

## PAIN

# Chronic Vulvar Pain After Female Genital Mutilation/Cutting: A Retrospective Study



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## ABSTRACT

**Introduction:** Chronic vulvar pain is a condition that affects many women during their lifetime, including women with Female Genital Mutilation/Cutting (FGM/C).

**Aim:** To study the prevalence and possible etiologies of chronic vulvar pain among women living with FGM/C.

**Methods:** We conducted a retrospective review of consecutive medical files of 506 women who consulted our specialized clinic for women with FGM/C between April 1, 2010 and December 31, 2017. We collected sociodemographic and clinical data including information on the type of FGM/C and its complications. We focused on studying the prevalence, etiologies and characteristics of chronic vulvar pain.

**Main outcome measures:** Prevalence and etiologies of vulvar pain in women with FGM/C.

**Results:** Chronic vulvar pain was present in 14 women (2.8%). Pain was unprovoked in one case (7.1%) and provoked in the 13 other cases (92.9%). In most of the cases, women presented vulvar pain related to scar complications such as clitoral or peri-clitoral adhesions or scar tissue (n = 3, 21.4%), bridle scars (n = 1, 7.1%), post-traumatic neuromas (n = 2, 14.3%) and vulvar cysts (n = 6, 42.9%), the latter being found more frequently in women with FGM/C type III. In 2 cases (14.3%) of chronic vulvar pain, no lesions other than FGM/C were visible at clinical examination. Among these 14 women, 12 suffered from superficial dyspareunia as well. The remaining ones had not had any sexual contact for several years.

Dyspareunia was present in 126 women (24.9%), among which 75 patients (14.8%) suffered from superficial dyspareunia and 25 patients (4.9%) complained of deep dyspareunia. Fourteen women (2.8%) reported both superficial and deep dyspareunia. Twelve women (2.3%) reported dyspareunia with no specified localization documented in the medical charts. Dyspareunia was significantly more frequent among infibulated women compared to women with FGM/C different from type III ( $P = .014$ ).

**Conclusion:** Chronic vulvar pain after FGM/C is probably associated with scar complications and FGM/C type III (infibulation). Dyspareunia is more frequent in women with FGM/C type III. **Bazzoun Y, Aerts L, Abdulcadir J. Chronic Vulvar Pain After Female Genital Mutilation/Cutting: A Retrospective Study. Sex Med 2021;9:100425.**

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**Key Words:** Female genital mutilation/cutting; Chronic vulvar pain; dyspareunia; Genital pain; Infibulation; Dyspareunia

## INTRODUCTION

Female genital mutilation/cutting (FGM/C) includes all procedures that involve removal or injury of female genital organs for non-medical reasons.<sup>1</sup> FGM/C exists in many regions of the world including Africa, Asia, the Middle East, some regions of Central and South America, and, with migration, high income countries as well.<sup>2</sup> According to the World Health Organization (WHO), more than 200 million women across the world are living with FGM/C.<sup>3</sup> At least half a million women are estimated to be affected or at risk in Europe<sup>4</sup> and in the United States.<sup>5</sup>

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**Table 1.** FGM/C classification according to the World Health Organization\*

Types of FGM/C		Description
Type I (clitoridectomy)	la	Removal/Cutting of the prepuce/clitoral hood
	lb	Removal/Cutting of glans with eventually part of the body of the clitoris
Type II (excision)	IIa	Removal/Cutting of inner labia
	IIb	Removal/Cutting of inner labia associated to cutting of the clitoris
	IIc	Removal/Cutting of inner labia associated to cutting of the clitoris and outer labia
Type III (infibulation)	IIIa	Removal/Cutting and apposition of inner labia (with or without excision of the clitoris)
	IIIb	Removal/Cutting and apposition of outer labia (with or without excision of the clitoris)
Type IV (all other practices)		Piercing, scraping, incising, pricking or cauterizing of the genital area. Stretching of the inner labia

\*Female genital mutilation. (n.d.). From <https://www.who.int/news-room/fact-sheets/detail/female-genital-mutilation>

The WHO classifies FGM/C into 4 types (Table 1).<sup>1</sup> FGM/C can cause immediate and long-term health complications.<sup>1</sup> Immediate complications include psychological consequences but also urinary lesions, impaired healing, infections (e.g. tetanus or HIV), severe genital pain, hemorrhage, shock and death.<sup>1</sup> Late complications can occur at any time during the girl and/or woman's life and include psychological, genitourinary, obstetric, sexual and infectious complications, as well as chronic pain such as chronic genito-pelvic pain, including dyspareunia and chronic vulvar pain.<sup>1</sup>

Chronic vulvar pain can be divided into 2 categories: vulvar pain caused by a specific disorder, including trauma such as FGM/C; and vulvodinia, referring to vulvar pain of unknown origin of at least 3 months.<sup>6</sup> The prevalence of chronic vulvar pain in the general population ranges from 3 to 15% in self report studies.<sup>7-9</sup> The pain can be generalized or localized, to one specific part of the vulva, such as the clitoris. It can be provoked (by contact, menstruation, sexual intercourse) or unprovoked (without contact) or mixed.<sup>6</sup> The development and persistence of chronic vulvar pain among women with and without FGM/C is associated with biological, psychological and inter-relational factors.<sup>10</sup> In case of FGM/C, biological factors can include the type of cutting, its severity and complications, past obstetric traumas, recurrent genitourinary infections, recurrent fissures or ulcers, abscesses, post traumatic granulomas and neuromas, vulvar, or clitoral cysts, keloids,

and adhesions, or bridles.<sup>11,12</sup> Psychological factors that are associated with chronic vulvar pain include depression, anxiety, and Post-traumatic Stress Disorder (PTSD).<sup>10</sup> Furthermore, social and personal coping strategies of the experience of FGM/C may influence the pain experience.<sup>13</sup> Although FGM/C may be a physically and psychologically traumatic event, a considerable number of women are capable of coping with most impediments and may regard the ritual as "normal" or "enhancing." Diversity in the interpretation, the memory and the experience of the event is crucial for pain psychopathology.<sup>14</sup> Some specific painful experiences such as labor, delivery and post-vulvar surgery pain can recall the pain of the FGM/C, triggering anxiety, depression, or relapse of a PTSD.<sup>15</sup> Relational and social factors that may be associated with chronic vulvar pain involve education and misconceptions about FGM/C, about female genital anatomy and physiology and about female sexuality. Furthermore, beliefs and cultural significance of sexuality and migration may influence chronic pain. For example, previous research has shown that young migrant women with FGM/C that grow up in the West and are exposed to negative or stigmatizing messages on their genital cutting, are at increased risk of sexual problems or a negative self-body/genitals perception.<sup>16</sup>

Finally, many women with FGM/C may have lived other past traumatic events that can contribute to the onset or maintaining of chronic pain (eg. rape, war, migration, death of family members/losses, forced and child marriage, reinfibulation after rape or after delivery).<sup>17,18</sup>

Previous research has shown that chronic vulvar pain can significantly affect the quality of life of women with FGM/C.<sup>12</sup> However, little is known about the bio-psycho-social etiologic factors of chronic vulvar pain after FGM/C. Most knowledge comes from expert opinions<sup>17,19</sup> and from a few single center case series or reports, mainly on vulvar cysts,<sup>20</sup> clitoral neuromas<sup>21</sup> and defibulation.<sup>22,23</sup> Research mainly focuses on FGM/C type III which represents 10% of FGM/C.<sup>24</sup> Furthermore, a recent mixed-method study on 14 infibulated Somali-Canadian women, focusing on the connection between peripheral nerve damage and chronic neuropathic pain, found that the participants reported low levels of pain on the Short-Form McGill Pain Questionnaire-2 while their vulvar pain thresholds were consistent with those reported by uncut women with chronic vulvar pain and dysmenorrhea.<sup>25</sup> The authors of this study insist on how assessing chronic vulvar pain can be challenging due to cultural differences influencing the way pain is experienced, described and verbalized.<sup>25</sup>

This study asks the following research questions. What are the prevalence, etiologies and possible biological, psychological and social factors of chronic vulvar pain in women with different types of FGM/C? Are the pain symptoms of women with FGM/C type III (infibulation) different from those of women having undergone other types of cutting that do not involve the narrowing of the vaginal introitus?

## MATERIALS AND METHODS

We retrospectively reviewed the consecutive medical files of women who consulted at the specialized clinic for women with FGM/C at the Gynecology Division of the Geneva University Hospitals between April 1, 2010 and December 31, 2017. The FGM/C clinic is an outpatient clinic where women and girls with FGM/C consult or are referred for different reasons, for example, information on FGM/C, counseling, health complications related to FGM/C, psychosexual care, perinatal care or request for defibulation or other surgical interventions.

Women and girls who consulted at the clinic during the pre-defined period were included. They were examined by 2 specialized gynecologists trained in vulva disease and sexual medicine who run the clinic. Patients were comprehensively and systematically interviewed on bio-psycho-social issues, including information on FGM/C, age and setting at which it was performed, immediate and late complications. Psychosexual and mental health, as well as chronic pain (eg, vulvar) and its characteristics were systematically investigated during the anamnesis. Pelvic examination always involved vulvar, anal, and perineal inspection. Depending on the patient, the type of genital cutting, her history, her symptoms, and the consultation's reasons, a speculum and a bimanual examination, a cotton-swab test, pelvic floor assessment and screening of recurrent infections and candidiasis were also performed.<sup>26–28</sup>

In absence of language barriers, a woman is received alone for all or for part of the consultation if she asks her partner, friend or family member to be in the room. The presence of an interpreter might cause the loss of some information or embarrassment in the patient. However, everything is done to minimize this: when an appointment is scheduled by women and girls who do not speak one of the languages spoken by the gynecologists, a female certified interpreter is scheduled as well. The female interpreters work for the Red Cross of Geneva; are trained and certified; trusted, well known and accepted in the communities. They participate in person to the consultation with no additional costs for the patient. During the clinical examination, depending on the patient's wishes, the interpreter remains behind a curtain or leaves the room momentarily. Our interpreters were also trained in FGM/C and female and sexual and reproductive health in a training program organized several years ago by the equality office of the Geneva Canton. They also routinely translate in our prospective research studies or during surgical procedures under local or locoregional anesthesia.

We collected sociodemographic and clinical data including information on the type of FGM/C and its complications and other accidental traumas. We focused on studying the prevalence, etiologies and characteristics of chronic vulvar pain. Given the retrospective nature of the study, information on cotton-swab test and pelvic floor assessment was not always documented in the medical files and for this reason, we did not focus our analysis on it. Informed consent was waived: re-contacting all women

by phone would have been difficult because of language barriers and frequent changes in contact details. The study research protocol was approved by the Institutional Review Board.

Statistical analysis was performed using IBM SPSS Statistics 25.0. Descriptive statistics are reported, both as numbers and percentages. Chi-square and *t*-test were applied to investigate differences between the population of women with FGM/C type III versus the population of women without infibulation (FGM/C type I, II and IV). Statistical significance was set at  $P < .05$ .

## RESULTS

We reviewed 506 medical charts of patients with FGM/C who attended our clinic. Our population was averagely  $29.70 \pm 7.99$  years old, with a minimum age of 10 and a maximum age of 82 years old.

Information on the date of arrival in Switzerland was available for 215 (42.5%) women who had averagely spent a period of  $4.37 \pm 6.42$  years in Switzerland, with a minimum of 1 month and a maximum of 35 years.

As summarized in Table 2, women were mainly born in Africa, mostly in East Africa. Four women were born in non-African countries: 2 (0.4%) in Asia and 2 (0.4%) in countries of Europe different than Switzerland (France and Portugal). One woman (originally from Mali) had undergone the cutting in her EU country and the other woman (originally from Guinea) during a trip to her original country.

Most women were Muslim ( $n = 201$ , 39.7%) and married ( $n = 306$ , 60.5%) or in a relationship ( $n = 97$ , 19.2%), involving sex.

Almost half of the sample ( $n = 245$ , 48.4%) needed a certified interpreter due to language barriers.

The majority of girls and women ( $n = 256$ , 50.6%) had undergone FGM/C type III (infibulation) (Table 3). Five women reported FGM/C in their medical history but presented with no visible scar during clinical examination, suggesting a possible FGM/C without removal of tissue or scar (eg, pricking or scraping). For 23 women, a written documentation of FGM/C type was unavailable, because they were not examined (eg, refusal) ( $n = 7$ ), did not attend the appointment for gynecological examination ( $n = 8$ ) or FGM/C documentation was missing in the medical chart ( $n = 8$ ).

Among women from Eritrea, Guinea, Burkina Faso, Mali and Senegal, FGM/C type II and III were equally frequent. Somali and Sudanese women were mostly infibulated (Table 4).

Late complications, referred as associated to FGM/C by the women, included chronic genito-pelvic pain ( $n = 183$ , 36.2%) such as dyspareunia, dysmenorrhea, vulvar pain, abdominal, pelvic or bladder pain; scar complications ( $n = 39$ , 7.7%) such as vulvar cysts, bridle scars or post-traumatic neuromas; recurrent

**Table 2.** Sociodemographic data

		n (%)
Country of origin	Eritrea	199 (39.3)
	Somalia	113 (22.3)
	Ethiopia	40 (7.9)
	Guinea	34 (6.7)
	Burkina Faso	23 (4.5)
	Sudan	23 (4.5)
	Senegal	14 (2.8)
	Mali	12 (2.4)
	Ivory Coast	11 (2.2)
	Egypt	10 (2.0)
	Nigeria	5 (1.0)
	The Gambia	4 (0.8)
	Guinea-Bissau	3 (0.6)
	Other*	4 (0.8)
	Sierra Leone	3 (0.6)
	Djibouti	2 (0.4)
	Cameroon	1 (0.2)
	Kenya	1 (0.2)
	Liberia	1 (0.2)
	Chad	1 (0.2)
Togo	1 (0.2)	
Rwanda	1 (0.2)	
Religion	Muslim	201 (39.7)
	Christian orthodox	70 (13.8)
	Christian catholic	30 (5.9)
	Christian protestant	11 (2.2)
	Christian	3 (0.6)
	Other†	4 (0.8)
	No religion	61 (12.1)
	Unknown (not documented or refusal to answer)	126 (24.9)
Marital status	Married	306 (60.5)
	In a relationship	97 (19.2)
	Single	84 (16.6)
	Divorced	19 (3.8)
Total	506 (100)	

\*Other countries: Portugal (n = 1), France (n = 1), Sri Lanka (n = 1), Cambodia (n = 1)

†Other religions: Buddhist (n = 1), reported as 'other religion' in medical file (n = 3)

genitourinary infections (n = 11, 2.2%) and, sexual dysfunction (n = 143, 28.3%) (Table 5). Some women reported to suffer from several co-existent complications.

Among the 183 women who suffered from genito-pelvic pain, the majority (n = 126, 68.8%) reported dyspareunia (Table 5): 75 patients (41.0%) suffered from superficial dyspareunia while 25 patients (13.6%) complained of deep dyspareunia. 14 (7.7%) women complained from both superficial and deep dyspareunia. Finally, 12 women (6.5%) reported dyspareunia with no specified localization in the medical charts.

**Table 3.** FGM/C types according to WHO classification in our sample

		n (%)
Type of FGM	Type I	48 (9.5)
	Type II	171 (33.8)
	Type III	256 (50.6)
	Type IV	3 (0.6)
	History of FGM/C without visible scar	5 (1.0)
	Not documented	23 (4.5)
Total		506 (100)

Chronic vulvar pain defined as vulvar pain for at least 3 months, provoked or unprovoked, was found in 14 (2.8%) girls and women (Table 6). Most of these (n = 12, 85.7%) had scar complications such as painful vulvar cysts (n = 6, 42.9%). Vulvar pain was mostly provoked by contact (eg, crossing legs, touching) (n = 13, 92.9%). One patient (7.1%) presented with a painful clitoral scar with constant and unprovoked vulvar pain. Among these 14 women, 12 suffered from superficial dyspareunia as well. The remaining ones had not had any sexual contact for several years.

Twenty-one women presented with a vulvar cyst (Table 7), among which only 6 (28.6%) were painful. The histological characteristics of both painful and painless resected cysts (n = 10, 47.6%) are summarized in Table 7. Painful cysts included 1 neuroma, 1 mullerian cyst, and 3 epidermoid cysts. Most of the cysts were a complication of FGM/C type III (Table 8). Two women had a history of a previous vulvar cystectomy performed in another clinic. Both were asymptomatic at the moment of their examination and no information about eventual past genital pain was reported in their medical files.

Information about age at which FGM/C was performed, was available in 198 files (39%). Age at excision was higher in women with genito-pelvic pain (mean age at FGM/C  $6.22 \pm 4.47$  years; median 7 years, IQR 0.75–9 years) compared to women without genito-pelvic pain (mean age at FGM/C  $3.85 \pm 5.13$  years; median 1 year, IQR 0–7.5 years). This was also the case for the subgroup of women with chronic vulvar pain who had a higher median age at excision (mean age at FGM/C  $8.32 \pm 3.68$  years; median 8.5, IQR 8–10.75 years) compared to women without chronic vulvar pain (mean  $4.79 \pm 4.98$  years; median 5, IQR 0–8 years).

Among women with chronic vulvar pain, 35.7% (n = 5) had a history of past traumatic events other than FGM/C and 28.6% (n = 4) had psychiatric comorbidities (3 suffered from PTSD and 1 from depression). Also, 28.6% women with vulvar pain (n = 4) complained of a negative self-image.

The prevalence of chronic pain was similar among women who required the presence of a certified interpreter (n = 84,

**Table 4.** FGM/C according to origin

	Type 1, n(%)	Type 2, n(%)	Type 3, n(%)	Type 4, n(%)	Non visible scar, n(%)	Unknown, n(%)
East Africa* (n = 388)	35 (9.0)	128 (33.0)	201 (51.8)	1 (0.3)	5 (1.3)	18 (4.6)
West Africa† (n = 112)	13 (11.6)	40 (35.7)	54 (48.2)	0 (0)	0 (0)	5 (4.5)
Central Africa‡ (n = 2)	0 (0)	1 (50.0)	0 (0)	1 (50.0)	0 (0)	0 (0)
Other§ (n = 4)	0 (0)	2 (50.0)	1 (25.0)	1 (25.0)	0 (0)	0 (0)

\*East African countries: Eritrea, Somalia, Ethiopia, Sudan, Egypt, Djibouti, Kenya.

†West African countries: Guinea, Burkina Faso, Senegal, Mali, Ivory Coast, Nigeria, The Gambia, Guinea-Bissau, Sierra Leone, Cameroon, Liberia, Togo.

‡Central African countries: Chad, Rwanda.

§Other countries: Portugal, France, Cambodia, Sri Lanka.

**Table 5.** Late complications

Total of patients with FGM/C (n = 506)	n (%)
Pain (n = 183) (several of these symptoms can be reported by the same patient)	Dyspareunia 126 (24.9)
	Dysmenorrhea 98 (19.4)
	Vulvar pain 14 (2.8)
	Vaginismus 6 (1.2)
	Pelvic pain 13 (2.6)
	Abdominal pain 4 (0.8)
	Abdominopelvic pain 1 (0.2)
	Bladder pain 1 (0.2)
Scar complications (n = 39)	Vulvar cysts 21 (4.2)
	Post-traumatic neuromas at histological analysis 7 (1.4)
	Bridles 9 (1.8)
	Keloids 2 (0.4)
Recurrent infections (n = 11)	Urinary 7 (1.4)
	Vaginal 3 (0.6)
	Both 1 (0.2)
Sexual dysfunction (n = 145)	Low desire 9 (1.8)
	Anorgasmia 9 (1.8)
	Pain (dyspareunia) 102 (20.2)*
	Multiple 25 (4.9)
Negative self-image	21 (4.2)
Total	506 (100)

\*In total, 126 women complained of dyspareunia: dyspareunia *alone* was observed in 102 patients, whereas 24 suffered from dyspareunia and other sexual dysfunctions and are thus listed under "multiple."

34.5% of 245 women) and who did not (89, 33% of 231). The same was for chronic vulvar pain: 6 women did not require translocation and 7 did.

We compared infibulated women (FGM/C type III) and cut but noninfibulated women (FGM/C types I, II and IV) to assess vulvar pain symptoms and dyspareunia. In order to limit classification bias, we only included women with a visible scar and a documented type of FGM/C. As summarized in Table 9, the presence of referred late complications in general ( $P = .007$ ), sexual dysfunctions ( $P = .015$ ), dyspareunia ( $P = .014$ ) were significantly more frequent among women with FGM/C type III. Vulvar cysts were also found more frequently in women with

FGM/C type III. Vulvar pain was equally frequent in infibulated women ( $n = 6$ ) and noninfibulated women ( $n = 7$ ).

Almost one third of women ( $n = 145$ , 28.7%) reported sexual dysfunction such as lack of or low desire ( $n = 9$ , 1.8%), anorgasmia ( $n = 9$ , 1.8%) and, mainly, dyspareunia ( $n = 102$ , 20.2%) as summarized in Table 5. Dyspareunia was reported by 126 women, 24 of whom had other sexual dysfunctions associated.

In 21 (4.2%) medical charts, a self-reported negative genital image was documented. Women with such negative genital self-image had lived for a significantly longer amount of time in Switzerland in comparison with women who did not actively complain of low self-body image ( $P < .001$ ).

**Table 6.** Chronic provoked and unprovoked vulvar pain (n tot=14)

Vulvar pain	Types of FGM/C	Scar complications
Provoked (n = 13)*	II: n = 1	Vulvar cysts (n = 6)
	III: n = 4	
	undocumented: n = 1	
	I: n = 1	Bridle and scar tissue complications (n = 5)
	II: n = 3	
Unprovoked (n = 1)	III: n = 1	Peri-clitoral adhesions (n = 1)
	II: n = 1	No scar tissue (n = 1) <sup>†</sup>
	III: n = 1	Post-reinfibulation vulvar wound (n = 1)
	II: n = 1	

\*Among women with provoked chronic vulvar pain, 11 also suffered from superficial dyspareunia while 2 had no sexual intercourse at the moment of the assessment.

<sup>†</sup>This woman also suffered from adenomyosis and had a suspicion of endometriosis.

**Table 7.** Histological characteristics of resected cysts

	Histology of cysts, n (%)	Painful cysts, n (%)
Epidermal	8 (38.1)	3 (37.5)
Mullerian	1 (4.8)	1 (100)
Neuroma	1 (4.8)	1 (100)
Total	10 (100)	5 (100)

**Table 8.** Vulvar cysts according to type of FGM/C

	n (%)
Type I	0 (0)
Type II	2 (9.5)
Type III	18 (85.7)
Type IV	0 (0)
Not documented	1 (4.8)
Total	21 (100)

In seventy-three women (14.4%), past traumatic events such as war, rape, forced marriage, domestic violence or violence during migration were documented in the medical file.

Psychiatric comorbidities such as depression, anxiety and PTSD (that may be linked to other factors than FGM/C alone) were documented in 65 women (12.8%).

## DISCUSSION

It has already been shown that women with FGM/C have higher risks of experiencing dyspareunia than women without

**Table 9.** Infibulated vs noninfibulated but cut women

	Infibulated women (n = 256) n (%)	Non-infibulated women (n = 222) n (%)	P value
Late complications (n = 141)	89 (34.8)	52 (23.4)	.007
Pain (n = 178)	103 (40.2)	75 (33.8)	.146
Dyspareunia (n = 122)	77 (30.1)	45 (20.3)	.014
Dysmenorrhea (n = 95)	52 (20.3)	43 (19.4)	.797
Vulvar pain (n = 13)	6 (2.3)	7 (3.2)	
Vaginismus (n = 6)	5 (2.0)	1 (0.5)	
Vulvar cysts (n = 20)	18 (7.0)	2 (0.9)	.001
Recurrent infections (n = 11)	9 (3.5)	2 (0.9)	
Sexual dysfunction (n = 140)	87 (34.0)	53 (23.9)	.015
Negative self-image (n = 20)	9 (3.5)	11 (5.0)	.433

FGM/C.<sup>29</sup> In our study, we aimed to assess the prevalence and possible etiologies of chronic vulvar pain, by retrospectively analyzing the records of 506 women who attended our specialized FGM/C outpatient clinic between 2010 and 2017.

Chronic vulvar pain was present in 2.8% of our patients with FGM/C. Previous studies on women without FGM/C reported a lifetime prevalence of chronic vulvar pain ranging from 3 to 15%.<sup>7,8</sup> However, prevalence of current chronic vulvar pain (point prevalence at the time of the survey) ranged between 1.6 and 7%.<sup>7,8</sup> Our study is retrospective and does not assess all previous experiences of chronic vulvar pain. It retrieves information about active complaints of pain that were recorded in the medical files. Still, our numbers may be underestimated for different reasons. Many uncut women with chronic vulvar pain do not seek medical help for it<sup>30</sup> and 45.1% of the women who do seek medical care, feel stigmatized by physicians.<sup>30</sup> Women and girls with FGM/C might fear even more stigma and consult less because of socioeconomic, cultural and language barriers and the stigma surrounding FGM/C in diaspora countries.<sup>16</sup> The safeguarding approach and discourse around FGM/C have indeed increased stigmatization and disconnection with the healthcare system.<sup>31</sup>

Some authors have also suggested that the population of women with FGM/C have socio-cultural backgrounds that may affect the way they experience and verbalize vulvar pain.<sup>25,32</sup> Thus, comparing our results with a prevalence found in a mainly Western and Caucasian population might be misleading. Jacobson and colleagues showed that many patients with FGM/C accepted chronic pain as being a normal part of a woman's life and did not necessarily associate their pain with FGM/C-related

complications.<sup>33</sup> In some settings, some women endured pain in silence as they saw pain as valuable and an integral part of a meaningful ritual that is FGM/C.<sup>33</sup> Remaining stoic about pain was found to be expected in certain cultures such as the Somali one<sup>34</sup> and expressing suffering and pain was found to be seen as shameful in a study on women from Djibouti, Eritrea, Ethiopia and Somalia.<sup>35</sup> A recent study showed that a small sample of Somali-Canadian infibulated women reported low pain levels on validated pain questionnaires and reported good general health while having pain thresholds as low as other women with chronic vulvar pain during quantitative sensory pain testing in the vulvar area.<sup>25</sup> Only when the participants were handed open-ended questionnaires, leaving space for self-expression of pain, did they report chronic disabling daily pain.<sup>25</sup> In our population, vulvar pain was linked to infibulation and vulvar scar complications, such as cysts, neuromas, scar tissue and bridles. As we present in another manuscript currently under review, surgical excision of such complications can reduce and treat such pain symptoms.

However, chronic vulvar pain is known to be associated to other factors<sup>10</sup> and cofactors in addition to FGM/C, such as pelvic floor hypertonia, recurrent genito-urinary infections and previous obstetric perineal trauma that could not be comprehensively assessed in our retrospective study and remain to be investigated.

Psychological and psychiatric factors can also be associated to chronic vulvar pain. 14.4% of the medical charts mentioned past traumatic events (war, rape, forced marriage, domestic violence, or violence during migration) and 12.8% psychiatric comorbidities such as depression, anxiety or PTSD, confirmed by the psychiatrist and/or psychologist of the outpatient clinic. PTSD as well as depression can mutually maintain pain<sup>36</sup> and be responsible for or worsen sexual dysfunction<sup>37</sup> and negative self-image. We found that an active complaint of negative self-image was significantly associated with a longer time spent in Switzerland. Stigma surrounding FGM/C in diaspora countries can be responsible for low self-esteem and feelings of « abnormality », « shame » and « deep aversion towards the own external genitalia », <sup>16</sup> contributing to psychological and sexual difficulties. The rate of past violent events different from FGM/C is certainly under-estimated by our retrospective review. In a prospective study we recently published, such events were referred by almost half of a sample of 124 participants.<sup>38</sup> As previously observed,<sup>39</sup> age at excision was higher in women with chronic genito-pelvic pain and vulvar pain compared to asymptomatic women in our sample. A higher age at excision could contribute to the pathophysiology of chronic vulvar pain, either psychologically or through biological mechanisms involving age and hormone-related remodeling of genital tissue. This could be further studied in the future. Chronic vulvar pain was equally frequent among infibulated and non-infibulated women. FGM/C types are sometimes overlapping in terms of tissue injury with equal risks of vulvar and clitoral pain due to

tissue/nerve damage and scar complications. For example, a woman with FGM/C type III might have experienced a less invasive (or no) cutting of the clitoris and the labia than a woman with type I or II. A previous study including mainly women from East Africa, concluded that the clitoris was found intact during defibulation (surgical opening of infibulation) in 48% of the 40 participants.<sup>23</sup>

Dyspareunia was present in 24.9% of women with FGM/C, which is a higher prevalence than 3 to 18% in the general population.<sup>40</sup> Among the 126 women suffering of dyspareunia, more than half complained of superficial dyspareunia (n = 75, 59.5%). Deep dyspareunia was less frequent and concerned 25 (19.8%) women. The presence of superficial dyspareunia can be explained by the presence of scar complications such as vulvar cysts, neuromas, scar tissue, bridles, and in the case of FGM/C type III, the cutaneous bridge of infibulation. Other factors such as pelvic floor muscle hypertonicity, can also provoke, contribute and maintain pain and remain to be studied. Deep dyspareunia can have several explanations different from FGM/C. However, FGM/C, especially type III, might contribute to it, through recurrent genital infections, particularly vaginosis<sup>41</sup> that might lead to Pelvic Inflammatory Disease (PID), and eventually, deep dyspareunia. In addition, painful or impossible and/or difficult penetration might lead to deep and superficial pelvic floor hypertonicity, also participating in chronic pain pathophysiology.

The discrepancy between the prevalence of chronic vulvar pain and that of dyspareunia confirms what we observe in our clinical practice. It can also be explained by the characteristics of our sample, half of whom are infibulated. Infibulation is a mechanical barrier to vaginal penetration responsible for pain during sex, sometimes impossible penetration, and possibly recurrent lesions, fissures and consequent tissue inflammation. Chronic vulvar pain was more frequent among women with scar complications such as neuromas, cysts, bridles and eventually infibulation.

Limitations of the study are mainly explained by its retrospective nature. A standardized assessment of pain intensity, pain localization and pain affect has not been performed: also, all women did not systematically undergo swab tests or pelvic floor exams, rendering the calculation of the prevalence of related diagnoses such as vulvodynia or pelvic floor hypertonia difficult.

The same is true for the assessment of sexual function which was not investigated through validated questionnaires. Furthermore, among infibulated women, we could not retrospectively differentiate between those who had and those who had not undergone cutting of their clitoris as this was not always documented. Also, our study included only 3 women with FGM/C type IV whose complications remain a research gap. Knowing that FGM/C is a risk factor for episiotomy and severe perineal tears,<sup>42</sup> we presume that past obstetric perineal traumas might also contribute to pain. Such information was not studied.

Finally, most of the women in our sample had FGM/C type III which is not representative of the distribution of types of FGM/C in the world, where infibulation represents 10% of all affected women.<sup>43</sup> This is due to the fact that our population is largely composed of Somali and Sudanese women, countries in which infibulation is most likely to occur<sup>43</sup> and that our study was conducted in a specialized clinic where women are often referred by other health professionals after detection of FGM/C and its complications, infibulation being the easiest type to detect and the one mostly associated to complications.

Strengths of this study are the size of the sample of women coming from several ethnic, cultural and religious backgrounds with different types of FGM/C and the use of well-documented computerized medical records of a specialized outpatient clinic run by 2 gynecologists trained in sexual medicine, vulva disease and management of FGM/C. Women who came to our specialized clinic over a period of 7 years, were all examined by these providers only. This guarantees a consistent and reliable classification and documentation of FGM/C types and complications, pain assessment, psychosexual response and history of trauma other than FGM/C. Data was retrieved by 1 author (YB) different from the 2 examining physicians. Finally, a major strength of our study is the availability of the histological results in case of surgical resection of the cysts for a better understanding of pathophysiological etiology of pain.

Future prospective studies could assess lifetime as well as point prevalence of chronic vulvar pain and dyspareunia in women with FGM/C, possibly using standardized, quantitative and qualitative tools, taking into account the cultural differences in expression of pain. They could also explore pelvic muscle floor dysfunctions as a potential contributory cause of chronic pain. Also, both superficial and deep dyspareunia and their prevalence in different types of FGM/C remain to be further investigated. Finally, the eventual impact of the presence of certified interpreters in the pain symptoms recollection and, as it has already been explored by previous studies on women with genital pain,<sup>44</sup> the role of psychological factors and the role of the partner on the onset and persistence of chronic pain could be further explored. Implications for clinical practice include a multidisciplinary approach of chronic vulvar pain with the consideration of FGM/C and its consequences and the psychosocial aspects that can be related to chronic pain. Women with a sexual dysfunction should be offered comprehensive psychosexual care with counseling and psychosexual therapy.

## CONCLUSIONS

Women with FGM/C are at risk of developing dyspareunia and vulvar scar complications, possibly causing chronic vulvar pain. Dyspareunia is mostly present in infibulated women. Vulvar and clitoral pain seem equally frequent in both infibulated and cut, noninfibulated, women.

Physical factors that may provoke pain include scar complications such as vulvar cysts, bridles, post-traumatic neuromas or the mechanical obstacle of infibulation. Specific psychological complications of FGM/C and socio-cultural factors may also interact with pain and sexual function.

Girls and women with FGM/C suffering from pain, should be informed, investigated and treated according to the best available scientific evidence, in a comprehensive, multidisciplinary, respectful, and culturally sensitive way.

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## STATEMENT OF AUTHORSHIP

Conceptualization, J.A.; Methodology, J.A. and Y.B.; Investigation, Y.B.; Writing – Original Draft, Y.B and J.A.; Writing – Review & Editing Y.B. and J.A. and L.A.; Supervision, J.A. and L.A.

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