

Research gaps in the care of women with female genital mutilation: an analysis

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Female genital mutilation (FGM) includes procedures involving the partial or total removal of the external female genitals for non-therapeutic reasons. They can have negative psychosexual and health consequences that need specific care. In this paper, we review some key knowledge gaps in the clinical care of women with FGM, focusing on obstetric outcomes, surgical interventions (defibulation and clitoral reconstruction), and the skills and training of healthcare professionals involved in the prevention and

management of FGM. We identify research priorities to improve the evidence necessary to establish guidelines for the best multidisciplinary care, communication, and prevention, and to improve health-promotion measures for women with FGM.

Keywords Clitoral reconstruction, defibulation, female genital cutting, female genital mutilation, female genital mutilation/cutting, obstetric outcome.

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Introduction

Female genital mutilation (FGM) are procedures involving the partial or total removal of the external female genitalia for non-therapeutic reasons. FGM violates the human rights of women and girls, has no health benefits, and can have significant, negative, psychophysical health outcomes.^{1–6}

The World Health Organization (WHO) defines four types of FGM (Table 1). These practices are prevalent in eastern and western Africa, among some ethnic groups in Indonesia, Malaysia, and areas of the Persian Gulf,^{1,2} and are increasingly common in the Western world as a result of migration. More than 125 million girls and women have been subjected to FGM, and at least 3 million girls are at risk every year.² Migration trends have resulted in an increased prevalence of FGM in Europe, USA, Australia, and Canada.^{3–7} According to the European Institute for Gender Equality, women with FGM live in at least 13 European countries.³ The estimates vary from 170–350 women in Hungary (2012) to 65 790 in the UK (2007).³

International attention has focused on efforts to end these practices. In 2012, the UN General Assembly adopted a resolution on eliminating FGM, and intensified action was called for across policy, community, and health sectors.⁸ Despite efforts to enact laws, and implement commu-

nity education programmes, support groups, medical guidelines, new surgical techniques, and specialized multidisciplinary centres for the care of women with FGM, progress has been limited in both preventing FGM, especially in developing countries, and caring for girls and women who have already undergone FGM. Several factors have contributed to a delay in eradicating FGM. These factors range from structural/policy to sociocultural issues and issues related to health-system capacity.⁸ Key knowledge gaps remain for both the prevention of FGM and evidence-based care to optimize health outcomes for girls and women with genital mutilation.

As important as identifying effective policies and interventions to eliminate FGM is the need for evidence on how to minimize negative health outcomes for women living with FGM. This includes improving the knowledge base about obstetrical and gynaecological consequences, as well as improved provider training. There is an urgent need to strengthen providers' capacity to deliver high-quality, evidence-based care for women with FGM, as well as to prevent healthcare workers from providing FGM (medicalisation of FGM).

In this paper we review the existing evidence on obstetric outcomes, surgical interventions (defibulation and clitoral reconstruction), and skills and training of health care professionals involved in the prevention and management of

Table 1. The 2007 WHO classification of FGM¹**Type I: partial or total removal of the clitoris* and/or the prepuce (clitoridectomy)**

Type Ia: removal of the clitoral hood or prepuce only

Type Ib: removal of the clitoris* with the prepuce

Type II: partial or total removal of the clitoris* and the labia minora, with or without excision of the labia majora (excision)

Type IIa: removal of the labia minora only

Type IIb: partial or total removal of the clitoris* and the labia minora

Type IIc: partial or total removal of the clitoris*, the labia minora, and the labia majora

Type III: narrowing of the vaginal orifice with the creation of a covering seal by cutting and apposition of the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation)

Type IIIa: removal and apposition of the labia minora

Type IIIb: removal and apposition of the labia majora

Type IV: unclassified

All other harmful procedures to the female genitalia for non-medical purposes: e.g. pricking, piercing, incising, scraping, and cauterisation

*When the total removal of the clitoris is reported, it refers to the total removal of the glans of the clitoris.²²

FGM. Key knowledge gaps in the clinical care of women living with FGM and priority research areas are identified.

Methods

Current recommendations regarding the health care of women with FGM differ among countries. We reviewed the available literature about the clinical care of women with FGM to identify the existing evidence base and research gaps.

We searched the PubMed database for articles regarding the care of women with FGM in any country, published in any language, from 1986 to January 2014. A combination of medical subject headings (MeSH), text, and keywords were used. Search terms included: female genital mutilation; female genital cutting; female genital surgeries; FGM; FGC; FGM/C; clitoris; defibulation; and clitoral reconstruction. Studies of all design and quality were considered. We included reviews, and retrospective and prospective cohort studies providing quantitative and qualitative data, audits, case reports, comments, guidelines, and experts' opinions. Articles reporting on any health consequence, complication, or clinical management of FGM were included. We included publications about healthcare providers' knowledge of FGM. We did not include studies pertaining to cosmetic surgery of the female genitalia.

The evidence was then categorised by themes. We did not subsequently include all possible aspects of clinical care in our review, but instead focused on four areas, prioritised by the WHO FGM Advisory Group. Thematic areas were selected and prioritised on the basis of the absence of clinical guidelines, controversy in management, and the potential to significantly affect the health of women living with FGM. Papers were reviewed and summarised by all three authors. The themes and evidence

summaries for each area were presented in February 2014 at a WHO technical consultation including global participants with expertise in FGM research and programmes. Participants identified specific research priorities for WHO to support the development of evidence-based clinical guidelines.

Results

Four thematic areas in the care of women with FGM were identified that had significant evidence gaps and controversy regarding optimal management. Themes identified were: (1) obstetric outcome and postpartum perineal re-education; (2) defibulation outside of pregnancy or labour; (3) clitoral reconstruction; and (4) training, skills, and confidence of healthcare providers. Our search identified research articles (all study designs), guidelines, expert opinions, commentaries, and policy statements. In the section below we summarize, by thematic area, the research and guidelines identified. Policy statements, commentaries, and expert opinions are referenced only for contextual information.

With respect to obstetric outcomes and postpartum perineal re-education, 24 references were identified (Table 2):^{9–32} 16 research studies;^{9–12,14–18,20,24,27,29–32} five clinical guidelines;^{21,23,25,26,28} one expert opinion;²² one policy statement;¹⁹ and one letter to the editor.¹³ On defibulation performed outside of pregnancy or labour, nine references were identified:^{21,22,33–39} four research articles;^{34–36,39} one guideline;²¹ three expert opinions;^{22,33,37} and one case report.³⁸ On clitoral reconstruction, ten relevant references were identified:^{22,26,39–46} five research articles;^{39–43} and five expert opinions,²² guidelines,²⁶ or commentaries.^{44–46} Twelve studies on the role of healthcare providers were identified.^{17,31,47–56}

Table 2. Summary of the evidence gaps and priority research topics, by thematic areas

Thematic area	Primary authors (year)	Type of study	Summary of the evidence gaps	Priority research topics
Obstetric outcome and postpartum perineal re-education	WHO (2006) ⁹	– Prospective observational study	The impact of healthcare quality and use on obstetric outcomes such as rates of caesarean, postpartum haemorrhage, extended hospital stay, and neonatal outcomes is unknown. No RCTs on interventions to improve the outcome and the quality of life of pregnant women with FGM exist. Timing of defibulation in pregnant women with FGM is controversial. Little to no evidence on perineal re-education in the postpartum period identified.	Determine obstetric outcomes by type of FGM: Results adjusted for age, health, disease affecting the pregnancy, weight and height of women, healthcare access during pregnancy, education, socio-economic status, and parity. Registration of type of delivery, reason for assisted delivery or caesarean section, stage of labour at which emergency caesarean section is performed. Identification of the best management to reduce some of the increased risks and improve satisfaction of women. Identify ideal timing of defibulation during pregnancy or labour (first/second stage) considering variables such as blood loss, rate of episiotomy/perineal tears, acceptability/satisfaction, reinfibulation demands, spontaneous re-stitching, and other complications. Rates of postpartum complications (e.g. urinary/stool incontinence) and effectiveness of treatments (e.g. perineal re-education). Sexual function, body image, and treatment of complications of type-III FGWC.
	Rouzi (2001) ¹⁰	– Retrospective study		
	Rouzi (2012) ¹¹	– Retrospective study		
	Kaplan (2013) ¹²	– Prospective observational study		
	Essén (2005) ¹⁴	– Prospective observational study		
	Wuest (2009) ¹⁵	– Retrospective study		
	Berardi (1985) ¹⁶	– Retrospective study		
	Paliwal (2013) ¹⁷	– Retrospective study		
	Berg (2013) ¹⁸	– Systematic review		
	Balagun (2013) ²⁰	– Systematic review		
	Thierfelder (2005) ²⁴	– Qualitative study		
	Al-Hussaini (2003) ²⁷	– Prospective cross-sectional study		
	Almorth (2005) ²⁹	– Prospective observational study		
	Knight (1999) ³⁰	– Retrospective study		
Momoh (2001) ³¹	– Retrospective study			
Rushwan (1980) ³²	–Prospective observational study			
Defibulation not performed during pregnancy or labour	Catania (2007) ³⁴	– Prospective observational study	Inconclusive evidence on the impact of defibulation on health outcomes (including sexual function) exists.	Improved understanding of the following variables and outcomes: Preoperative expectations and motivations False beliefs about female and clitoral anatomy and physiology of women Postoperative satisfaction, outcome, and complications Outcomes on body image, gender, vulvar pain, and sexual functioning Histological characteristics of the removed periclitral fibrotic tissue Outcome of psychosexual therapy associated with surgery
	Krause (2011) ³⁵	– Prospective observational study		
	Nour (2006) ³⁶	– Retrospective study		
	Paterson (2012) ³⁹	–Review		
	Paterson (2012) ³⁹	– Review		
	Foldès (2012) ⁴⁰	– Prospective cohort study		
Clitoral reconstruction	Foldès (2006) ⁴¹	– Prospective cohort study	Limited evidence exists on the effectiveness and safety of clitoral reconstruction. No study examines the histological characteristics of the periclitral fibrosis removed, and any potential correlation with dyspareunia.	
	Ouedraogo (2013) ⁴²	– Prospective cohort study		
	Thabet (2003) ⁴³	– Case-control study		
		– Case-control study		

Table 2. (Continued)

Thematic area	Primary authors (year)	Type of study	Summary of the evidence gaps	Priority research topics
Training, skills, and confidence of healthcare providers	Paliwal (2013) ¹⁷ Momoh (2001) ³¹ Jäger (2002) ⁴⁷ Leye (2008) ⁴⁸ Chalmers (2000) ⁴⁹ Zenner (2013) ⁵⁰ Relph (2013) ⁵¹ Zaidi (2007) ⁵² Mostafa (2006) ⁵³ Ali (2012) ⁵⁴ Abdulcadir (2014) ⁵⁵ Vangen (2004) ⁵⁶	– Retrospective study – Retrospective study – Survey – Survey – Survey – Survey – Survey – Survey – Survey – Survey – Retrospective study – Survey	Providers lack awareness on the prevalence, diagnosis, and management of FGM. Difficulties identifying and categorising FGM according to the WHO classification exist. The most effective intervention or tools to strengthen provider capacity are unknown.	Beliefs on anatomy, physiology, and sexuality of women with FGM/C held by caregivers in both Western settings and countries where FGM/C is practiced Knowledge, confidence, and skills on FGM/C Personal emotional distress, reactions, and fears Identification and evaluation of teaching measures

We summarize the evidence and guidelines identified and reviewed by each thematic area, and then highlight the proposed research priorities for each topic (Table 2).

Summary of existing evidence

Obstetric outcome and postpartum perineal re-education

Obstetric outcome. Studies conducted in Africa have shown that FGM is associated with increased risks of caesarean section, postpartum haemorrhage, episiotomy, extended maternal hospital stay, resuscitation of the infant, low-birthweight infant, and inpatient perinatal death.^{9,12,13} Studies performed in Western settings, however, suggest that a high standard of obstetric care (e.g. defibulation and follow-up of the pregnancy) can minimise these risks.^{14–17} Risks of episiotomy or third-degree perineal tears seem to remain significantly higher in some studies.¹⁵ A recent systematic review suggested a disparity between women with and without FGM for prolonged labour, obstetric lacerations, instrumental delivery, obstetric haemorrhage, and difficult delivery. The authors encourage additional studies to better investigate if true causality exists.¹⁸ It has been reported that serious obstetric complications are caused by the scarring and inelastic tissue resulting from FGM;¹⁵ however, few studies have focused on the different degrees and types of scar, depending on the kind of cutting and complications. Miscommunication, distrust, delays in seeking care, and avoiding medical interventions can contribute to negative obstetric outcome.^{14,19}

Significant limitations in the current literature exist. Studies are limited by being of observational design and of small sample size. The FGM types of the women included are often only self-reported, instead of being documented with a vulvar exam.^{18,20} No randomised controlled trials (RCTs) on interventions to improve the outcome and the quality of life of pregnant women with FGM were identified.²⁰ Additionally, existing evidence does not differentiate complications and obstetric outcome for the different types of FGM, nor does it adequately control for healthcare access, use, and quality: factors that influence outcome. Few studies explored the indications for caesarean section or assisted delivery in women with FGM.

Defibulation is a surgery performed in women who have undergone type-III FGM. Partial defibulation exposes the vaginal opening and the urethral meatus only, whereas total defibulation also uncovers clitoral tissue.^{10,11,21–23} Defibulation can be performed both during a pregnancy (antenatal or intrapartum) and outside of pregnancy. The timing of defibulation in pregnant women is controversial, and many gaps in the evidence exist. Because of these gaps the available recommendations on the timing of defibulation during pregnancy or labour, as well as on episiotomy, differ

among countries and centres, and are based solely on expert opinion, as summarised in Table 3.^{21,23–28}

A retrospective cohort study reported on outcomes by timing of defibulation during pregnancy.¹⁷ A total of 253 women with type-III FGM who gave birth at a single hospital in the UK during 1 year were included. Of this cohort, nine women were defibulated antenatally, 18 in labour, 18 women declined defibulation, and 208 had undergone defibulation in a previous pregnancy. Although not significant, there was a trend towards increased blood loss and spontaneous tears in the case of intrapartum defibulation. Women with an antenatal defibulation were noted to have a higher episiotomy rate ($P < 0.01$).¹⁷ The small sample size precludes any definitive conclusion and additional research is needed.

Women with FGM have been reported as being at increased risk for vaginal and urinary infections throughout their life.^{29,32} This evidence is limited to studies with small samples,³² or to prospective cohort studies of women or girls with mostly type-III FGM.²⁹ The risk of such infections during pregnancy is not known.

Postpartum perineal re-education. Until now, studies on the obstetric outcome of women with FGM have paid little or no attention to the postpartum period; however, if there is an increased risk of episiotomy, perineal lacerations,^{9,12} or third-degree tear,¹⁵ a greater incidence of long-term perineal complications such as urinary or stool incontinence would be expected.

Defibulation not performed during pregnancy or labour

No prospective multicentre study exists about sexuality, body image, and the treatment of complications of type-III

FGM after defibulation performed outside of pregnancy/delivery. Few studies, with small sample sizes have been published on this subject. This surgery is technically simple and can significantly improve infibulated women's health.^{21,22,34–36,39} Limited evidence (case reports) suggests that defibulation can effectively treat symptoms such as dysmenorrhea, dyspareunia,^{34–36,39} and urinary complications, including overactive bladder, by removing the obstacle of the bridge scar.^{21,34–38}

According to observational studies and expert opinions, women may need specific counselling before and after defibulation, as this represents an important change in culture, physiology (e.g. micturition), and body image.^{11,22,33} Some women may not want to feel *completely opened*, and ask for the incision to be stopped just above the urethral meatus to ensure normal micturition.^{22,33} It has also been reported that some married women will only accept, or ask for, defibulation with the husband's agreement. The operation is then kept secret to avoid exposing the husband to ridicule from their own family and community, as the defloration of the scar is a demonstration of virility.^{33,34}

Women may have a variety of common medical or psychosexual conditions, without disclosing to their healthcare provider that they have undergone type-III FGM. Likewise, they may not request defibulation. Caregivers must enquire specifically and appropriately about genital mutilation and infibulation, as part of a comprehensive gynaecological history, and explain the option of defibulation.³¹ Improving caregivers' knowledge on the common doubts and fears manifested by women concerning the procedure should improve preoperative counselling and care, and may improve acceptance rates of defibulation.

Table 3. Recommendations on timing of defibulation in pregnancy/labour in women with type-III FGM and episiotomy in women with FGM

Source	Recommendations on timing of defibulation in pregnancy/labour in women with FGM type III and episiotomy in women with FGM
Johnson (2007) ²¹ Royal College of Obstetricians and Gynaecologists (2009) ²³	Defibulation is recommended preconception or during mid pregnancy (around 20 weeks of gestation). ^{21,23} When performed in labour, defibulation is recommended during the first stage of labour. ²³ Intrapartum episiotomy is recommended in women with FGM if inelastic scar tissue prevents progress. In general, a low threshold for performing episiotomy is advised, ²³ despite the absence of studies on the real benefits of episiotomy with each type of FGM.
Thierfelder (2005) ²⁴ Swiss Society of Gynaecology and Obstetrics (2005) ²⁵	Defibulation is recommended during delivery and not during pregnancy in order to avoid any 'unnecessary trauma' for women. ²⁴ As the obstetrical outcome does not change if defibulation is performed during pregnancy or at delivery, defibulation should be performed during pregnancy only if vaginal examination is impossible. ²⁵
Gynaecology without borders, Ministry of Health and Sports of France (2010) ²⁶	Defibulation is recommended during the second stage of labour or during pregnancy. ²⁶
Al-Hussaini (2003) ²⁷ WHO (2001) ²⁸	Opening up of infibulation during antenatal period or during delivery, ^{27,28} without details on when.

Clitoral reconstruction

The impact of FGM on sexuality, including orgasm, is unknown. Limited research, with significant methodological limitations, has investigated this topic.³⁹ It has been reported that healthy women with FGM are able to reach orgasm;^{34,39} however, the published literature is not conclusive. No study has differentiated between women according to the type of FGM and clitoral integrity. Furthermore, no study has compared the sexuality of women with FGM with an intact or cut clitoris.³⁹ No study considered fundamental factors such as body image and partner relationship, which significantly contribute to sexuality.

Clitoral reconstruction is a relatively new surgical technique that involves the resection of the scar covering the clitoral stump, sectioning the suspensory ligament, removing the fibrosis surrounding the mobilized stump, and repositioning it as a neoglans.^{26,40–42} The technique described first by Thabet,⁴³ and by Foldès,^{40,41} reduced clitoral pain and improved pleasure in about 40% of 841 women. It was reported to have a complications rate (mostly haematoma, dehiscence, and infection) of 5.3% and a readmission rate of 3.7%.⁴⁰ Outcomes were evaluated in four studies,^{40–43} by empiric scales,⁴⁴ from an aesthetic point of view,⁴⁴ and only in one case at 1 year post surgery.⁴⁰ This operation is covered by health insurance in France,⁴⁰ and is becoming increasingly advertised in the Western world and in some African countries,⁴² in spite of debates and concerns about its potential psychophysical harmful consequences.^{45,46} The surgery is often seen as a way of promoting female completeness and supporting gender identity, rather than improving sexual pleasure.^{22,44}

Few studies and no official medical guidelines exist on clitoral reconstruction, a surgery with health, sociocultural, gender, anthropological, and psychosexual implications.⁴⁴ Young circumcised women growing up in Western countries, reported to be at higher risk of sexual problems,⁴⁰ can sometimes ask for surgery even before having started sexual intercourse, because of negative expectations regarding sexuality or for aesthetic reasons.⁴⁴ It has been stressed that clitoral reconstruction should always be accompanied by standardised and culturally competent counselling and explanations on FGM, female anatomy, physiology, and sexuality. A key component of clitoral reconstructive surgery is psychosexual evaluation and follow-up.⁴⁴

Training, skills, and confidence of healthcare providers

Provider training is an essential component of improving clinical outcomes for women. Currently FGM is not included in the curriculum of most medical, nurse, midwifery, and public health training,^{47,48} and recommendations about clinical management, reinfibulation, and legislation on FGM are not well known.⁴⁹ Some studies

have investigated the knowledge, awareness, and attitudes of healthcare professionals in both Western and African settings.^{17,31,47–56} In Canada, women with FGM were reported to be unhappy with both clinical practice and the quality of care received during pregnancy and childbirth.⁴⁹ In the UK, significant gaps were found in the provision of appropriate antenatal care for women who have undergone FGM, and their at-risk daughters, despite available guidelines. This is believed to arise from insufficient awareness, a failure to identify FGM, and an absence of training.⁵⁰

Studies have described a lack of provider awareness of the prevalence, diagnosis, and management of FGM, and difficulties in identifying and classifying FGM according to the WHO classification.^{47–56} A UK survey found that only half of the 79 participants were aware that there are four types of FGM,⁵¹ and in another study, only 58% of the 45 respondents were able to list the different categories.⁵² In Egypt, a country with a high prevalence of FGM, poor knowledge on the issue was reported among medical students.⁵³ In Sudan, another country with a high prevalence of FGM, a study among midwives reported that 80% of the respondents used to practice FGM, but that only 7% were able to correctly identify the four types.⁵⁴ A study on a sample of 39 women with FGM in the UK showed that often the FGM was not identified until the onset of labour.⁵⁰ In Norway, a qualitative study found both disempowerment and a lack of awareness among gynaecologists and midwives regarding FGM and infibulation as a medical problem.⁵⁶ In Switzerland, opportunities to identify FGM are frequently missed (37%) or the FGM type is often misclassified (23%), in spite of the available guidelines for gynaecologists, obstetricians, and midwives, professionals who must be trained to correctly screen, refer, and care for women with FGM.⁵⁵

A lack of visual documentation on the different types of FGM, complications, and surgeries perpetuates the challenges that providers face in correctly identifying FGM subtypes. Some pictures of FGM and their complications are available in articles published in the literature;⁵⁷ however, no didactic atlas exists. In addition, textbooks (e.g. *Netter's Obstetrics & Gynaecology*) may present a different classification of FGM than the official classification proposed by the WHO:¹ for example, type-IV FGM is illustrated as a severe infibulation (type III), instead of FGM by pricking, piercing, incising, scraping, or cauterisation.⁵⁸

The lack of recognition or misclassification of FGM jeopardises the health care of women: no recognition impedes diagnosis, which precludes appropriate care, counselling, and treatment. Appropriately trained personnel could lead to improved communication, diagnosis, and documentation, and to better health care and the prevention of this practice for future generations.⁵⁵

Training of healthcare providers by individuals with expertise in FGM should include cultural, psychosexual, and legal information, along with medical and surgical care and obstetric management. It should include didactic pictures and videos, discuss the importance of prevention, and address the medicalisation of FGM. Communication simulations, or role play, may improve provider comfort and ability to address the sensitive sexual and cultural issues encompassed by FGM. Some resources are already available.^{21,57,59} As one common identified problem is classification, caregivers could be provided with a pocket flyer with pictures and descriptions of the four types of FGM, the countries considered at risk, and the main complications to be recognised during the vulvar examination.⁵⁵

Summary of research gaps

Obstetric outcome and postpartum perineal re-education

Obstetric outcome. Obstetric outcomes should be prospectively evaluated adjusting the results for age, socio-economic status, reproductive history, health, diseases affecting the pregnancy, and education, as performed by WHO in 2006.⁹ Importantly, results should also be interpreted in the context of healthcare use and quality, such as the type of health care available, or the presence of a dedicated clinic for women with FGM. It is fundamental to distinguish the obstetric outcome for each type of FGM and to register the type of delivery, with the reason for assisted delivery or caesarean section indicated, and the stage of labour at which emergency caesarean section is performed. The definitions used to measure common outcomes should be standardised (e.g. prolonged labour).

Evidence on the ideal timing of defibulation during pregnancy is urgently needed. It is not known if the timing of defibulation affects the acceptability of the procedure or health outcomes, or whether the demand for postpartum reinfibulation varies with the timing of defibulation during pregnancy. One could hypothesise that women who had their genitalia defibulated during pregnancy have the opportunity to become accustomed to the new body image, and do not experience postpartum and post-defibulation anatomical and physiological changes at the same time. Defibulation is technically simple, but may require supportive care as the woman can experience doubts, and resistance or fear of exclusion from her own community, and can dislike the new body image and physiology.³⁰ A well-designed study, with adequate sample size, that prospectively compares antepartum and intrapartum defibulation, with respect to blood loss, rates of episiotomy, perineal lacerations, demand of reinfibulation (postpartum restitching), and acceptability to women is needed.

Evidence on how to manage intrapartum defibulation is needed. Defibulation in pregnancy, at the first and at the

second stage of labour, should be prospectively compared for blood loss, rate of episiotomy, perineal tear, demand for reinfibulation, and acceptance and satisfaction of the women. The choice of the woman between defibulation in pregnancy or at delivery should be evaluated according to the gestational age at which the woman is referred: if women are informed about defibulation only at the end of the pregnancy, they will not have a choice between defibulation during pregnancy or in labour. The age of pregnancy at referral could also be an indicator of the attention paid to FGM by caregivers, who often think about FGM only when the delivery is approaching.

Evidence is needed on the incidence of urinary tract and vaginal infections during pregnancy, and their health consequences in women with FGM. It is unknown whether antenatal defibulation, in the case of type III, could decrease the frequency of such infections.

Postpartum perineal re-education. Further studies could evaluate long-term postpartum complications, such as prevalence of incontinence postpartum, or the effectiveness of treatments, such as perineal re-education (e.g. biofeedback or Kegel exercises). Perineal re-education could improve not only lower urinary tract symptoms and dyspareunia, but could also increase the woman's self-knowledge of anatomy and physiology, which may improve satisfaction with genitalia image after delivery. Improved satisfaction with vulvar appearance may lead to decreased requests for postpartum reinfibulation.

Defibulation not performed during pregnancy or labour

Further studies should investigate how defibulation can improve infibulated women's health and sexuality, and how it modifies body image. Prospective studies should focus on the women's motivations and medical indications for the procedure, the closure type (subtypes of type-III FGM, with or without the cutting of the clitoris), the type of defibulation (partial or total) preferred by women, the resolution of symptoms after surgery (e.g. dysmenorrhea, urinary complications, and genitourinary infections), and the anaesthesia (general or local) preferred by women. Intraoperative and postoperative complications should be recorded. Sexual function and body image before and after defibulation should be evaluated with validated tools. When and where women seek care for defibulation, who performs it, and what access and care is offered could also be investigated.

Clitoral reconstruction

Future sexuality research in women with FGM, including clitoral reconstruction, should clearly define appropriate control groups, adjust for key demographic differences,³⁹ and choose or create validated questionnaires to measure sexuality outcomes, including orgasm.

Important research questions exist concerning clitoral reconstruction, such as the impact of this surgery on the health outcomes of vulvar pain and sexual functioning.

The preoperative expectations of patients and the degree of postoperative satisfaction in terms of body image, and global sexual function, are relevant outcomes to assess with this surgery. An improved understanding of the roles played by anatomy, body self-image, and identity is needed.⁴⁴ Future studies should focus on identifying the motivations of women asking for clitoral reconstruction, such as social and aesthetic reasons, change of body image, ideal of beauty, factors linked with gender identity, and feelings of rehabilitation or empowerment. Studies on the best care of young, migrant, circumcised women growing up in host countries are also needed. These young women are reported to be at greater risk of sexual problems than adult women with FGM in their original countries.^{40,59}

Training, skills, and confidence of healthcare providers

Future studies should evaluate whether, in addition to a lack of time and training on FGM, the present counselling of caregivers and practice result from a desire to avoid a subject that is considered taboo, or from a concern about stigmatising women with their questions. Training including cultural skills in discussing sexuality and FGM may improve counselling and care. It is crucial to study the beliefs on anatomy, physiology, and sexuality of women with FGM held by caregivers in both Western settings and in countries where FGM is practiced. If providers managing an FGM complication consider FGM as an irreversible and untreatable condition, they may not offer appropriate care and counselling.

Further studies on healthcare providers, in particular maternity staff and paediatricians, interpreters, and social workers, could help to assess knowledge and skills on FGM, personal emotional distress, reactions, and fears, confidence, personal beliefs, willingness to talk about FGM with a woman affected, and documentation of the medical file. According to the results, measures could be taken to improve communication, FGM diagnosis and care, and documentation.

The effectiveness of the implemented measures should be evaluated. Evaluation measures could include questionnaires administered before and after training, or behaviour changes in patient care (although these latter changes could be difficult to study).

Conclusion

There is an urgent need for well-designed research to inform evidence-based guidelines, and to improve the health care of women and girls with FGM. Future studies should focus on addressing existing research gaps such as obstetric outcome, complications, sexuality, and therapeutic surgeries. They

should take into consideration the diversity of women with FGM: different types of cutting, origins, cultures, experience, complications, and migration. Ideally, future studies should be multicentre and prospective, and should involve countries where FGM is practiced as well as countries of migration. Circumcised women's groups should also be involved to help us understand what research they want and need. Training of caregivers represents another large field of work and research. Evidence will help to establish guidelines for the best multidisciplinary care, communication, prevention, and improvement of health promotion measures.

Disclosure of interests

The authors have no conflicts of interest to disclose. Two of the authors are WHO staff members. The views expressed in this document are solely the responsibility of the authors and do not necessarily represent the views of the World Health Organization or its member countries.

Contribution to authorship

Conception and planning: JA, LS, and MIR. Carrying out the research: JA, MIR, and LS. Analysing and writing up the results: JA, MIR, and LS. Revision and final approval: JA, MIR, and LS.

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References

- 1 Eliminating female genital mutilation: an interagency statement UNAIDS, UNDP, UNECA, UNESCO, UNFPA, UNHCHR, UNHCR, UNICEF, UNIFEM, WHO. ISBN 978 92 4 159644 2. World Health Organization. 2008 http://www.un.org/womenwatch/daw/csw/csw52/statements_missions/Interagency_Statement_on_Eliminating_FGM.pdf Accessed 11 December 2013.
- 2 Female Genital Mutilation/Cutting: Data and Trends. Update 2010. Population Reference Bureau. [<http://www.prb.org/pdf10/fgm-wall-chart2010.pdf>]. Accessed 11 December 2013.
- 3 European Institute for Gender Equality. Female genital Mutilation in the European Union and Croatia Report. European Union 2013.

- ISBN 978-92-9218-118-5. [<http://eige.europa.eu/content/document/female-genital-mutilation-in-the-european-union-and-croatia-report>]. Accessed 11 December 2013.
- 4 Female Genital Mutilation in Switzerland. Risks, dimensions of the practice, urgent actions. Unicef Switzerland. Survey 2012.
 - 5 2008 Africa population data sheet. Population Reference Bureau and African Population and Health Research Center. 2008 Population Reference Bureau. [<http://www.prb.org/pdf08/africadatasheet2008.pdf>]. Accessed 11 December 2013.
 - 6 Perron L, Senikas V, Burnett M, Davis V, Social Sexual Issues Committee, Burnett M, Aggarwal A, Bernardin J, Clark V, Davis V, Fisher W, Pellizzari R, Polomeno V, Rutherford M, Sabourin J, Ethics Committee, Shapiro J, Akhtar S, Camire B, Christilaw J, Corey J, Nelson E, Pierce M, Robertson D, Simmonds A. Female genital Cutting. *J Obstet Gynaecol Can* 2013;35:e1–18.
 - 7 Australian Government Department of Immigration and Citizenship. *Settler Arrivals 1998–99 to 2008–09, Australia, States and Territories*. Canberra: DIC, 2009.
 - 8 UN. General Assembly. Sixty-seventh session. Third Committee. Agenda item 28 (a). Advancement of women. [<http://www.un.org/News/Press/docs/2012/gashc4061.doc.htm>]. Accessed 16 November 2012.
 - 9 WHO study group on female genital mutilation and obstetric outcome, Banks E, Meirik O, Farley T, Akande O, Bathija H, Ali M. Female genital mutilation and obstetric outcome: WHO collaborative prospective study in six African countries. *Lancet* 2006;9525:1835–41.
 - 10 Rouzi AA, Aljhadali EA, Amarin ZO, Abduljabbar HS. The use of intrapartum defibulation in women with female genital mutilation. *BJOG* 2001;108:949–51.
 - 11 Rouzi AA, Al-Sibiani SA, Al-Mansouri NM, Al-Sinani NS, Al-Jahdali EA, Darhouse K. Rouzi defibulation during vaginal delivery for women with type III female genital mutilation. *Obstet Gynecol* 2012;120:98–103.
 - 12 Kaplan A, Forbes M, Bonhoure I, Utzet M, Martín M, Manneh M, et al. Female genital mutilation/cutting in The Gambia: long-term health consequences and complications during delivery and for the newborn. *Int J Womens Health* 2013;17:5. <http://www.dovepress.com/female-genital-mutilation-cutting-in-the-gambia-long-term-health-conseq-peer-reviewed-article-IJWH>
 - 13 Meirik O, Banks E, Farley T, Akande O, Bathija H, Ali M. Female genital mutilation and obstetric outcomes: flawed systematic review and meta-analysis does not accurately reflect the available evidence. *Obstet Gynecol Int* 2014;2014:205230. <http://www.hindawi.com/journals/ogi/2014/205230/>
 - 14 Essén B, Sjöberg NO, Gudmundsson S, Ostergren PO, Lindqvist PG. No association between female circumcision and prolonged labor: a case control study of immigrant women giving birth in Sweden. *Eur J Obstet Gynecol Reprod Biol* 2005;121:182–5.
 - 15 Wuest S, Raio L, Wyssmueller D, Mueller MD, Stadlmayr W, Suberk DV, et al. Effects of female genital mutilation on birth outcomes in Switzerland. *BJOG* 2009;116:1204–9.
 - 16 Berardi JC, Teillet JF, Godard J, Laloux V, Allane P, Franjou MH. Obstetrical consequences of female circumcision. Study in 71 circumcised African women. *J Gynecol Obstet Biol Reprod (Paris)* 1985;14:743–6.
 - 17 Paliwal P, Ali S, Bradshaw S, Hughes A, Jolly K. Management of type III female genital mutilation in Birmingham, UK: A retrospective audit. *Midwifery* 2014;30:282–8.
 - 18 Berg RC, Underland V. The obstetric consequences of female genital mutilation/cutting: a systematic review and meta-analysis. *Obstet Gynecol Int* 2013;2013:496564. Epub 2013 Jun 26. <http://www.hindawi.com/journals/ogi/2013/496564/>
 - 19 Public Policy Advisory Network on Female Genital Surgeries in Africa. Seven things to know about female genital surgeries in Africa. *Hastings Cent Rep* 2012;42:19–27. <http://onlinelibrary.wiley.com/doi/10.1002/hast.81/full>
 - 20 Balogun OO, Hirayama F, Wariki WM, Koyanagi A, Mori R. Interventions for improving outcomes for pregnant women who have experienced genital cutting. *Cochrane Database Syst Rev* 2013;28:2.
 - 21 Johnson C, Nour NM. Surgical techniques: defibulation of Type III female genital cutting. *J Sex Med* 2007;4:1544–7.
 - 22 Abdulcadir J, Margairaz C, Boulvain M, Irion O. Care of women with female genital mutilation/cutting. *Swiss Med Wkly* 2011;140:w13137. <http://www.smw.ch/content/smw-2011-13137/>
 - 23 Royal College of Obstetricians and Gynaecologists. Female Genital Mutilation and its management - Green-top Guideline No. 53 [Internet]. 2009 [<http://www.rcog.org.uk/files/rcog-corp/Green-Top53FemaleGenitalMutilation.pdf>]. Accessed 11 December 2013.
 - 24 Thierfelder C, Tanner M, Bodiang CMK. Female genital mutilation in the context of migration: experience of African women with the Swiss health care system. *Eur J Public Health* 2005;15:86–90.
 - 25 Amman C, Cotting A, Hanselmann V, Held P, Hohlfeld P, Hollinger E, Jäger F, Kessler BC, Maury-Pasquier L, Schuerch B, Spycher C, Thierfelder C. Mutilations génitales féminines: recommandations suisses à l'intention des professionnels de la santé. SSGO 2005. [http://sggg.ch/files/Mutilations_genitales_feminines.pdf]. Accessed 11 December 2013.
 - 26 Gynécologie Sans Frontières, Ministère de la Santé et des Sports, République Française. Le praticien face aux mutilations sexuelles féminines 2010 [<http://www.gynsf.org/MSF/praticienfaceauxmsf2010.pdf>]. Accessed 11 December 2013.
 - 27 Al-Hussaini TK. Female genital cutting: types, motives and perineal damage in laboring Egyptian women. *Med Princ Pract* 2003;12:123–8.
 - 28 Management of pregnancy, childbirth and the post partum period in the presence of female genital mutilation. Report of a WHO Technical Consultation. Geneva, 15-17 October 1997. Department of Gender, Women and Health. Department of Reproductive Health and Research. Family and Community Health World Organization 2001.
 - 29 Almroth L, Bedri H, El Musharaf S, Satti A, Idris T, Hashim MS, et al. Urogenital complications among girls with genital mutilation: a hospital-based study in Khartoum. *Afr J Reprod Health* 2005;9:118–24.
 - 30 Knight R, Hotchin A, Bayly C, Grover S. Female genital mutilation—experience of The Royal Women's Hospital, Melbourne. *Aust N Z J Obstet Gynaecol* 1999;39:50–4.
 - 31 Momoh C, Ladhani S, Lochrie DP, Rymer J. Female genital mutilation: analysis of the first twelve months of a Southeast London specialist clinic. *BJOG* 2001;108:186–91.
 - 32 Rushwan H. Etiologic factors in pelvic inflammatory disease in Sudanese women. *Am J Obstet Gynecol* 1980;138:877–9.
 - 33 Abdulcadir OH, Catania L. Deinfibulazione terapeutica. Il Ginecologo Rivista di Ostetricia e Ginecologia Vol.1, n. 2, Giugno 2006.
 - 34 Catania L, Abdulcadir O, Puppo V, Verde JB, Abdulcadir J, Abdulcadir D. Pleasure and orgasm in women with Female Genital Mutilation/Cutting (FGM/C). *J Sex Med* 2007;4:1666–78.
 - 35 Krause E, Brandner S, Mueller MD, Kuhn A. Out of Eastern Africa: defibulation and sexual function in woman with female genital mutilation. *J Sex Med* 2011;8:1420–5.
 - 36 Nour NM, Michels KB, Bryant AE. Defibulation to treat female genital cutting: effect on symptoms and sexual function. *Obstet Gynecol* 2006;108:55–60.

- 37 Teufel K, Dörfler DM. Female genital circumcision/mutilation: implications for female urogynaecological health. *Int Urogynecol J* 2013;24:2021–7.
- 38 Abdulcadir J, Dällenbach P. Overactive bladder after female genital mutilation/cutting (FGM/C) type III. *BMJ Case Rep* 2013;4:2013.
- 39 Paterson LQP, Davis SN, Binik YM. Female genital mutilation/cutting and orgasm before and after surgical repair. *Sexologies* 2012;21:3–8.
- 40 Foldès P, Cuzin B, Andro A. Reconstructive surgery after female genital mutilation: a prospective cohort study. *Lancet* 2012;380:134–41.
- 41 Foldès P, Louis-Sylvestre C. Results of surgical clitoral repair after ritual excision: 453 cases. *Gynecol Obstet Fertil* 2006;34:1137–41.
- 42 Ouédraogo CMR, Madzoy S, Touré B, Ouédraogo A, Ouédraogo S, Lankoandé J. Pratique de la chirurgie plastique reconstructrice du clitoris après mutilations génitales au Burkina Faso. A propos de 94 cas. *Ann Chir Plast Esthet* 2013;58:208–15.
- 43 Thabet SM, Thabet AS. Defective sexuality and female circumcision: the cause and the possible management. *J Obstet Gynaecol Res* 2003;29:12–9.
- 44 Abdulcadir J, Boulvain M, Petignat P. Reconstructive surgery for female genital mutilation. *Lancet* 2012;380:90–2.
- 45 Zhang GY, Li QF, Cai JL, Fu XB, Gao WY. Reconstructive surgery after female genital mutilation. *Lancet* 2012;380:1468–9. author reply 1469–70.
- 46 Creighton S, Bewley S, Liao LM. Reconstructive surgery after female genital mutilation. *Lancet* 2012;380:1469. author reply 1469–70.
- 47 Jäger F, Schulze S, Hohlfeld P. Female genital mutilation in Switzerland: a survey among gynaecologists. *Swiss Med Wkly* 2002;132:259–64.
- 48 Leye E, Ysebaert I, Deblonde J, Claeys P, Vermeulen G, Jacquemyn Y, et al. Female genital mutilation: knowledge, attitudes and practices of Flemish gynaecologists. *Eur J Contracept Reprod Health Care* 2008;13:182–90.
- 49 Chalmers B, Hashi KO. 432 Somali women's birth experiences in Canada after earlier female genital mutilation. *Birth* 2000;27:227–34.
- 50 Zenner N, Liao LM, Richens Y, Creighton SM. Quality of obstetric and midwifery care for pregnant women who have undergone female genital mutilation. *J Obstet Gynaecol* 2013;33:459–62.
- 51 Relph S, Inamdar R, Singh H, Yoong W. Female genital mutilation/cutting: knowledge, attitude and training of health professionals in inner city London. *Eur J Obstet Gynecol Reprod Biol* 2013;168:195–8.
- 52 Zaidi N, Khalil A, Roberts C, Browne M. Knowledge of female genital mutilation among healthcare professionals. *J Obstet Gynaecol* 2007;27:161–4.
- 53 Mostafa SR, El Zeiny NA, Tayel SE, Moubarak EI. What do medical students in Alexandria know about female genital mutilation? *East Mediterr Health J* 2006;12(Suppl 2):S78–92.
- 54 Ali AA. Knowledge and attitudes of female genital mutilation among midwives in Eastern Sudan. *Reprod Health* 2012;28:23.
- 55 Abdulcadir J, Dugerdil A, Boulvain M, Yaron M, Margairaz C, Irion O, et al. Missed opportunities for diagnosis of female genital mutilations/cuttings. *Int J Obst Gyn* 2014;125:256–60.
- 56 Vangen S, Johansen RE, Sundby J, Traeen B, Stray-Pedersen B. Qualitative study of perinatal care experiences among Somali women and local health care professionals in Norway. *Eur J Obstet Gynecol Reprod Biol* 2004;112:29–35.
- 57 Anand M, Stanhope TJ, Occhino JA. Female genital mutilation reversal: a general approach. *Int Urogynecol J* 2014;25:985–6.
- 58 Smith RP. Female circumcision. In: O'Grady E, Thiel M editors. *Netter's Obstetrics and Gynecology*, 2nd edn. Philadelphia, PA: Saunders; 2009. pp. 194–5. ISBN-13: 978-1416056829. [http://www.fgmresource.com/]. Accessed 13 July 2014.
- 59 Johnsdotter S. How pro-orgasm intentions in anti-FGM campaigning backfire. 20th World Congress for Sexual Health; Glasgow; June 12–16, 2011.