan tas en avgjørelse:

1) I dette prosjektet skal man forske på kjønnslemlestelse som er forbudt ved norsk lov. Det skal rekrutteres omlag 200 personer fra berørte miljøer i Norge (jenter 16-18 år og foreldre/foresatte), samt 80 helsepersonell. Blant deltagerne kan det være personer, for eksempel foreldre, som har medvirket til kjønnslemlestelse av døtrene sine, som ved deltagelse i prosjektet kan komme i fare for å angi seg selv.

Komiteen ønsker prosjektleders refleksjoner rundt det faktum at forskergruppen kan få kunnskap om at norsk lov er brutt, spesielt med tanke på varslingsplikten.

2) Det kommer ikke klart frem hvilken hjelp deltagerne kan få hvis det avdekkes behov for det, annet enn at «De som trenger ekstra hjelp vil bli henvist videre og få bistand om de ønsker det». Komiteen ber om at det utarbeides en konkret plan for oppfølging/beredskap, både i Norge og i Gambia.

3) Når det gjelder rekruttering av deltagere i Norge, opplyses det i søknaden om at man vil benytte brukergrupper som man har laget samarbeidsavtaler med som «gate opener». Komiteen ønsker en nærmere beskrivelse av disse brukergruppene, hvem de er og hvilke samarbeidsavtaler som er inngått.

4) Det er utarbeidet 3 informasjonsskriv til prosjektet. I det engelske skrivet som skal brukes i Gambia, brukes ordet «female cirumcision» konsekvent. I det norske informasjonsskrivet brukes ordene kvinnelig omskjæring og kjønnslemlestelse om hverandre. Komiteen mener kjønnslemlestelse er den nøytrale termen som bør benyttes i de norske skrivene. I de norske skrivene bør det også komme klart frem at kjønnslemlestelse er brudd på norsk lov. Forkortelser, som for eksempel FGM/C, må skrives ut."

Prosjektleder har nå sendt tilbakemelding, mottatt 18.07.2014. Prosjektleder redegjør i sin tilbakemelding for at de mener det ikke er brudd på norsk lov å ha medvirket til kjønnslemlestelse dersom dette skjedde før innreise og bosetting i Norge. Prosjektleder viser videre til at dersom kjønnslemlestelsen skjer etter at familien var bosatt i Norge, så er dette en engangshandling, og det foreligger derfor ikke en generell meldeplikt.

Prosjektleder er klar på at forsker har en avvergelsesplikt dersom de får kunnskap om konkret planlagt kjønnslemlestelse. Dette er tatt inn i informasjonsskrivet, slik at respondentene på forhånd er kjent med avvergelsesplikten.

I sin tilbakemelding beskriver prosjektleder en mal for oppfølgingsberedskap, som vil bli brukt både i Norge og Gambia dersom behov. Etter komiteens syn er denne beredskapen tilfredsstillende.

Komiteen finner at prosjektleder har kommet med gode og utfyllende tilbakemeldinger på komiteens merknader. Komiteen har ingen innvendinger til at prosjektet gjennomføres som beskrevet i søknad, protokoll og tilbakemelding fra prosjektleder.

Vedtak

Med hjemmel i helseforskningsloven § 9 jf. § 33 godkjenner komiteen at prosjektet gjennomføres.

Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknad og protokoll, og de bestemmelser som følger av helseforskningsloven med forskrifter.

Tillatelsen gjelder til 01.04.2021. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 01.04.2026. Forskningsfilen skal oppbevares atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder for «Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse og omsorgssektoren».

Dersom det skal gjøres vesentlige endringer i prosjektet i forhold til de opplysninger som er gitt i søknaden, må prosjektleder sende endringsmelding til REK.

Prosjektet skal sende sluttmelding på eget skjema, senest et halvt år etter prosjektslutt.

Komiteens avgjørelse var enstemmig.

Klageadgang
REKs vedtak kan påklages, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst D. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst D, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Med vennlig hilsen

Finn Wisløff
Professor em. dr. med.
Leder

Camilla Bø Standal
Seniorrådgiver

Kopi til: Nasjonalt kompetansesenter om vold og traumatisk stress ved øverste administrative ledelse: postmottak@nkvts.unirand.no

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Finn Skre Fjordholm	22845821	16.05.2019	2017/977 REK sør-øst D
			Deres dato:	Deres referanse:
			07.05.2019	

Vår referanse må oppgis ved alle henvendelser

Inger-Lise Lien
Nasjonalt kunnskapssenter om vold og traumatisk stress

2017/977 Fysisk og psykisk helsehjelp for jenter og kvinner utsatt for kjønnslemlestelse

Forskningsansvarlig: Nasjonalt kunnskapssenter om vold og traumatisk stress
Prosjektleder: Inger-Lise Lien

Vi viser til søknad om prosjektendring datert 07.05.2019 for ovennevnte forskningsprosjekt. Søknaden er behandlet av sekretariatet for REK sør-øst D på fullmakt, med hjemmel i helseforskningsloven § 11.

Vurdering

REK har tidligere godkjent at det sendes et spørreskjema til helsepersonell. Spørreskjemaet er vedlagt prosjektendringssøknaden. Det er besluttet at det skal sendes til 4100 fastleger i Norge av firmaet IQVIA. Skjemaet spør ikke etter opplysninger om enkeltpasienter og skal besvares anonymt.

Sekretariatet i REK har vurdert den omsøkte endringen, og har ingen forskningsetiske innvendinger til endringen slik den er beskrevet i skjema for prosjektendring.

Vedtak

Sekretariatet har gjort en forskningsetisk vurdering av endringen i prosjektet og godkjenner prosjektet slik det nå foreligger, jfr. helseforskningsloven § 11, annet ledd.

Tillatelsen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden, endringssøknad, oppdatert protokoll og de bestemmelser som følger av helseforskningsloven med forskrifter.

Vi gjør samtidig oppmerksom på at etter ny personopplysningslov må det også foreligge et behandlingsgrunnlag etter personvernforordningen. Det må forankres i egen institusjon.

Klageadgang

Vedtaket kan påklages, jf. forvaltningslovens § 28 flg. Eventuell klage sendes til REK sør-øst. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Vi ber om at alle henvendelser sendes inn på korrekt skjema via vår saksportal: http://helseforskning.etikkom.no . Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansenummer i korrespondansen.

Knut Ruyter
avdelingsdirektør
REK sør-øst sekretariatet

Kopi til: *Nasjonalt kompetansesenter om vold og traumatisk stress ved øverste administrative ledelse: postmottak@nkvts.unirand.no*

Nasjonalt kunnskapssenter
om vold og traumatisk stress a/s

Postadr.: Pb 181 Nydalen,
N-0409 Oslo
Tlf.: +47 22 59 55 00
Org.nr. 986 304 096

Would you like to participate in a study on health care for circumcised women and children in Norway?

The Norwegian Centre for Violence and Traumatic Stress Studies (NKVTS) is conducting a study called 'Health Care for circumcised women and children living in Norway'.

Why are we conducting this study

Several hospitals in Norway offers help for women and children who have been circumcised. We will examine what people know about this, what they think, and their experiences, why some seek help and others do not, and how communities regard such help. We have contacted you because you have connections to a country where female circumcision is a tradition.

What happens if you say yes

We arrange to meet when and where it is convenient to talk about your thoughts and/or experiences with health care for women and children who have experienced circumcision. We will address some themes, and you can decide what you want to say. If there is anything you do not want to answer, it is ok. The interview will take approximately one hour. We can meet several times if necessary. The interview is voluntary. You can change your mind at any time, even during or after the interview.

This happens to the information you give

We will write notes and/or use a tape recorder while we speak. We will not include details that can make you identifiable such as your real name etc. Both notes and recordings/transcriptions will be stored confidentially, using codes to replace names, in a locked cabinet in a maximum of five years after the interview. Thereafter, both the recordings and codes linking your identity to the notes and transcriptions will be permanently deleted. Information gathered from many people will be analyzed together and the final result will be disseminated through scientific papers and presentations in a way that ensures anonymity.

You will receive no payment for participation, but can get a symbolic gift certificate for cinema ticket, transport money or its equivalent.

Ethics and safety

The study is approved by NSD- the Norwegian Social Science Data Services. We will ensure that the study is conducted in an orderly manner that does not lead to discomfort among the participants and that the data is stored and presented in a way that ensures anonymity.

About the researchers

We are two researchers. The project leader, Elise Johansen, is a social and medical anthropologist. She is a single mother of three teenage children. The children's father is from Tanzania, and she has visited and lived in several African countries. The other researcher, Mai M. Ziyada, is a medical doctor and public health expert from Sudan. We can conduct the interviews in the following languages: Norwegian, English, Arabic, Kiswahili and French. If you prefer another language, we can arrange for an interpreter.

Contacts

Project leader: Elise Johansen
Telephone: 93011902
e-mail: r.e.johansen@nkvts.no.

Project member: Mai M. Ziyada
Telephone: 41587569
e-mail: m.m.ziyada@nkvts.no.

………

Consent form

I have read / been read to and explained to, and understood the information about the study and agree to participate in the interview

……………………………… ………………………………

Place and date Signature

Nasjonalt kunnskapssenter
om vold og traumatisk stress a/s

Postadr.: Pb 181 Nydalen,
N-0409 Oslo
Tlf.: +47 22 59 55 00
Org.nr. 986 304 096

Would you like to participate in a study on health care for circumcised women and children in Norway?

The Norwegian Centre for Violence and Traumatic Stress Studies (NKVTS) is conducting a research project called 'Physical and psychological Health Care for circumcised women and children living in Norway'.

Why are we conducting this study

The main objective of the research project is to provide healthcare providers and policy makers with knowledge necessary to ensure adequate access to health care for women and girls with health problems related to circumcision. The project has several sub-studies that includes this PhD study.

Several hospitals in Norway offers health care services for women and children who have been circumcised. For the PhD study, I will examine what people know about these offered services, what they think, what they have experienced, why some seek help and others do not, and how communities regard such help. I have contacted you because you have connections to a country where female circumcision is a tradition.

What happens if you say yes

We arrange to meet when and where it is convenient to you to talk about your thoughts and/or experiences with health care for women and children who experienced health problems related to circumcision. I will address some themes, and you can decide what you want to say. If there is anything you do not want to answer, it is ok. The interview will take approximately one hour. We can meet several times if necessary. The interview is voluntary. You can change your mind at any time, even during or after the interview.

This happens to the information you give

I will write notes and/or use a tape recorder while we speak. I will not include details that can make you identifiable such as your real name etc. Both notes and recordings/transcriptions will be stored confidentially, using codes to replace names, in a locked cabinet for a maximum of five years after the interview. Thereafter, both the recordings and codes linking your identity to notes and transcriptions will be permanently deleted. Information gathered from many people will be analyzed together and the final result will be disseminated through scientific papers and presentations in a way that ensures anonymity.

You will receive no payment for participation, but can get a symbolic gift certificate for cinema ticket, transport money or its equivalent.

Ethics and safety

The study is approved by REK - the Regional Committees for Medical and Health Research Ethics. I will ensure that the study is conducted in an orderly manner that does not lead to discomfort among the participants and that the data is stored and presented in a way that ensures anonymity.

In Norway, circumcision of girls and women is referred to as "female genital mutilation" and is prohibited under Norwegian law. However, it is paramount to know that it is not a crime/illegal to have been subjected to female genital mutilation. A person is also not criminally liable, if he/she had participated in subjecting a daughter to female genital mutilation before entry and settlement in Norway. Furthermore, in contrast to the ongoing abuse of a child or spouse, female genital mutilation is mostly a one-off act. Subsequently, the general duty to report such a crime typically does not apply to female genital mutilation under Norwegian law. A researcher who becomes aware of a completed crime of female genital mutilation will therefore not be obliged to report such crime.

Nevertheless, it is conceivable that I could gain knowledge about specific plans regarding subjecting a daughter to female genital mutilation. To prevent a child from being exposed to a criminal act, as a researcher, I will have a duty to report such cases to the child welfare service or the police.

This duty to report a planned crime is called "duty to avert," and I want you as a potential participant to know about this duty.

About the researcher

My name is Mai M. Ziyada, and I am a Sudanese researcher at NKVTS, a medical doctor and public health expert. I am also a PhD candidate at the Faculty of Medicine, University of Oslo. I can conduct the interviews in English and Arabic. If you prefer another language, we can arrange for an interpreter.

Contacts

PhD candidate: Mai M. Ziyada
Telephone: 41587569
e-mail: m.m.ziyada@nkvts.no.

………..

Consent form

I have read / been read to and explained to, and understood the information about the study and agree to participate in the interview

………………………………　　　　　　　　…………………………………

Place and date　　　　　　　　　　　　　Signature

Fysisk og psykisk helsehjelp for kvinner utsatt for kjønnslemlestelse: en studie blant allmennleger i Norge

Side 1

Rundt 17.300 jenter og kvinner i Norge er estimert å være utsatt for kjønnslemlestelse før migrasjon til Norge, og rundt 2 prosent (44,467) av den norske befolkningen kommer fra land som praktiserer kjønnslemlestelse. Kjønnslemlestelse er funnet assosiert med både akutte medisinske komplikasjoner og kroniske urogenitale helseplager. Studier har funnet økt risiko for komplikasjoner i forbindelse med svangerskap og fødsel, seksuell dysfunksjon, samt psykiske lidelser.
Vi vet imidlertid fortsatt for lite om relaterte psykiske helseplager, samt tilgjengelighet og bruk av både somatiske og psykiske helsetjenester for denne gruppen i Norge. Denne studien har som målsetting å få svar på dette.

Det tar 5-10 minutter å besvare spørreskjemaet. Undersøkelsen er anonym. Det innebærer at det ikke er mulig å direkte eller indirekte identifisere enkeltindivider ved kombinasjonen av opplysninger som gis i undersøkelsen. Det lagres ikke opplysninger om hvem som har svart. Lenken til undersøkelsen er felles for alle inviterte.

Takk for at du tar deg tid til å besvare spørreskjemaet!

Sideskift

Side 2

S1. Bakgrunnsopplysninger for allmennleger/fastleger

S1.1 Kjønn

○ Kvinne

○ Mann

S1.2 Hva er din alder?

○ Under 30

○ 30-39

○ 40-49

○ 50-59

○ 60 eller eldre

S1.3 I hvilken helseregion jobber du?

○ Nord-Norge

○ Midt-Norge

○ Vest-Norge

○ Sør-Norge

○ Øst-Norge

Sideskift

Side 3

S1.4 Jobber du i:

○ By

○ Tettsted

S1.5 Hvor lang arbeidserfaring har du etter medisinstudiet?

○ Inntil 5 år

○ 6-15 år

○ 16-25 år

○ 26-35 år

○ 36 år eller mer

S1.6 Hvor lang arbeidserfaring har du etter fullført spesialisering i allmennmedisin?

○ Har ikke fullført spesialisering ennå

○ Inntil 5 år

○ 6-15 år

○ 16-25 år

○ 26-35 år

○ 36 år eller mer

	Ja	**Delvis**	**Nei**
S1.7 Er du utdannet i Norge?	○	○	○
S1.8 Har du hatt undervisning om kjønnslemlestelse (generelt) i løpet av medisinstudiet?	○	○	○
S1.9 Har du hatt undervisning om kjønnslemlestelse (generelt) i løpet av videreutdanning/ etterutdanning?	○	○	○

S1.10 Har du hatt undervisning om helseskader relatert til kjønnslemlestelse?	○	○	○

Sideskift

Side 4

S2. Kunnskap og kompetanse om kjønnslemlestelse

Klassifisering og lovverk

	Ja	Delvis	Nei
S2.1 Har du behov for mer kunnskap om WHO klassifikasjon av forskjellige typer kjønnslemlestelse (I-IV)?	○	○	○
S2.2 Er du kjent med eget kodesystem/ registrering ved kjønnslemlestelse (ICD-10, eller NCMP-NCPS-NCPR)?	○	○	○
S2.3 Har du behov for å vite mer om lovverk om kjønnslemlestelse?	○	○	○

Sideskift

Side 5

Kulturell kompetanse

	Ja	Delvis	Nei
S2.4 Synes du at du har tilstrekkelig kunnskap om årsaker til at kjønnslemlestelse blir praktisert?	○	○	○
2.5 Kjenner du til hvilken tydning nskjæring/kjønnslemlestelse kvinner har kulturelt og disjonelt?	○	○	○

S2.6 Synes du det er vanskelig å snakke om kjønnslemlestelse med berørte pasienter?	○	○	○
S2.6.1 Hvis ja på 2.6, handler det om forhold ved pasienten?	○	○	○
S2.6.2 Hvis ja på 2.6, handler det om forhold ved deg selv?	○	○	○

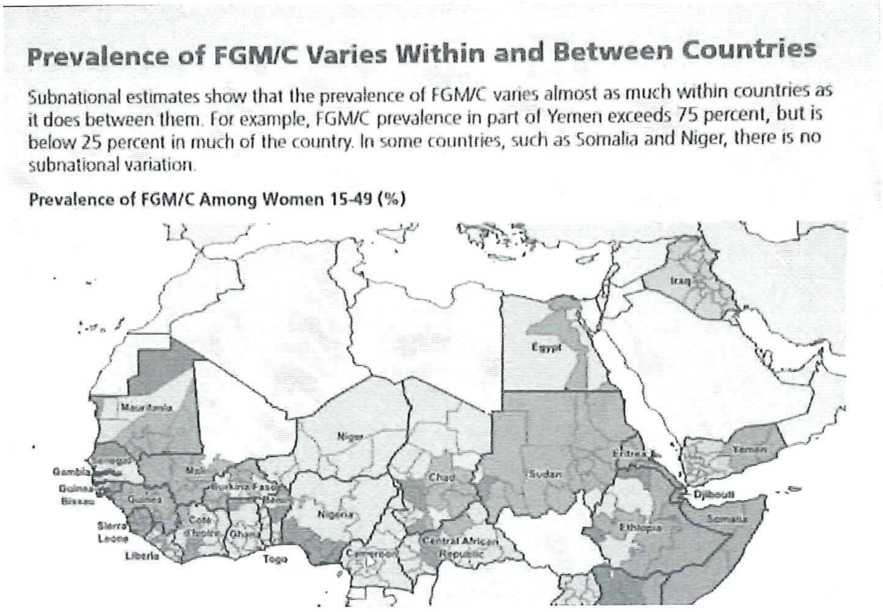
Sideskift

Side 6

S2.7 Ved hvilke helseplager spør du rutinemessig om kjønnslemlestelse hvis pasienten kommer fra et land hvor dette praktiseres (se kart)?

	Ja	Av og til	Nei
S2.7.1 Urogenitale	○	○	○
S2.7.2 Svangerskap	○	○	○
S2.7.3 Barnemedisinske	○	○	○
S2.7.4 Psykiske	○	○	○
S2.7.5 Seksuelle	○	○	○

FGM/C = Female Genital Mutilation/Cutting = kjønnslemlestelse



Prevalence of FGM/C Varies Within and Between Countries

Subnational estimates show that the prevalence of FGM/C varies almost as much within countries as it does between them. For example, FGM/C prevalence in part of Yemen exceeds 75 percent, but is below 25 percent in much of the country. In some countries, such as Somalia and Niger, there is no subnational variation.

Prevalence of FGM/C Among Women 15-49 (%)

S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse? *

○ Ja

○ Nei

Sideskift

Side 7

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

3. Henvendelser

S3.1 Har du fått henvendelser fra pasienter som direkte angir sine helseplager å være relatert til kjønnslemlestelse?

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

○ Ja

○ Nei

S3.2 Har du fått henvendelser fra pasienter som har helseproblemer relatert til kjønnslemlestelse, men som ikke selv relaterer sine plager til dette?

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

○ Ja

○ Nei

S3.3 Hvor ofte har du fått henvendelse fra pasienter med helseproblemer knyttet til kjønnslemlestelse?

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

○ Daglig

○ Ukentlig

○ Månedlig

○ 2-3 ganger i året

○ Årlig

○ Sjeldnere enn årlig

○ Aldri

Sideskift

Side 8

S3.4 Hvilke aldersgrupper jenter/ kvinner utsatt for kjønnslemlestelse har du fått henvendelse fra? (kryss av flere hvis det er aktuelt)

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

☐ 0-10 år

☐ 11-20 år

☐ 21-30 år

☐ 31-40 år

☐ 41-50

☐ Over 50

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

S3.5 Hvilke av følgende helseplager har du fått henvendelse om fra denne pasientgruppen:

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

	Aldri	Sjelden	Av og til	Ofte	Svært ofte
S3.5.1 Genitale smerter	○	○	○	○	○
S3.5.2 Genitale cyster eller arrvev	○	○	○	○	○
S3.5.3 Problemer med vannlating	○	○	○	○	○
S3.5.4 Residiverende UVI	○	○	○	○	○
S3.5.5 Menstruasjonsplager	○	○	○	○	○

S3.5.6 Helseplager i forbindelse med svangerskap/fødsel	○	○	○	○	○
S3.5.7 Dyspareuni	○	○	○	○	○
S3.5.8 Anorgasme/manglende seksuell lyst eller glede	○	○	○	○	○
S3.5.9 Angst/depresjon	○	○	○	○	○
S3.5.10 Somatisering	○	○	○	○	○
S3.5.11 Psykologiske traumer	○	○	○	○	○
S3.5.12 Psykose	○	○	○	○	○

S3.5.13 Andre relevante helseplager

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

Sideskift

Side 9

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

4. Tilgjengelighet av helsetilbud

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

S4.1 I hvilken grad opplever du at følgende spesialisthelsetjenestetilbud er tilgjengelige for pasienter med helseplager relater til kjønnslemlestelse?

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

	I stor grad	**I noen grad**	**I liten grad**
S4.1.1 Gynokologi/obstetrikk	○	○	○
S4.1.2 Regionalt spesialist-tilbud ved	○	○	○

kvinneklinikk			
S4.1.3 Kirurgi	○	○	○
S4.1.4 Urologi	○	○	○
S4.1.5 Barnemedisinsk	○	○	○
S4.1.6 Psykisk helse	○	○	○
S4.1.7 Sexologi	○	○	○

S4.1.8 Annet - tilgjengelighet av helsetilbud

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

Sideskift

Side 10

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

5. Benyttelse av helsetilbud

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

S5.1 Hvilke av de skisserte helsetilbud har du erfaring med at denne pasientgruppen gjerne benytter seg av ved indikasjon for henvvisning til spesialisthelsetjenesten?

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

	I stor grad	I noen grad	I liten grad	Vet ikke
S5.1.1 Gynekologi/ obstetrikk	○	○	○	○
S5.1.2 Regionalt spesialist-tilbud ved kvinneklinikken	○	○	○	○
S5.1.3 Kirurgi	○	○	○	○
S5.1.4 Urologi	○	○	○	○
S5.1.5 Barnemedisinsk	○	○	○	○

S5.1.6 Psykisk helse	○	○	○	○
S5.1.7 Sexologi	○	○	○	○

S5.1.8 Annet - benyttelse av helsetjenestetilbud

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

Dette elementet vises kun dersom alternativet «Ja» er valgt i spørsmålet «S2.8 Har du noengang fått henvendelse fra kvinner med helseplager relatert til kjønnslemlestelse?»

Tusen takk for at du tok deg tid til å svare på spørsmålene!

Se nylige endringer i Nettskjema (v652_1rc1)

Physical and psychological healthcare for women subjected to female genital mutilation: a study among general practitioners in Norway

1. Background information

1.1. Gender
☐ Female
☐ Male
1.2. How old are you?
☐ < 30 years
☐ 30-39 years
☐ 40-49 years
☐ 50-59 years
☐ ≥ 60 years
1.3. In which health region do you work?
☐ North Norway
☐ Middle Norway
☐ West Norway
☐ South Norway
☐ East Norway
1.4. You work in:
☐ City
☐ Rural area
1.5. How long is your work experience after completing medical training?
☐ ≤ 5 years
☐ 6-15 years
☐ 16-25 years
☐ 26-35 years
☐ ≥ 36 years
1.6. How long is your work experience after completing a specialization in general practice?
☐ I have not completed my specialization yet.
☐ ≤ 5 years
☐ 6-15 years
☐ 16-25 years
☐ 26-35 years
☐ ≥ 36 years
1.7. Did you receive your medical training in Norway?
☐ Yes
☐ Partly
☐ No
1.8. Did you receive training on female genital mutilation (in general) during your medical training?
☐ Yes
☐ Partly
☐ No
1.9. Did you receive training on female genital mutilation (in general) during your further/continuous medical training?

☐ Yes
☐ Partly
☐ No

1.10. Have you received training on health complications related to female genital mutilation?

☐ Yes
☐ Partly
☐ No

2. Knowledge and competence on female genital mutilation

Classification and legislation

2.1. Do you need more knowledge on the WHO classification of the different types of female genital mutilation (I – IV)?

☐ Yes
☐ Partly
☐ No

2.2. Are you familiar with the medical codes for female genital mutilation (ICD-10 or NCMP-NCPS-NCPR)?

☐ Yes
☐ Partly
☐ No

2.3. Do you need to know more about the legislation related to female genital mutilation?

☐ Yes
☐ Partly
☐ No

Cultural competence

2.4. Do you think you have adequate knowledge concerning why female genital mutilation is practiced?

☐ Yes
☐ Partly
☐ No

2.5. Do you think you have adequate knowledge concerning the traditional and cultural meaning of female genital mutilation for women?

☐ Yes
☐ Partly
☐ No

2.6. Do you find it uncomfortable to talk to affected patients about female genital mutilation?

☐ Yes
☐ Partly
☐ No

2.6.1. If you answered yes in question 2.6., is this because of patient's related issues?

☐ Yes
☐ Partly
☐ No

2.6.2. If you answered yes in question 2.6., is this because of personal-related issues?

☐ Yes
☐ Partly
☐ No

2.7. In your consultations with female patients originating from countries where female genital mutilation is practiced (See the map), do you routinely ask the patients whether they have been subjected to female genital mutilation when they present with any of the following health problems?

2.7.1. Urogenital problems

☐ Yes
☐ Sometimes
☐ No

2.7.2. During pregnancy

☐ Yes
☐ Sometimes
☐ No

2.7.3. Mental health problems

☐ Yes
☐ Sometimes
☐ No

2.7.4. Sexual health problems

☐ Yes
☐ Sometimes
☐ No

2.8. Have you ever been consulted by women who had health problems related to female genital mutilation?

☐ Yes
☐ No

3. Consultations

This section is only visible for those who select the "yes" option in question 2.8.

3.1. Have you been consulted by women who directly indicated that their health problems are related to female genital mutilation?

☐ Yes
☐ No

3.2. Have you been consulted by women who had health problems related to female genital mutilation but were unaware of the link between their problems and female genital mutilation?

☐ Yes
☐ No