

Reasons for and Experiences With Surgical Interventions for Female Genital Mutilation/Cutting (FGM/C): A Systematic Review



Rigmor C. Berg, PhD,^{1,2} Sølvi Taraldsen, MD,³ Maryan A. Said, RN,^{3,4} Ingvil Krarup Sørbye, MD, PhD,³ and Siri Vangen, PhD^{3,5}

ABSTRACT

Background: Because female genital mutilation/cutting (FGM/C) leads to changes in normal genital anatomy and functionality, women are increasingly seeking surgical interventions for their FGM/C-related concerns.

Aim: To conduct a systematic review of empirical quantitative and qualitative research on interventions for women with FGM/C-related complications.

Methods: We conducted systematic searches up to May 2016 in 16 databases to obtain references from different disciplines. We accepted all study designs consisting of girls and women who had been subjected to FGM/C and that examined a reparative intervention for a FGM/C-related concern. We screened the titles, abstracts, and full texts of retrieved records for relevance. Then, we assessed the methodologic quality of the included studies and extracted and synthesized the study data.

Outcomes: All outcomes were included.

Results: Of 3,726 retrieved references, 71 studies including 7,291 women were eligible for inclusion. We identified three different types of surgical intervention: defibulation or surgical separation of fused labia, excision of a cyst with or without some form of reconstruction, and clitoral or clitoral-labial reconstruction. Reasons for seeking surgical interventions consisted of functional complaints, sexual aspirations, esthetic aspirations, and identity recovery. The most common reasons for defibulation were a desire for improved sexual pleasure, vaginal appearance, and functioning. For cyst excision, cystic swelling was the main reason for seeking excision; for reconstruction, the main reason was to recover identity. Data on women's experiences with a surgical intervention are sparse, but we found that women reported easier births after defibulation. Our findings also suggested that most women were satisfied with defibulation (overall satisfaction = 50–100%), typically because of improvements in their sexual lives. Conversely, the results suggested that defibulation had low social acceptance and that the procedure created distress in some women who disliked the new appearance of their genitalia. Most women were satisfied with clitoral reconstruction, but approximately one third were dissatisfied with or perceived a worsening in the esthetic look.

Clinical Translation: The information health care professionals give to women who seek surgical interventions for FGM/C should detail the intervention options available and what women can realistically expect from such interventions.

Strengths and Limitations: The systematic review was conducted in accordance with guidelines, but there is a slight possibility that studies were missed.

Conclusion: There are some data on women's motivations for surgery for FGM/C-related concerns, but little is known about whether women are satisfied with the surgery, and experiences appear mixed. **Berg RC, Taraldsen S, Said MA, et al. Reasons for and Experiences With Surgical Interventions for Female Genital Mutilation/Cutting (FGM/C): A Systematic Review. J Sex Med 2017;14:977–990.**

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Key Words: Female Genital Mutilation/Cutting; Circumcision; Surgery; Systematic Review

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¹Norwegian Institute of Public Health, Oslo, Norway;

²University of Tromsø, Tromsø, Norway;

³Norwegian National Advisory Unit on Women's Health, Division of Gynecology and Obstetrics, Oslo University Hospital HF Rikshospitalet, Oslo, Norway;

⁴Oslo University Hospital Ullevål Hospital, Oslo, Norway;

⁵Institute of Clinical Medicine, University of Oslo, Oslo, Norway

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INTRODUCTION

Female genital mutilation/cutting (FGM/C) involves the partial or total removal of, or injury to, the female external genital tissue for non-therapeutic purposes. Cutting differs for the three most common procedures—clitoridectomy, excision, and infibulation—from partial removal of the prepuce or clitoris to narrowing the vaginal orifice and creating a covering seal by cutting and appositioning the labia minora and majora in apposition after excision of the clitoris and prepuce.¹ Despite the international health and medical establishment's call for complete elimination of the practice,^{1,2} an estimated 200 million girls and women worldwide are living with FGM/C.³ In fact, estimates show that if the present prevalence rates remain stable across the 29 countries in Africa and the Middle East where FGM/C is concentrated, there will be an increase in the number of girls with FGM/C as the population of girls in affected countries increases.⁴

Systematic reviews^{5–7} and subsequent primary studies^{8–10} have shown that girls and women who have undergone FGM/C can experience lifelong complications, particularly sexual problems such as dyspareunia. Correspondingly, FGM/C-related management and surgical interventions such as clitoral-labial surgery are in increasing demand. A joint report by the United Nations Population Fund and the United Nations Children's Fund found that in 15 countries in Africa, at least 216 facilities had integrated FGM/C-related treatments into their services.¹¹ Similarly, specialization units for women with FGM/C are appearing in Western countries.^{12–14}

One common health care option to redress FGM/C-related concerns is defibulation (also called de-infibulation). This is a surgical procedure to widen the vaginal opening in women with infibulation by making an incision of the midline scar tissue of the fused labia and suturing the cut edges so that the introitus remains open.¹⁵ Reconstructive surgery, such as clitoral-labial reconstruction, involves grafting clitoral and labial tissues with the aim of restoring normal anatomy and functionality as much as possible.¹⁶ It follows that such surgical interventions for women with FGM/C have the potential to alleviate problems, facilitate sexual intercourse, and create a genital appearance similar to that of women without FGM/C.

To date, few reviews have addressed issues related to interventions for improving outcomes for women who have undergone FGM/C. However, one review addressed the impact of interventions to improve outcomes in pregnant women who underwent FGM/C. The search for this systematic review was done in 2012 and the review included no studies.¹⁷ A second review addressed safety and efficacy of clitoral reconstruction in women with FGM/C. It described the results of four studies and concluded that additional research is needed.¹⁶ Currently, there are no systematic reviews on the effectiveness of the range of reparative interventions for women with FGM/C. Moreover, there are no systematic reviews on women's reasons for and experiences with reparative interventions for FGM/C. A gap

remains for a systematic review that can support the provision of evidence-based health care services for women who seek assistance for their FGM/C-related concerns or complications.

OBJECTIVES

The aim of this systematic review was to identify and summarize research on the range of reparative interventions for women with a FGM/C-related concern, and the overall purpose was to support evidence-based health care services for women who seek assistance for their FGM/C-related concerns or complications and to improve the quality of health care management and reparative services for women with FGM/C.

The systematic review had three specific objectives: (i) to identify and map all empirical research on the range of reparative interventions for women with FGM/C, (ii) to summarize empirical quantitative and qualitative research describing women's motivations for and experiences with reparative interventions for FGM/C, and (iii) to summarize empirical quantitative research describing the outcomes of reparative interventions for women with FGM/C. In this article, we present the results of objectives i and ii. Results of objective iii are presented in a separate publication.¹⁸

METHODS

We followed the guidelines in the Cochrane Handbook for Systematic Reviews of Interventions.¹⁹ For objective i, we also adhered to the recommended framework for mapping and describing the evidence base on a particular topic.^{20–22} Our protocol was published in PROSPERO (CRD4201501985) on April 24, 2015 and study reporting follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Inclusion Criteria

We included all study designs of research that reported on outcomes (benefit and harm) associated with any reparative intervention for women with a FGM/C-related concern and all studies that reported on women's motivations for (reasons) or experiences with such interventions. The population was composed of girls and women of any age and nationality who had been subjected to any type of FGM/C according to the World Health Organization's modified typology.¹ Accordingly, we excluded studies in which genital cutting or other alteration was performed for medically indicated or purely cosmetic reasons. Any reparative intervention for a FGM/C-related complication was eligible for inclusion, and we included all types of outcomes, including short- and long-term benefits and harms experienced by women. Inclusion criteria related to effect (objective iii) are described elsewhere.¹⁸ Concerning objective ii, we included the range of self-perceived reflections, impressions, satisfaction, motivation, and similar, reported by women seeking and having received an intervention for a FGM/C-related

concern. Qualitative studies were included because this type of data is uniquely suited to describe the lived experiences of and reflections on a therapeutic procedure. Unpublished reports, abstracts, book chapters, and brief and preliminary reports were considered for inclusion, as were publications in all languages, but we limited publication years from 1980 to our date of search.

Literature Search

We conducted a comprehensive and systematic search in 16 international databases: African Index Medicus, British Nursing Index, CINAHL, Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, Database of Abstracts of Reviews of Effects, Health Technology Assessment Database, EMBASE, MEDLINE, MEDLINE In-Process & Other Non-Indexed Citations, PILOTS, POPLINE, PsycINFO, Social Services Abstracts, Sociological Abstracts, and WHOLIS. These databases were searched from 1980 up to January 2012. We updated the search in May 2016 for the six databases that provided the largest and most relevant yield (EMBASE, MEDLINE, MEDLINE In-Process & Other Non-Indexed Citations, PILOTS, POPLINE, and PsycINFO). The searches were planned and executed by an information search specialist. The strategy used for MEDLINE was:

1. Circumcision, Female/
2. ((female\$ or wom#n or girl\$1) adj3 (mutilation\$ or circumcis\$ or cutting\$)).tw
3. "fgm/c".tw
4. ((removal\$ or alteration\$ or excision\$) adj6 female genital\$).tw
5. pharaonic circumcision\$.tw
6. sunna.tw
7. (clitoridectom\$ or clitorectom\$).tw
8. (infibulat\$ or reinfibulat\$ or deinfibulat\$).tw
9. or/1-8

To maximize the sensitivity of searches, we applied neither methodology search filters nor language delimiters. Complementary methods included following up on citations and manually searching and scanning the reference lists of relevant articles.

Selection of Studies and Quality Assessment

Retrieved citations were imported into EndNote 7.5 (Clarivate Analytics, Philadelphia, PA, USA). Screening and quality appraisal were independently undertaken by two researchers, with discrepancies resolved by re-examination of the study record and discussion. The two researchers confirmed the eligibility of the titles and abstracts and then the full texts. Quality assessment of the identified quantitative studies was undertaken as recommended in the Cochrane Handbook using design-specific checklists based on the user's guide framework.²³ This was done at the study level. For qualitative studies, we used the

assessment tool designed by the Critical Appraisal Skills Programme²⁴ to assess the studies' methodologic quality. No checklist was used for case reports.

Data Extraction and Analysis

The first author extracted data from the included studies using a piloted data extraction form. Another author subsequently confirmed or disconfirmed the data. Disagreements were solved by re-examination of the study and discussion. A few investigators were contacted for clarification. We extracted data (34 variables) on publication details, study focus and methods, population, intervention, and results. We extracted only those data relevant to the objectives of our review, so that some data are a subsample of the full study. Similarly, information in some studies was poorly reported and therefore some of our variables had missing data. Assessment of and data extraction from publications in languages not mastered by the research team were done by language-proficient colleagues in close collaboration with the main researcher, and some text was translated using Google Translate.

The data were compiled in a single spreadsheet for coding. Then, we carried out descriptive analyses by running frequencies and cross-tabulations. When possible, we pooled results. Further, we stratified studies according to their focus (motivation, experience, or outcome) and ran descriptive analyses on these subsets. For qualitative research articles, study findings were defined as all text results or findings in the publications, including the investigators' interpretations and participants' statements.²⁵ All findings—in the form of sentences, phrases, or text units dealing with motivation and experiences—were copied verbatim onto the data extraction form. The planned analysis was thematic, that is, it identified prominent or recurring themes in the literature and summarized the findings of the different studies under thematic headings.²⁶ The latter step was analytically invalid because of the limited and divergent studies identified. Analyses of the effect of the interventions are described elsewhere.¹⁸

RESULTS

The searches yielded 3,726 unique citations and we considered 132 publications in full text, as shown in the PRISMA diagram (Figure 1).

Characteristics of Included Studies

We included 71 studies (k) published from 1980 to 2016 (Table 1).^{27–97} Characteristics of the included studies are presented in Tables 1 and 2. Half the eligible studies were published from 2010 to 2016. There were two eligible conference abstracts^{59,70} and one book chapter⁹⁴ and the rest were articles published in 45 different peer-reviewed journals. As characterized by the lead investigator's reported institutional affiliations, the country of origin of the lead investigator was largely a Western country (56%), and the remaining studies had lead investigators

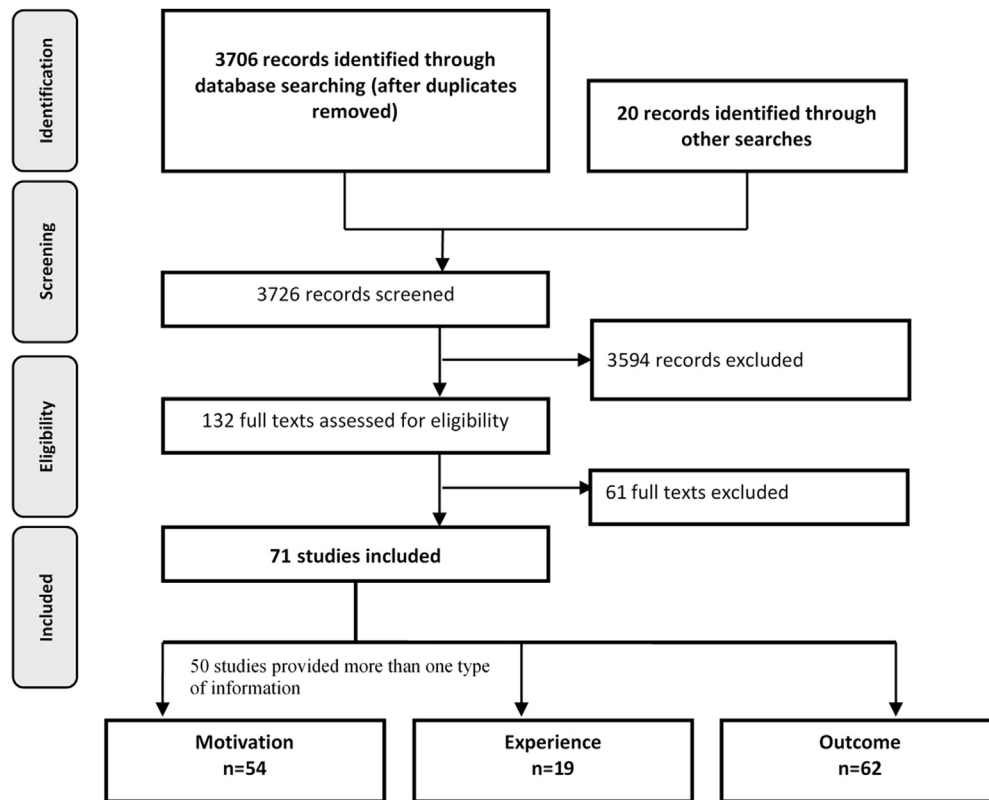


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of literature reviewing process.

located in Africa (33%) or the Middle East (11%). In all but two cases, the country of the lead investigator was identical to the country setting of the study.

Notably, in approximately three fourths of the studies ($k = 50$), multiple types of information eligible for inclusion were presented, such as reasons for seeking a surgical intervention and outcomes of the intervention. Similarly, multiple types of surgical interventions were sometimes presented in one study ($k = 6$). Study size ranged from 1 to 2,938 (mean = 103).

Study Design and Methodologic Quality

The overwhelming majority of studies (90%; $k = 64$) were case reports and case series (Tables 1 and 2). There were two qualitative studies. Four case series, all retrospective, compared at least two groups of women who had been subjected to FGM/C in which at least one group had received an intervention,^{27,34,83,86} as did the two cohort studies^{42,75} and the controlled before-and-after study.⁹⁵ Another six studies provided pre- and post-data on one group of women who received a surgical intervention.^{60,61,65,67,73,82} Results of the methodologic quality assessment showed that 47% of the eligible studies had low, 17% had moderate, and 36% had high methodologic study quality.

Population

Overall, we extracted data on 7,291 women, from infants to women in their 70s. Eight studies included children only

($n = 106$), but most female study participants were 18 to 42 years old. Almost all the women had FGM/C type III (69%) or type II (28%). FGM/C status was verified by gynecologic examination in 80% of studies and self-reported in 12.7%. Although a minority of studies took place in an African country where FGM/C is commonly practiced, almost all women in the included studies originated from one of these countries. The most frequent countries of origin of the study participants were Somalia, Sudan, Burkina Faso, and Nigeria.

Types of Reparative Interventions

We identified three different types of reparative interventions—all were surgical: defibulation or surgical separation of fused labia, excision of a cyst with or without some form of reconstruction of the clitoris and/or labia, and clitoral or clitoral-labial reconstruction.

Defibulation was the most commonly reported intervention, addressed in 32 studies (~2,500 women). Few studies described the timing and mode of defibulation, but those that did reported that defibulation was undertaken at various times: unrelated to or in preparation for pregnancy, antenatally, or intrapartum. The instrument used was in almost all cases scissors but also included CO₂ laser and electrosurgery (Bovie electrocautery on cut mode). The procedure took place in various settings, often a university hospital, and was undertaken with various types of anesthesia (described as general, regional, spinal, or local). There was no timing or anesthesia used for defibulation that seemed more

Table 1. Characteristics of included studies (K = 71)

Author, year	Study design	Quality	n	Country or setting	Focus or data type	Intervention	Outcomes*
Abdulcadir, 2016	Case series	High	129	Switzerland	Multiple	Defibulation	Obstetrics
Abdulcadir, 2015	Case report	NA	1	Switzerland	Multiple	Reconstruction	Recovery, sexuality
Abdulcadir, 2013	Case report	NA	2	Switzerland	Multiple	Defibulation	Recovery, voiding
Abdulcadir, 2012	Case report	NA	1	Switzerland	Multiple	Excision of cyst	Pain, general condition
Abramowicz, 2016	Case series	High	30	France	Multiple	Reconstruction	Sexuality, appearance
Adekunle, 1999	Case series	Low	39	Nigeria	Multiple	Separation of labia, excision of cyst	General condition
Akotionga, 2001	Case series	Low	49	Burkina Faso	Multiple	Defibulation	Recovery
Albert, 2015	Case series	High	63	England	Outcome	Defibulation	Obstetrics
Amu, 2012	Case report	NA	1	Nigeria	Multiple	Excision of cyst	Recovery
Anand, 2014	Case report	NA	1	USA	Multiple	Defibulation	Recovery, sexuality
Asante, 2010	Case report	NA	1	USA	Multiple	Excision of cyst	Recovery, sexuality
Awang, 2004	Case report	NA	1	Malaysia	Multiple	Separation of labia	Healing, voiding
Aziem, 2011	Case report	NA	1	Sudan	Multiple	Excision of cyst	Complications
Baaij, 1999	Case report	NA	3	Netherlands	Multiple	Defibulation, excision of cyst	General condition
Baker, 1993	case report	NA	1	USA	Multiple	Defibulation	Healing, sexuality
Bikoo, 2006	Cohort [†]	Mod	26	England	Outcome	Defibulation	Obstetrics
Bonessio, 2001	Case report	NA	2	Italy	Outcome	Defibulation	General condition
Brisson, 2001	Case report	NA	1	USA	Multiple	Defibulation	General condition
Catania, 2007	cross-sectional	Low	15	Italy	Multiple	Defibulation	Sexuality
Chen, 2004	Case report	NA	1	USA	Multiple	Defibulation	Healing, sexuality
Diejomaoh, 1981	Case series [†]	Low	12	Nigeria	Outcome	Separation of labia	General condition
Diouf, 2014	Case series	Low	8	Senegal	Multiple	Excision of cyst	Healing, sexuality
Dirie, 1991	Case series [†]	Mod	118	Somalia	Multiple	Excision of cyst	General condition
Dorflinger, 2000	Case series	Low	10	Sudan	Reason	Defibulation	NA
Dun, 2016	Case report	NA	1	USA	Outcome	Excision of cyst	general condition
Duvie, 1980	Case series	Low	31	Nigeria	Reason	Excision of cyst	NA
Ekenze, 2009	Case series	Low	21	Nigeria	Multiple	Separation of labia, excision of cyst	NA
Ekenze, 2007	Case series [†]	Low	18	Nigeria	Multiple	Separation of labia, excision of cyst	Complications
El-Agwani, 2015	Case report	NA	1	Egypt	Multiple	Excision of cyst	Recovery
Erian, 1995	Case report	NA	3	Australia, UK	Multiple	Defibulation, separation of labia	Sexuality, appearance
Ezem, 2007	Case report	NA	1	Nigeria	Multiple	Excision of cyst	Complications
Fazari, 2013	Case report	NA	1	Sudan	Multiple	Excision of cyst	Complications
Fazari, 2011	Case series [†]	NA	666	Sudan	Experience	Reconstruction	NA
Foldès, 2012	Case series ^{†,‡}	Mod	2938	France	Multiple	Reconstruction	Complications, sexuality
Foldès, 2006	Case series [†]	Low	453	France	Multiple	Reconstruction	Complications, sexuality
Gordon, 2007	Case series	Low	227	England	Outcome	Defibulation	Hospital stay
Gudu, 2014	Case report	NA	1	Ethiopia	Multiple	Excision of cyst	Healing, general condition
Hanly, 1995	Case series	Low	10	Saudi Arabia	Reason	Excision of cyst	NA
Hussen, 2006	Case series ^{†,§}	Unclear	90?	Italy	Multiple	Defibulation	Sexuality
Ibekwe, 2004	Case report	NA	1	Nigeria	Multiple	Defibulation	Healing, sexuality
Krause, 2011	Case series [†]	High	18	Switzerland	Outcome	Defibulation	Healing, sexuality
Kroll, 2000	Case report	NA	1	USA	Multiple	Excision of cyst	Healing, sexuality
Lashley, 2009	Case report	NA	1	Netherlands	Multiple	Excision of cyst	Healing
Ling, 2013	Case report	NA	1	England	Multiple	Excision of cyst	Voiding
Lopez-Olmos, 2016	Case report	NA	1	Spain	Multiple	Reconstruction	General condition

(continued)

Table 1. Continued

Author, year	Study design	Quality	n	Country or setting	Focus or data type	Intervention	Outcomes*
Mack-Detlefsen, 2015	Case report	NA	1	Germany	Multiple	Excision of cyst	Voiding, appearance
Merckelbagh, 2015	Case series [§]	Unclear	61	France	Multiple	Reconstruction	Sexuality, appearance
Millogo-Traore, 2002	Case report	NA	3	Burkina Faso	Multiple	Defibulation	Complications, sexuality
Minsart, 2015	Cohort [†]	Mod	471	Djibouti	Outcome	Defibulation	Obstetrics
Mistry, 2015	Case report	NA	2	England	Multiple	Defibulation	Recovery, healing
Momoh, 2001	Case series	Low	52	England	Reason	Defibulation	Na
Moxey, 2016	Qualitative	High	10	England	Experience	Defibulation	Na
Nour, 2006	Case series	Mod	40	USA	Multiple	Defibulation	Complications
Osifo, 2010	Case series [†]	High	37	Nigeria	Multiple	Excision of cyst	Recovery, sexuality
Osifo, 2009	Case series [†]	High	51	Nigeria	Reason	Separation of labia, excision of cyst	Na
Ouedraogo, 2013	Case series	Low	94	Burkina Faso	Multiple	Reconstruction	Complications, sexuality
Paliwal, 2014	Case series	High	253	England	Outcome	Defibulation	Obstetrics
Penna, 2002	Case series	Low	25	Italy	Multiple	Defibulation, excision of cyst	Complications, appearance
Quilichini, 2011	Case report	Na	1	France	Multiple	Reconstruction	Sexuality
Raouf, 2011	Case series	High	250	England	Outcome	Defibulation	Obstetrics
Rizk, 2007	Case report	Na	2	UAE	Multiple	Excision of cyst	General condition
Rouzi, 2014	Case report	Na	1	Saudi Arabia	Multiple	Separation of labia	Healing, voiding
Rouzi, 2012	Case series	High	388	Saudi Arabia	Outcome	Defibulation	Obstetrics
Rouzi, 2010	Case series	High	29	Saudi Arabia	Multiple	Excision of cyst	Complications
Rouzi, 2001	Case series	Mod	325	Saudi Arabia	Outcome	Defibulation	Complications, obstetrics
Rouzi, 2001	Case series	Low	21	Saudi Arabia	Multiple	Excision of cyst	Complications
Safari, 2013	Qualitative	High	9	England	Experience	Defibulation	Na
Sirigatti, 2006	Cross-sectional	Low	15	Italy	Multiple	Defibulation	Sexuality
Thabet, 2003	CBA [†]	High	147	Egypt	Outcome	Reconstruction, excision of cyst	Sexuality
Victoria-Martinez, 2016	Case report	NA	1	Spain	Multiple	Excision of cyst	Pain, appearance
Yoong, 2004	Case report	NA	1	England	Multiple	Excision of cyst	Complications, general condition

CBA = controlled before and after study; mod = moderate; NA = not applicable; UAE = United Arab Emirates; UK = United Kingdom; USA = United States of America.

*For studies with multiple outcome categories, the two that subsumed most outcomes are listed.

†Prospective.

‡The investigators labeled it a cohort study, but it appears to be a prospective case series.

§The description is limited, but it appears to be a case series (quality assessment not possible).

common. Two studies noted operating time, which ranged from 4 to 45 minutes, and the women were generally discharged the same day (range = 1–10 days). Surgical separation of the labia is similar to defibulation. However, rather than infibulation, the women have been subject to another FGM/C procedure with subsequent unintended fusion of the labia. Such separation was described in nine studies.^{32,38,47,53,54,56,66,81,88}

For excision of vulvar or clitoral cysts, there were 23 studies (~270 women) that described such an excision, usually with some form of reconstructive repair of the clitoris and/or labia or surgical separation of the labia. All cysts were caused by FGM/C

and located on the vulvar or clitoral area, which typically meant that once it was removed, genital structures underwent repair, as in this example: “The tumor ... was carefully enucleated after midline diathermic skin incision. Using bipolar forceps it was completely removed on its stalk (peduncle) without perforation. The labia minora were then reconstructed using the two remaining skin flaps.”⁷² The setting was typically a hospital and the surgery was undertaken with various types of anesthesia, but most frequently general anesthesia. According to the one study that reported operating time,⁹⁰ the surgery took approximately 1 hour. Women were generally discharged 48 to 72 hours after surgery.

Table 2. Summary characteristics of included studies (N = 71)

Characteristics	n (%)
Year of publication	
2015–2016	13 (18.3)
2010–2014	22 (31.0)
2005–2009	13 (18.3)
2000–2004	15 (21.1)
Before 2000	8 (11.3)
Country or setting	
Australia	1 (1.4)
Burkina Faso	3 (4.3)
Djibouti	1 (1.4)
Egypt	2 (2.8)
England	11 (15.5)
Ethiopia	1 (1.4)
France	5 (7.0)
Germany	1 (1.4)
Italy	5 (7.0)
Malaysia	1 (1.4)
Netherlands	2 (2.8)
Nigeria	10 (14.1)
Saudi Arabia	6 (8.5)
Senegal	1 (1.4)
Somalia	1 (1.4)
Spain	2 (2.8)
Sudan	4 (5.7)
Switzerland	5 (7.0)
United Arab Emirates	1 (1.4)
United States of America	8 (11.3)
Language of publication	
Dutch	2 (2.8)
English	57 (80.3)
French	8 (11.3)
German	1 (1.4)
Italian	2 (2.8)
Spanish	1 (1.4)
Study design	
Case report	32 (45.1)
Case series	32 (45.1)
Cohort study	2 (2.8)
Controlled before and after study	1 (1.4)
Cross-sectional study	2 (2.8)
Qualitative study	2 (2.8)
Focus or information*	
Motivation	54 (76.1)
Experience	17 (23.9)
Outcome	62 (87.3)
Type of intervention	
Defibulation or surgical opening	32 (45.0)
Reconstruction	10 (14.1)
Excision of cyst ± reconstruction	23 (32.4)
Multiple types presented	6 (8.5)

*Multiple foci are possible; therefore, numbers and percentages do not sum to 100%.

Ten studies (4,392 women) addressed reconstruction. The first published study on reconstruction in women with FGM/C was a controlled before-and-after study from Egypt that described clitoral-labial reconstruction.⁹⁵ Details of the reconstruction technique were sparse, but seemed similar to the technique of clitoral reconstruction, which was described in eight subsequent studies.^{28,31,60,61,71,73,82,85} With data on 453 women recruited from 1992 to 2005 in France, Foldès and Louis-Sylvestre⁶¹ offered the first detailed account of clitoral reconstruction. All but two of the subsequently published studies on reconstruction^{28,73} stated that they used this technique. In these two studies, the surgery was labeled clitoral reconstruction and clitoral reconstructive surgery, respectively. A minority of studies provided surgical details. However, in the four studies that reported on who performed the surgery, this was specified as a surgeon, and in most cases, general anesthesia was used. Based on data from four studies, operating time was approximately 30 minutes (range = 30–90 minutes) and hospital stay was 24 to 48 hours. The final study, by Fazari et al,⁵⁹ is not available in full text and the abstract labels the intervention only as “reconstruction”; thus, the details of the procedure are unavailable. However, the abstract offered data on women’s experiences with reconstruction (described below).

Motivation for Seeking Surgical Interventions

There were 54 studies (~4,400 women) providing information on women’s motivations or reasons for seeking a surgical intervention. The vast majority of studies (92%) stated a functional (physical) complication as one of the reasons. Indeed, 19 studies offered information on women’s reasons for seeking defibulation, with an infibulation complication being the most frequently mentioned reason in 16 studies. The most common complications were sexual problems (inability to penetrate, painful sexual intercourse) and voiding and menstruation difficulties. In addition, in 14 studies, women responded that preparation for vaginal birth, a desire for more pleasurable sexual intercourse, improvement of vaginal appearance, and restoration of vaginal functioning were their reasons for seeking defibulation. Relatedly, 22 studies with data on women’s motivation for seeking a surgical intervention concerned excision of a cyst. The cystic bulge, or swelling, was the reason for seeking excision, coupled with, most commonly in order of frequency, sexual problems, pain, restriction of movement, and discomfort.

Of the 10 studies that addressed clitoral or clitoral-labial reconstruction, eight offered information on women’s motivation for seeking reconstruction. This set of studies encompassed approximately 3,600 women of whom 61% had FGM/C type III and 39% had type II. The four case series from France^{31,60,61,73} reported similar categories of reasons for seeking reconstruction: to improve sex life, recover identity, and decrease pain. Although Foldès and Louis-Sylvestre⁶¹ simply stated that these were the women’s objectives for seeking reconstruction (no data were

provided), the three other studies gave data that we could pool ($n = 3,029$). The result showed that almost all women (98%) certified that their objective for seeking reconstruction was identity, 79% stated that it was sexual, and 28% stated that it was to decrease pain (they could select multiple reasons). Abramowicz et al³¹ also included the category “sexual identity,” which was the stated reason for 47% of women ($n = 14$) in that study. In a case series of 94 women from Burkina Faso,⁸² the women’s reasons for wanting clitoral reconstruction were to overcome frigidity (40%), dyspareunia (27%), and restoration of the anatomy of the clitoris (26%). A desire for esthetic and sexual improvements were the women’s reasons for wanting reconstruction in the three case reports about clitoral reconstruction.^{28,71,85}

Experiences With Surgical Interventions

There were 19 studies, primarily case reports, providing information on women’s experiences with a surgical intervention. Most studies ($k = 11$) addressed experiences with the intervention through short narrative statements that generally indicated that the patient(s) was satisfied with the result, particularly as it related to sexuality, such as “the patient was very satisfied on all accounts, particularly her new sexual life.”⁵⁸ None of these studies reported any negative experiences or dissatisfaction with the interventions.

Concerning women’s experiences with defibulation, five studies ($n = 164$) directly addressed this issue. In a case series of mainly Somali women residing in the United States by Nour et al,⁷⁹ all were satisfied with the result, and 94% would recommend it to others and found the procedure and post-operative course to be less painful and traumatic than anticipated. A study of Somali women residing in Italy by Hussen and Catania⁶⁵ found that 50% of women were satisfied with the defibulation because of improvements with intercourse, menstruation, and voiding. The women’s reactions when seeing their vulva after defibulation for the first time were mixed: they felt a sense of freedom (67%), perceived the genitals as more beautiful (7%), perceived the genitals as more ugly (7%), felt strange because they were not used to being open (47%), and felt more sexually available (27%). Similarly, of the 15 Somali women in a study by Sirigatti et al,⁹⁴ the changes women most appreciated after defibulation were experiencing less pain during sex (73%), less menstrual pain (47%), and ability to urinate more easily (47%).

Moxey and Jones⁷⁸ and Safari⁹³ examined Somali women’s perceptions of defibulation in a qualitative study from England. The study by Moxey and Jones related to defibulation relative to antenatal and intrapartum care, and Safari addressed women’s experiences with defibulation and its aftermath; thus, a synthesis of the qualitative evidence was not possible. Moxey and Jones’ main findings were that many women did not recognize defibulation as an option (believing the husband had to open them physically), they preferred to have intrapartum defibulation rather than antenatal (to avoid two operations if an episiotomy was

anticipated), and they reported positive experiences and easier births after the procedure. Also Safari⁹³ found that her informants believed defibulation had low social acceptance and could affect marital and sexual relationships. In addition, many women disliked the altered appearance of the genitalia, which they perceived as abnormal. One woman explained, “It does not look good and I do not feel comfortable with the look of it” (p 157).

There were three studies ($n = 821$), all case series, that included information about women’s experiences with reconstruction. Fazari et al⁵⁹ reported that 86% of participants, all Sudanese women, were very satisfied and 14% were satisfied with the result of the reconstructive surgery “with regard to healing, shape of the vulva, disappearance with discharge and impact on sexual activity” (p S20). Of 94 patients who underwent clitoral reconstruction in a study by Ouedraogo et al,⁸² 71% were satisfied with the esthetic look, whereas 29% were not satisfied at 6-month follow-up. Of 61 women who underwent clitoral reconstructive surgery in a study by Merckelbagh et al,⁷³ 64% perceived an improvement in esthetics (11% worsening, 25% no change), and 64% perceived an improvement in femininity (2% worsening, 34% no change).

DISCUSSION

This systematic review found that the empirical literature on reparative interventions for women with FGM/C is limited but rapidly expanding. Large numbers of journals and investigators appear to be active in the area. This suggests the topic is of cross-disciplinary interest, particularly among researchers from Western countries.

Despite our generous inclusion criteria, we found that there are broadly three types of surgical interventions for FGM/C. Defibulation is the simplest surgical procedure. It is undertaken unrelated to or in preparation for pregnancy or childbirth, typically with scissors. Although details and data of the second type of surgery are sparse, vulvar or clitoral cyst removal and repair was performed when a cystic bulge caused problems or discomfort. Defibulation and cyst removal appear to be performed by various types of health care professionals, generally gynecologists, and with various types of anesthesia in a range of health care settings. Female genital reconstruction is a more comprehensive surgery. Whether it is called clitoral-labial reconstruction, clitoral reconstruction, or clitoral reconstructive surgery, it appears to entail removing scar tissue and re-creating the labia minora and a more accessible clitoral glans. In fact, many regard it as a plastic or cosmetic surgery (see Abdulcadir et al⁹⁸), and our data suggest that clitoral reconstruction requires greater clinical skills, because it is performed at a hospital by a specially trained surgeon and under general anesthesia. The reconstructive procedure that has become the de facto reconstruction technique is the “Foldès technique,” named after Pierre Foldès, a surgeon and principal investigator of two large prospective studies from France.

In contrast to the other two surgeries, reconstructive surgery is inaccessible for most women because of the high cost and limited

provision associated with the procedure. The authors of the largest included study on reconstruction⁶⁰ explained that in most developed and in all developing countries, reconstructive surgery is prohibitively expensive and considered in many countries as cosmetic surgery that is not covered by the health care system. Even in France, where it is considered a therapeutic procedure and the cost is covered by the national health care system, only a handful of surgeons have been trained in clitoral reconstruction technique and fewer than 10 offer the procedure.⁶⁰

Overall, although women living with FGM/C seek surgical interventions for a range of different reasons, across the three types of therapeutic surgeries, a functional FGM/C-related complaint or complication was the most commonly reported reason. Clearly, with the increasing number of girls and women with FGM/C-related problems, the health care system is seeing a corresponding demand for treatment of complications. In addition to functional complaints, there are three other categories of motivation: esthetic aspirations, sexual aspirations, and identity recovery. Specifically, the most frequently mentioned reasons for seeking defibulation were a desire for improved sexual pleasure, vaginal appearance, and vaginal functioning. Women who seek clitoral reconstruction also wish to recover sexual pleasure and identity. Interestingly, Abramowicz et al³¹ found that women who presented for identity issues were more satisfied with the clitoral reconstruction result than women who presented for sexual health concerns, suggesting an association between an indication for surgery and satisfaction. As discussed by researchers such as Abdulcadir et al,⁹⁹ identity can be a complicated issue for people navigating African and Western cultures. In fact, our review found some indication that specified reasons among women residing in Western countries and those in African countries are distinctive, with women in the West more often stating restoration of identity and esthetic improvement as motivations. This could be an indication that women in the West to a greater extent are exposed to and influenced by mass media's female genitalia beauty images. Sharp et al¹⁰⁰ found that media exposure (by television, the internet, advertising, or pornography) to images of female genitalia was the strongest predictor of whether women would be interested in undergoing labioplasty.

Based on existing data, it is unclear whether defibulation and reconstruction strategies are acceptable to most women with FGM/C. First, our qualitative results indicate that awareness of defibulation might be limited among women with FGM/C in Western countries, and that defibulation has low social acceptance among women and possibly among their husbands and the larger community. In contrast, when done in relation to childbirth, it seems most women find that defibulation facilitates an easier birth, and they prefer to have the procedure done during labor rather than antenatally. Second, our results from mainly case reports and case series show that women's experiences with surgeries for FGM/C are mixed. Most women are satisfied with the surgery, with overall patient satisfaction in the range of 50% to 100%, typically because of improvements in their sexual lives,

but surgery creates distress in some women who dislike the new appearance of their genitalia. For many who undergo defibulation, the genitalia become "abnormal." This finding draws attention to the different "normal" female genital appearances that exist, and that for women in diaspora, culturally determined esthetic ideologies can conflict and affect expectations particularly in the realms of sexuality and femininity. Up to approximately one third of women who undergo reconstruction seem to be dissatisfied with or perceive a worsening in the esthetic appearance. However, follow-up beyond 1 year is missing and women's satisfaction could improve over time. Currently, the Royal College of Obstetricians and Gynaecologists guideline on FGM/C recommends that "reconstruction should not be performed because current evidence suggests unacceptable complication rates without conclusive evidence of benefit" and calls for trials to examine its safety and effectiveness.¹⁰¹ Evidence about benefit and harm from genital surgeries and concordance with guidelines are discussed elsewhere.¹⁸

With respect to implications, it bears mention that although the female genitals normally are not visible, esthetic genital preferences are salient to a sense of bodily beauty and in turn sexual satisfaction. An expanding body of research has found evidence of a correlation between the perceptions a woman has about her genitalia and sexual pleasure.^{102,103} However, there is a wide variety in characteristics of the clitoris, labia, and vagina,¹⁰⁴ and it is unclear to what extent women with FGM/C are aware of the range of "normal" female genital appearances. We found that the identified surgeries imply esthetic and physiologic changes that create mixed reactions in women. In addition, results of our analyses of the outcomes of surgeries suggest benefits and possible harms.¹⁸ Thus, the information given to the woman in consultations before and after the surgery is important. Health care professionals should provide thorough information about the range of "normal" female genital appearances, the intervention options available, and what women can realistically expect from surgeries. This would allow the woman to make an informed choice, carefully consider the optimal way forward, and prepare for the result of a possible surgery. There is some evidence that when women who seek reconstructive surgery receive multidisciplinary counseling, most women opt out of surgery.^{28,73,105} In a study by Ndiaye et al,¹⁰⁵ only one of every five women eventually chose to undergo surgery. Multidisciplinary treatment approaches are advocated by experts in the field,^{105–107} but findings from the present systematic review and others specifically focusing on supportive psychotherapy,¹⁰⁸ counseling for defibulation,¹⁰⁹ and sexual counseling¹¹⁰ show that there are no studies on the effectiveness of non-surgical interventions for women with FGM/C-related problems. Thus, there is no evidence about whether multidisciplinary treatment should be considered a first-line approach, applied before, in place of, or in conjunction with surgical interventions for women with FGM/C-related problems.

Our systematic review exposes not only health care implications but also research gaps. It is important to encourage more

research from countries where FGM/C is customarily practiced. This would provide a more “inside” perspective from those who understand the context and it could lead to improved patient management. There is a need for studies that investigate the most acceptable reparative interventions for women living with FGM/C, what women are seeking when requesting repair, and what their experiences with the interventions are, including whether their expectations are met through the care they receive. There is a need for especially qualitative research and prospective research with follow-up beyond a few months. In addition, as we highlight elsewhere,¹⁸ to learn more about not only motivation and experiences but also effect, there is a need for studies that include preoperative assessments (eg, sexual function, genital self-image), validated instruments, and the viewpoints of men as partners. As indicated by our findings, male partners can play an important role in overall acceptability of interventions and women’s decision making in pursuing various interventions. Moreover, as mentioned by others,¹¹¹ it would be important to initiate studies that address effect and acceptability of non-surgical approaches to management of FGM/C complications, such as pelvic floor physical therapy, sexual counseling, and use of vibrators to enhance genital response.

Limitations to our systematic review should be noted when considering its findings. One of the limitations is that new studies are being published quite regularly in different journals, and some might have been missed in this review. Moreover, different researchers can interpret what counts as a reparative intervention for a FGM/C-related concern slightly differently. Conversely, strengths of our review include our systematic approach, including searches, selection, and data extraction. The use of a standard data extraction framework enabled consistency and the data analysis enabled us to identify commonalities and trends regarding surgeries for FGM/C-related concerns. Although the World Health Organization recently released a series of reviews on interventions to address complications of FGM/C,^{108–110,112–116} our review has a more recent literature search and broader scope, including an assessment of women’s motivations for and experiences with reparative interventions.

CONCLUSIONS

We found that research into the care of women with FGM/C is attracting increasing attention, particularly in Western care settings. However, despite a rapidly expanding number of studies, methodologically valid investigations of reparative interventions for FGM/C-related problems are sparse. Of the three types of identified reparative interventions—defibulation, cyst removal and repair, and clitoral-labial reconstruction—defibulation is the simplest and most accessible procedure, whereas accessibility for reconstruction is limited. To date, there are some data on women’s motivations for surgery, with motives falling into the categories functional complaints, esthetic aspirations, sexual aspirations, and identity recovery. Little is known about whether

women are satisfied with the surgery, and experiences appear mixed. Further research in this area of inquiry is needed.

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Corresponding Author: Rigmor C. Berg, PhD, Norwegian Institute of Public Health, PO Box 4404, Nydalen, N-0403 Oslo, Norway. E-mail: rigmor.berg@fhi.no

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STATEMENT OF AUTHORSHIP

Category 1

(a) Conception and Design

Rigmor C. Berg

(b) Acquisition of Data

Rigmor C. Berg; Sølvi Taraldsen; Maryan A. Said; Ingvil Krarup Sørbye; Siri Vangen

(c) Analysis and Interpretation of Data

Rigmor C. Berg

Category 2

(a) Drafting the Article

Rigmor C. Berg

(b) Revising It for Intellectual Content

Rigmor C. Berg; Sølvi Taraldsen; Maryan A. Said; Ingvil Krarup Sørbye; Siri Vangen

Category 3

(a) Final Approval of the Completed Article

Rigmor C. Berg; Sølvi Taraldsen; Maryan A. Said; Ingvil Krarup Sørbye; Siri Vangen

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