



Addressing FGM with Multidisciplinary Care. The Experience of the Belgian Reference Center CeMAViE

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Abstract

Purpose of Review To describe the multidisciplinary approach of the Brussels-based referral center, one of the two centers for women living with female genital mutilation (FGM) in Belgium. This approach is contextualized and compared to the latest literature on the subject.

Recent Findings According to the World Health Organization, women who have undergone FGM should be able to benefit from multidisciplinary care. Clitoral reconstructive surgery appears to be a crucial but controversial element of this holistic treatment; its long-term benefits and role in sexual satisfaction are still the focus of many questions.

Summary Clitoral reconstructive surgery has been reimbursed by Belgian social security since 2014 only in conjunction with multidisciplinary care. In our referral center, the care is provided by a gynecologist, a midwife, a psychotherapist, and a sexologist. Five preoperative consultations are mandatory to obtain the refund. CeMaVie's first line of treatments is non-surgical therapies.

Keywords Female genital mutilation · Gender-based violence · Multidisciplinary care · Clitoris reconstructive surgery · Sexology · Psychotherapy

Introduction

Female genital mutilation (FGM) consists of the partial or total removal of the external female genitalia for cultural or non-therapeutic reasons [1]. According to the latest estimates, FGM affects 200 million women around the world [1]. FGM is practiced predominantly in Sub-Saharan Africa, in the Middle East such as Iraq and Yemen, and in some countries in Asia like Indonesia. There is also evidence of the practice in

Dagestan, Colombia, India, Malaysia, Oman, Saudi Arabia, and the United Arab Emirates [2, 3]. However, due to migration, FGM has become a human rights issue that affects girls and women worldwide. The practice is mostly performed on underage girls without their consent. FGM is a violation of the human rights and the bodily integrity of women [1]. Various justifications for the practice are given among different FGM-practicing communities. Commonly mentioned reasons are marriageability, the preservation of virginity before marriage, and marital fidelity, which are all linked to the underlying expectation that women's sexuality needs to be controlled [4–7]. Other common reasons are “purity”—according to local conceptions—and esthetics [8]. Despite the sexual and psychological violence that women are subject to through FGM, having gone through the practice grants women special status within their community [9, 10]. Those who refuse to go through the practice are often subject to abuse, social exclusion, and stigmatization [11, 12].

The WHO has classified FGM into four categories: type I, often referred to as clitoridectomy; type II, often referred to as excision; type III or infibulation; and type IV, which includes other types of practices such as pricking or cauterization [1].

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The injury to the vulva can have an impact on the health of women that goes beyond the genital sphere and can severely alter their quality of life [13••]. Immediate complications include as follows: acute pain that may have an impact on women for decades, severe bleeding, hypovolemic shock and death, urinary reflex retention, infection, swelling, and impaired wound healing. There is currently no data available on the mortality rate of FGM. However, many women we encountered during consultation have a close or distant relative who have died from FGM. Long-term consequences include vaginal discharge and itching, urinary tract infection and complications, sexual difficulties, and dyspareunia and obstetric complications [13••, 14••]. There is no available evidence that correlates FGM with infertility or with transmission of HIV or other sexually transmitted diseases [13••].

First described by S Thabet in 2003, clitoral reconstruction is a surgical procedure with the aim of reconstructing the clitoris to achieve clitoral relief, in women who request it. Developed by the French urologist P. Foldes, the operation quickly received a lot of media attention and more than 6000 women have gone through operation in France between 1998 and 2017 [15]. Rather than a reconstruction, this procedure is the translocation of the residual clitoral body to the skin. By severing the suspensory ligament of the clitoris, a 2- to 3-cm stump can be liberated while preserving the neurovascular pedicle. However, there is limited evidence on the safety of the operation and its impact on pain and sexuality due to extensive heterogeneity of the data and lack of statistical power [14••]. While strong evidence is still needed, multidisciplinary units are emerging and are in the process of developing coherent care pathways. Many countries have now integrated FGM into their health protocols to monitor pregnancy and childbirth [16].

In Belgium, two FGM multidisciplinary centers have been accredited since 2014 to perform reconstructive surgery of the clitoris, as well as psychological care and sexual therapy. All the costs are covered by Belgian social security. The objective of this paper is to describe the approach and the patient's pathways in CeMAViE (Centre d'Aide Médicale aux Victimes de l'Excision - Medical Center in Aid of Victims of Excision), one of the two Belgian FGM reference centers located in the University Hospital Saint Pierre in Brussels.

The Belgian Context

According to the latest estimates, more than 13,000 women are currently living with FGM in Belgium [17]. Since 2001, FGM has been outlawed and is a punishable crime in Belgium. However, to date, no trials have been held. In 2008, the Belgian Ministry of Health requested the Superior Health Council to consider the relevance of clitoral reconstruction surgery and the possibility of reimbursement of the

procedure through the Belgian social security. In 2009, the Superior Health Council gave a positive answer for reconstructive surgery under two conditions: (a) it should be performed in accredited multidisciplinary centers in conjunction with sex therapy and psychotherapy as complementary components of the care. It was recommended that those therapies could also be offered to women as stand-alone treatment for those who request it without any surgery. (b) Research should be undertaken to evaluate the short- and long-term impact of surgery as evidence was and still is scarce. Two accredited centers finally opened in 2014 after an agreement with the State health care insurances (called “mutuelles” in French) through specific conventions. If the reimbursement file is accepted by the health care insurance, patients receive a total of 15 “credits” to spend on the consultations: each consultation for psychosexual care and midwife costs one “credit,” and gynecology consultations are de facto reimbursed. The clitoral surgery cost is 4.5 “credits.”

The Pathways of Care at CeMAViE

At CeMAViE, which is the referral center for the French-speaking part of Belgium, women are seen by a FGM expert midwife, a gynecologist, a sexologist, and a psychologist.

Five consultations are mandatory before the surgery. The surgery will not be reimbursed without multidisciplinary care (Fig. 1).

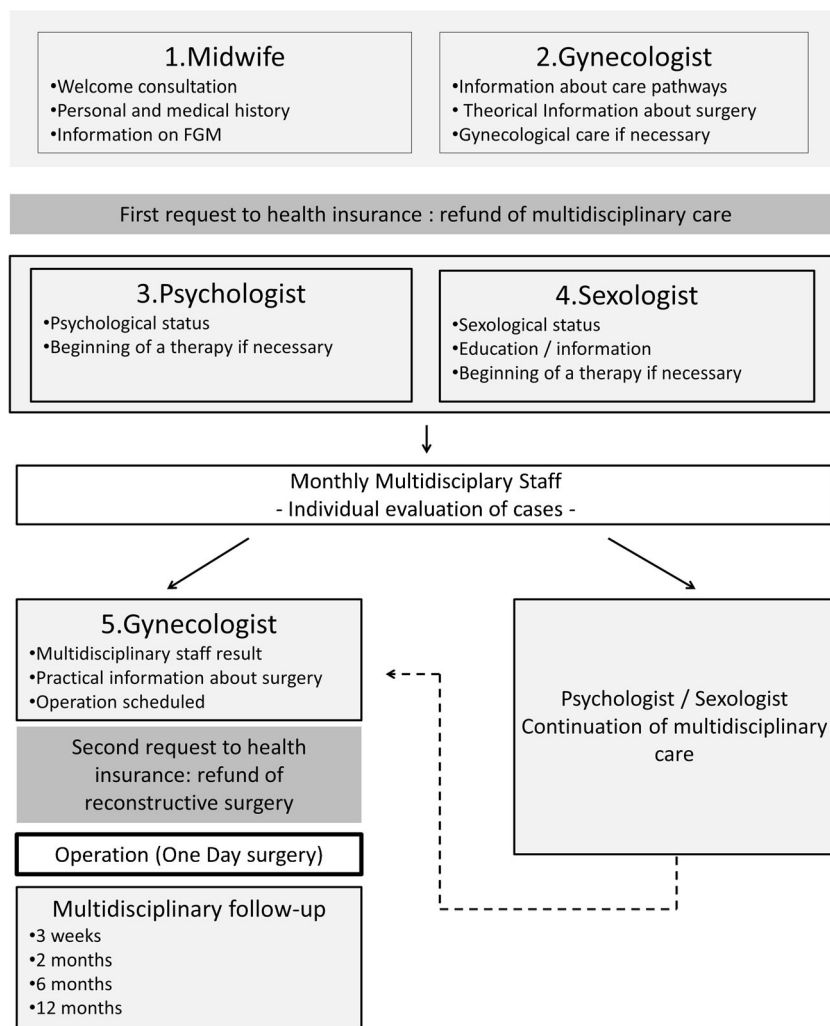
Patient Reception

The first point of contact is with a FGM expert midwife. An interpreter is provided if there are comprehension difficulties. The expert midwife's role is to identify demands and expectations related to care and surgery. She collects personal and medical history and tries to identify any form of gender-based violence. Most of the patients are victims of forced marriage or sexual violence. She also reassures the patient about the clinical exam and shows her drawings of FGM types and a 3D clitoris to inform the patient about the anatomy of the clitoris and the impact of FGM. During the exam, mirrors can be used if the woman wants to see her genitalia to facilitate explanations of what has or has not been cut. The midwife also facilitates links with specialized NGOs and social workers. The woman's feelings and motivations before the operation are reported in the medical record to compare with her words after the intervention.

Gynecology

The gynecologist sees the woman just after the midwife. He notes down any difficulties women are experiencing related to

Fig. 1 Pathways of care



FGM and answers questions of a medical or surgical nature. After welcoming the patient, the consultation always begins with the same question: *what do you think this surgery will bring to you in the future?* This allows us to understand the patient's level of information and expectations and to assess whether her request corresponds with what surgery can offer, based on the available evidence. If the expectations of the patient are in line with the benefits of the intervention, we address the issue of the anatomical outcome, convalescence, and potential complications. The anatomical result is most often evaluated by the surgeon himself using un-validated scales [18, 19, 20]. In our experience, the final size of the neoglans is difficult to anticipate. Preoperative evaluation by palpation of residual clitoral body size is discussed with the patient: if the residual stump is not very palpable, the risk of postoperative burying is increased. We apply the Foldes technique modified by Ouedraogo which seems promising by obtaining a clitoris of satisfactory size in very large majority of cases [20].

Although the surgical procedure is relatively easy and reproducible, it is essential to inform women about the

postoperative period, especially with regard to pain and complication rates. The duration of healing can extend beyond 12 weeks, and the patient sometimes has to deal with severe pain, which may require the use of level 3 analgesics. Women thus need to be cautioned about this risk, which may trigger memories of violence that are difficult to manage such as posttraumatic stress disorder [21]. If such items are identified, our psychologist offers the patient continued psychotherapy. The short-term complications most commonly described include bleeding, loosened sutures, infection, and urine retention. In the first series published by Foldes in 2006, this rate rises to 23.6% [18]. The recent review of Berg mentions an average rate of 15.4%, with 5.3% of immediate complications involving re-hospitalization [22]. So far, no deaths or life-threatening complications have been reported. There is no evidence yet on the role of clitoral reconstruction on the obstetrical outcome.

Once the patient has seen the expert midwife and the gynecologist, the first demand for reimbursement is sent to the health care insurances for agreement. At CeMaViE, the patient is given complete and evidence-based information on the

outcome of the surgery based on the most recent findings in the scientific literature and after the overall assessment of their case. About 27% of women requesting reconstruction underwent the procedure between 2014 and 2016 ($n = 107$).

Sex Therapy and Psychotherapy

Appointments with the psychologist and the sexologist are scheduled after the preliminary consultations with the midwife and the gynecologist.

The role of psychologist is to evaluate the demand for reconstructive surgery and to provide a therapeutic management of psychotrauma if needed. This therapy is based on eye movement desensitization and the reprocessing (EMDR) method. Sometimes, a request for reconstruction is the first demand of the patient, but it can hide other needs. Patients' given motivations for reconstructive surgery have been "to have less pain during the first night" (forced marriage) or "to allow the man to penetrate" (vaginismus). Family violence has also been discovered behind a request for surgery. In these cases, we explained that an operation would have a limited or negative impact and that it was probably wiser to work on these issues before undertaking any surgical procedure. CeMaViE works closely with gender-based violence services, as it is crucial for women to be accompanied while seeking support and trying to overcome traumatic experiences.

The sexology consultation covers five areas: (a) anatomy, (b) the impact of female genital mutilation on the sexual response of women, (c) the reality of female sexual response, (d) false beliefs, and (e) sexuality as an active learning process (test, try, and improve). If the patient seeks an improvement of sexual satisfaction through surgery, it is crucial to investigate whether the patient has explored different avenues of sexual satisfaction. Some of our patients believed that the clitoris is *like a switch that can be turned on and off* and through which sexual satisfaction is guaranteed. Sex education and an improved understanding of sexual functions are crucial to reconnect the patient with physiological realities.

Surgical or Non-surgical Pathway

In our opinion, this multidisciplinary approach with experienced specialists allows patients to be confronted with their false expectations, which is why the majority end up opting for non-surgical therapies. After having met the four health professionals for between 30 and 60 min each, the patient's case is discussed at the monthly multidisciplinary team meeting. Since 2014, only one candidate has been refused due to severe malnutrition from anorexia nervosa. Besides these kinds of medical contraindications, trauma or lack of sexual education may affect the well-being of the patient which may influence the outcome of the surgery and can be reasons to postpone the operation. If this is the case, then psychological

or sexological approaches are recommended, rather than surgery. If the decision of the meeting is favorable to the surgical procedure, the practical details are reviewed again with the patient together with the gynecologist at the fifth consultation to ensure her full understanding of the procedure and postoperative care. The practical aspects of the surgery are explained, and the intervention scheduled. It is important to note that if the team agrees that the patient is suitable and ready for surgery, the final decision for reconstruction nevertheless depends on the patient herself.

Assessing Patient's Satisfaction

After the first reconstruction procedures, we received very positive feedback from our patients. There was an increase in self-esteem: "I walk with my head up," "I finally feel like a woman," bodily image: "I feel complete," "I'm not ashamed of my body anymore", and empowerment: "I feel stronger," "now I'm ready to find a new job." The aspects related to the quality of sexual life improvement go in the same direction; most of our patients describe an increase in sexual desire, sexual arousal, and sexual pleasure as described in available studies [19, 20]. It is important to mention that we have also seen significant progress in patients who engaged in psychotherapy or sexotherapy. The nature of these personal developments is complex, especially those that consist of profound changes in self-perception and changes impacting on the patients' lives. Some demands for reconstructive surgeries ended after the in-depth introspective work with the holistic team, with such outcomes as leaving a violent husband, starting to look for a job to get financial autonomy, and obtaining a driving license. Data on self-esteem and empowerment are in the process of being collected using qualitative research methods undertaken by an anthropologist specialized in FGM. Quantitative data are also being collected using validated questionnaires: Hospital Anxiety and Depression (HAD) scale, Brief Index of Sexual Functioning for Women (BISFW), and Female Genital Self-Image Scale (FGSIS) [23–25].

Discussion

At CeMaViE, the main reason given to undergo surgical reconstruction is "I want to be whole," "I want to be complete again." This quest for bodily integrity was also the first request in Foldes's 2012 study [19]. The motivations, however, may vary. In Ouagadougou, women who attended Ouedraogo's clinic were mostly looking for an improvement of their sexual satisfaction [26]. This difference suggests that care should adapt to the cultural context of the population treated and the clinical expectations [27]. If we look at the studies available on this

topic, it seems that the translocation of the residual clitoral stump is satisfactory: 99% of women in the Foldes' study reported an improved perception of their body image [19].

In our view, the enhancement in body image and self-esteem is likely to have a positive impact on the improvement of sexual experiences. However, demonstrating the functional benefit of this procedure remains challenging because randomized double-blind trials are not an option: a patient will always know if she was operated on or not.

Strikingly, we have observed that patients who have undergone FGM but have a preserved clitoris, as well as those who are completely intact but believe that they have been cut, have similar complaints to women with an injured or absent glans. This is despite the fact that the entire clitoris contributes in orgasm, not only the glans, in addition to pleasure of extragenital origin [28]. Abdulcadir summarizes, "Female sexuality is multifactorial. Women's sexuality depends on anatomical, hormonal, psychosexual, cultural, contextual, and partner factors, and personal experience" [27]. Even if surgery appears attractive at first sight, the quality of a patient's sex life may be reduced in the interest of the integrity of an organ—whether it was partially restored or moved. This is a trap, which practitioners should be cautious not to fall into. Abramowicz analyzed the postoperative satisfaction based on the first reason for consultation and found that women wishing to improve their sex life were more often disappointed than those desiring to improve their bodily integrity [29]. It is therefore crucial to analyze the patient's request according to her initial wishes and to rationalize this demand by providing complete and objective information based on the available evidence. If not, we take the risk to face enormous disappointments. Until further evidence becomes available, it is important to remain cautious.

FGM is a violation of human rights, and whatever the arguments used to continue with the tradition, its direct or indirect goal is the social and political control of women by controlling their sexuality. Many women come to our clinic because they want to regain control of their own lives again and/or of their selves as "complete women," be it through bodily image, or to improve their sexual satisfaction. Their motivations confirm the well-known facts—that FGM can have a significant impact on the health and quality of life of women.

According to studies published to date, a significant proportion of women report an improvement in their sex life within 1 year after experiencing clitoral reconstruction [18, 19, 26, 29, 30]. In the cohort study conducted by Foldes on 2938 women, 81% (701) of 866 women who attended the follow-up visit reported an improvement in their sex life, and 51% (430) of 841 women reported orgasm at 1 year [19]. Berg highlights improvements in sexual pleasure (63%, range 60.7–88.5%), desire (50.8%, range 46.8–55.7%), and

the frequency of intercourse (41%) as well as a decrease in pain during coitus (average = 43%, range 8–76.9%) [22••].

Merckelbagh describes a diminution in vaginismus and vaginal dryness (26%), bleeding during intercourse (15%), and even a 5% decreased urine leakage rate during the sexual act [30]. On the other hand, Foldes found a decrease in the ability to reach orgasm in 23% of women, which is not negligible. This fact must be mentioned at the preoperative visit, as well as the risk of seeing a postoperative chronic *de novo* pain, even if this risk is less than 1% [19]. In a study of 30 women, Abramowicz found a difference, not significant, between the functional result obtained in women who had been excised before the age of four (36 versus 67% of achieving an orgasm) [29]. It is important to mention that the questionnaires used in these studies were not validated.

For many patients, the final appearance of the vulva and especially the presence of the reconstructed clitoris are the main concern. Berg demonstrated that the patient can expect to obtain a visible clitoris in 77.5% of cases on average [22••]. The acceptance of the final size of the neo clitoris varies greatly from one patient to another. The perception of a "normal" size seems to correlate more with intimate expectations and the individual image of the "ideal clitoris" than the social norms of their country of residence.

Conclusion

Since 2014, reconstructive surgery is only reimbursed if performed at a referral center approved by the health authorities in Belgium. The condition for reimbursement is the provision of multidisciplinary care with at least five preoperative consultations. Multidisciplinary care is crucial in order to be able to respond to the patients' individual needs as, according to our experience, the motivations for clitoral reconstruction are often based on false expectations and/or limited knowledge of sexual functions and sexuality. In addition, many women who requested reconstruction at our clinic suffer from trauma related to FGM or other forms of violence that affects their sexuality and well-being. Such issues need to be dealt with before surgery. This holistic approach is a unique opportunity for the emancipation and empowerment of women living with FGM which we believe will have a greater impact than the surgical procedure alone.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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