Analysis of a UK specialist service for non-pregnant women with Female Genital Mutilation/Cutting (FGM/C) 2008 to 2019: a retrospective case note review

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ABSTRACT

Background

This paper analyses data from a UK specialist clinic for non-pregnant women with Female Genital Mutilation (FGM). This midwife-led trauma-informed service integrates health advocates and counsellors into a model of holistic woman-centred care and was the blueprint for new national clinics opened in 2019. This unique dataset contributes insights into clinical presentations and help-seeking practices and can inform FGM-related national service developments.

Methods

A retrospective case note review examining referral patterns, clinical findings and interventions over a period of eleven years.

Results

Overall, more than 2,000 consultations were conducted. 541/808 women (67%) were diagnosed with Type 3 FGM; 104 (13%) with history of/previous Type 3; 82 (10%) with Type 2; 26 (3%) with Type 1; 6 (1%) with Type 4. In 49 cases (6%) no specific Type was recorded.

593/808 (73.4%) women were of Somali origin. 18 other ethnic backgrounds were represented. Approximately 10% of attendees were healthcare professionals. Nearly 5% were refugees/asylum seekers. All were historic cases of FGM.

Route of referral was predominantly word of mouth, internet, self or General Practitioner (GP). Women presented with dysuria, dyspareunia/apareunia, dysmenorrhea, recurrent infections, PTSD, nightmares, flashbacks and psychosexual issues.

Therapeutic interventions included: - 452 deinfibulations under local anaesthetic, (mostly same-day walk-in cases); clinical reports for asylum applications; trauma counselling; and uro-gynaecology referral for other complications.

There were 12 social care referrals; 3 Mandatory Reporting Duty referrals and two FGM Protection Orders. Intersectional violence was mostly reported amongst women of West African origin. Overall, women rarely said they wanted to continue practising FGM.

Conclusions

This retrospective case note review illustrates there are significant numbers of non-pregnant women with FGM from multiple ethnicities with physical and psychosocial needs.

Data suggest simple deinfibulation under local anaesthetic can be safely performed by an expert Midwife in a community or outpatient setting and is acceptable to clients.

The impact of 2015 UK legislation upon access to services is unknown and requires investigation. Innovative means used to publicise clinics may ensure early signposting to specialist services, and non-pregnant women particularly may benefit from being asked about FGM during gynaecological consultations and during GP registration.

Keywords: gynaecology; female genital mutilation; public health; review; United Kingdom

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Introduction

Female genital mutilation (FGM) is defined as "all procedures that involve partial or total removal of the external female genitalia, or other injury to the female genital organs for non-medical reasons"(1). An estimated 200 million women and girls worldwide (2) have experienced the physical, psychological, and social sequelae of FGM with associated healthcare costs of 1.4 billion US Dollars per year (1). In 2011, it was calculated that 137,000 women and girls with FGM resided in England and Wales, (3) costing approximately £100 million annually to the National Health Service (NHS) (4).

FGM is recognised as a form of gender-based violence and human rights violation rooted in gender inequality (1) and is a global public health concern, presenting an increasing challenge to countries with large diaspora. Despite prevention efforts, the pace of decline is uneven and UNICEF estimate that an additional 2 million girls could be at risk of FGM by 2030 due to COVID-19 (5). The practice, which has been illegal in the United Kingdom (UK) since 1985, is often justified by cultural or religious reasons underpinned by the desire to control female sexuality (6).

Between 2015 and 2022, more than 80,000 women and girls with FGM accessed NHS services in England (8). Eighty percent of these were identified attending maternity services, suggesting that non-pregnant women are less likely to present (9). This may be because

FGM specialist clinics in areas of high prevalence tend to be placed within maternity services and rarely cater to non-pregnant women (27).

In 2015 a Mandatory Reporting Duty was introduced in England and Wales (only) for healthcare professionals, social workers and teachers to report girls identified with FGM, under the age of 18 years, to the police (15). The same year a compulsory FGM Dataset collection was introduced in England (only), requiring healthcare professionals to record attendances of women and girls with FGM when presenting to Acute and Mental Health Trusts and GP surgeries(8) (12).

In 2019 NHS England commissioned five clinics for non-pregnant women in areas of high prevalence and gave additional funding to three pre-existing clinics (including the one described here). These services were modelled upon the midwife-led multi-disciplinary care pathway initiated in the Acton clinic (16).

This paper explores trends in demographic, clinical and therapeutic variables over an eleven-year period. This demonstrates how changes in presentation and management have taken place over time and can help to inform future service commissioners. A further publication will examine changes to clinical practice.

Development of a specialist FGM clinic

In response to a clear unmet need (proven by a series of community consultations and preceded by closure of a previously well attended local hospital service (10)), the first dedicated community-based clinic for non-pregnant women, the Acton African Well Woman Clinic, was set up in 2007 by a midwife from Imperial College Healthcare NHS Trust and a Somali community health advocate from Ealing Primary Care Trust. A tripartite model integrated Midwife, Health Advcoate and Trauma counsellor into a holistic woman-centred service. Two specialist midwives, experienced in perineal suturing, were trained to perform

simple deinfibulation under local anaesthetic (see table 1), after attending an FGM module at Kings College University, London. Governance was provided by quarterly steering group meetings consisting of team members, an FGM survivor, representatives from the local acute NHS Trust, primary care NHS Trust and specialist charity, FORWARD.

In 2017, due to funding problems, the clinic was re-located to Gynaecology Outpatients at Queen Charlotte's & Chelsea Hospital (QCCH) alongside a pre-existing clinic for pregnant women. The service was renamed the 'Sunflower Clinic' in recognition of the fact that FGM is not solely an African practice.

Table 1: Clinical Definitions for FGM-related procedures

Previous or 'History of Type 3'	Refers to the current state where a woman originally had Type 3 FGM but has been deinfibulated/opened prior to presenting to the clinic.
Deinfibulation	Opening the sealed vulva of a woman with Type 3 FGM to expose the vaginal opening and urinary meatus.
Simple deinfibulation	Deinfibulation carried out under local anaesthetic. Maybe on the same day in hospital outpatients or community setting. There is usually no attempt to expose the clitoral glans and/or prepuce. (In some countries this might be carried out by a traditional circumcizer on the wedding night or even forcibly by the husband).
Complex deinfibulation	When Type 3 FGM is accompanied by a cyst, keloid scar or other complex presentation, deinfibulation is carried out by a suitably trained Doctor. This may require epidural, spinal or general anaesthesia and be undertaken in theatre as day case surgery. There may be an attempt to expose clitoral tissue (11).
Reinfibulation	The procedure to re-close the vulva opening in a woman after she has been deinfibulated (i.e., after childbirth); Illegal in UK
Reconstruction	A surgical procedure carried out to restore original genital appearance. Clinics exist in some countries in Europe, Africa and in USA. Not available in UK.

The clinic model, described in Table 2, was designed to reduce barriers to accessing services for FGM survivors, providing a culturally sensitive trauma-informed approach to care (12). These principles emphasise establishing trust, ensuring safety, and yielding control to the patient, whilst minimising discomfort, re-traumatisation, and shame (particularly important when performing genital examinations for FGM survivors, as this can elicit flashbacks or vasovagal response (12)).

Table 2: Key elements of the specialist clinic model

	All-female team; Midwife-led. Non-pregnant women only.
	Holistic tripartite model of care, integrating & co-locating a counsellor and Somali/Arabic-speaking health advocate into consultations and offering support during deinfibulation.
	Easy access – community-based/hospital outpatients; accepting self-referrals; no geographical boundaries; women seen within 2 weeks of making contact.
	Offering walk-in same day deinfibulation under local anaesthetic or fast track deinfibulation under general anaesthetic (within 4-6 weeks)
	Counsellor provides initial psychological assessment and up to 8 weekly 1-1 psycho-sexual/trauma sessions with flexible extension period if required
	Health advocates provide language and emotional support; engage with local FGM practising communities; advertise clinic and are bridge between staff and patients
	Link to named gynaecology consultant for complex case referral

Each consultation includes: - taking a medical history; safeguarding assessment;, genital examination to diagnose FGM Type; psychological assessment; discussion about the UK law and FGM as a human rights violation; exploring reasons why the woman believes FGM was carried out; discussing her right to physical integrity and giving detailed information of the health consequences of FGM. This model of care is described in more detail in a previous paper (13).

Key variables were routinely recorded for individual patients to ensure a robust safeguarding assessment, clinical history and record of intervention. In 2015 several new items were added to the data collection. For example, questions related to who perpetrated the cutting

(to determine whether there was an increasing trend in medicalization) and whether the woman had spoken to a professional about FGM before.

Background to this paper

This paper aims to fill a gap in UK FGM research regarding care of non-pregnant women with FGM. A study, published by Gordon et al in 2007, presented longitudinal data from an FGM service in West London for both pregnant and non-pregnant women over a ten-year period, from 1995 to 2005(10). They saw 767 new cases in this period; performed 215 deinfibulations as day case inpatient surgery, (mostly under spinal or epidural anaesthesia) and reportedly two women complained of psychosexual problems. They recommended that FGM services should employ a trusted interpreter and expedite access to deinfibulation for newly married and pregnant women. Audits from other FGM specialist services have subsequently been published (14)(15)(16)(17)(18)(12), but these are primarily restricted to annual figures, are for pregnant women only or combined maternity and gynaecology services, and are all published prior to significant changes in FGM legislation in 2015. To our knowledge no other papers have examined longitudinal data from a dedicated non-pregnant women's FGM specialist service within the context of recent national policy changes and increasing international work to eliminate FGM.

Methods

A retrospective case note review was conducted of clinic records from 1st October 2008 to 31st December 2019. Information on demographic (year and country of birth, length of time in the UK, level of English spoken), clinical (type of FGM, details of procedure, concomitant

symptoms and intervention received, age when cut, and route of referral to the service) and therapeutic (psychological assessment) variables were retrieved.

Relevant data were accessed from the hospital database using a standardized excel spreadsheet, stored in encrypted files and anonymized prior to analysis. Due to service relocation, from the original GP-based community venue to the acute Trust in 2015, we were unable to retrieve original records before this date, however a summary of recorded data from this period was used.

Patients did not participate in the writing of this review, however, the steering committee (including FGM survivors) met regularly and contributed to the ongoing design and development of the service.

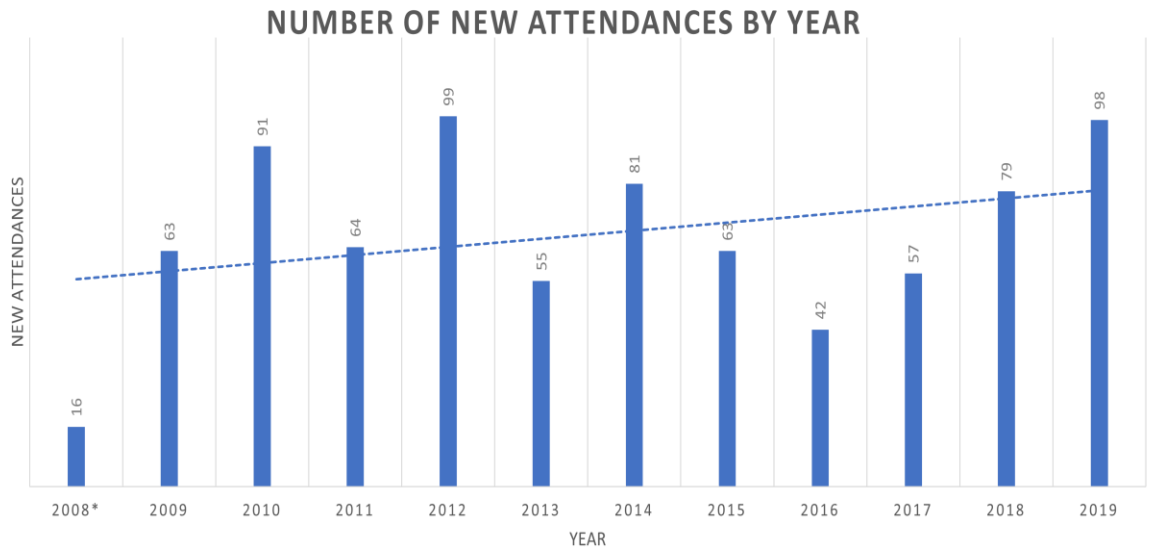
The study was registered as a clinical audit on the 02/12/2020 (#562) by Imperial College Research Ethics Committee, and an ethics exemption was granted. Informed Consent was waived as data was accessed retrospectively and de-identified prior to analysis. The study was carried out in compliance and following the principles outlined in the Declaration of Helsinki.

Results

Demographic Variables

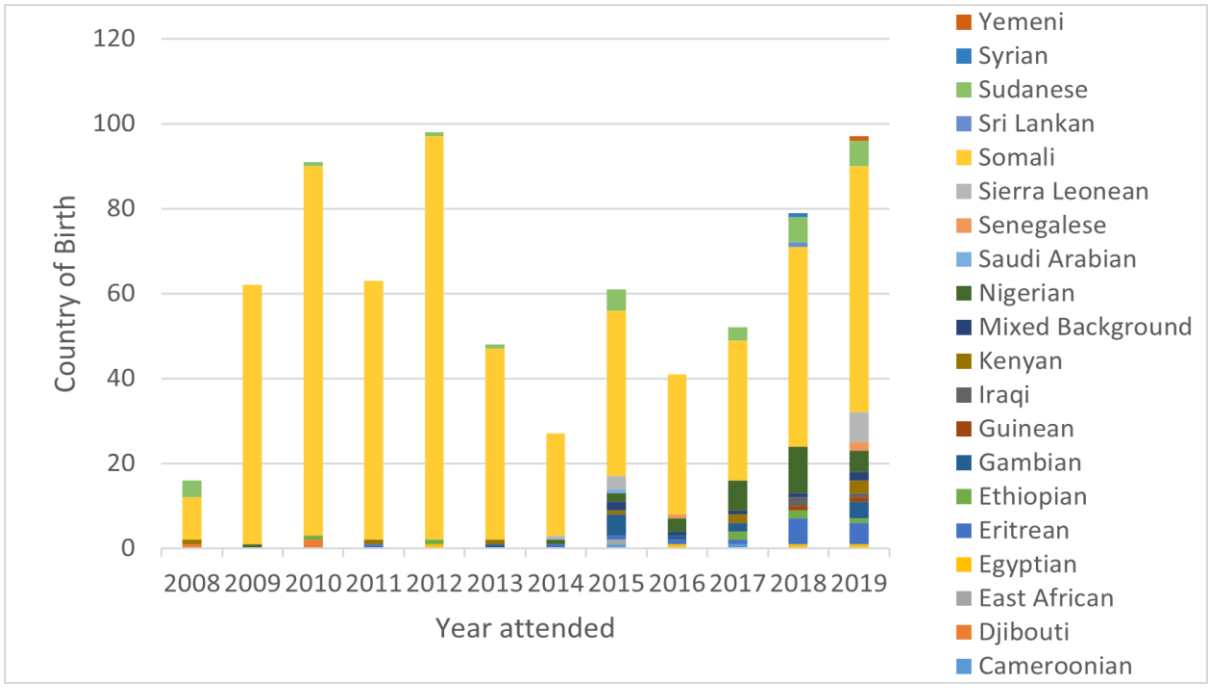
808 new clients/first consultations were recorded from October 2008 to December 2019. New attendances by year are presented in Figure 1. Including follow up appointments and counselling sessions, there were more than 2,000 total attendances over this period.

Figure 1: Number of new attendances by year



Women's ethnicity (see Figure 2) was recorded according to their mother's ethnic background, but there were several examples of mixed ethnicity. In total 18 ethnic origins were documented. Most women 593/808 (73.4%) were of Somali background. Prior to 2015, 5.4% (22/405) of attendees were from other ethnic groups (Djibouti, Egyptian, Eritrean, Ethiopian, Gambian, Kenyan, Nigerian, Sierra Leone, Sudanese), whilst 383 were Somali. However, between 2015 and 2019, 36% (120/330) of women were from backgrounds other than Somalia.

Figure 2: Women's Ethnic Origin by year attended



More than 90% of women were born in Africa, including one Caucasian woman with Type 2 FGM. The remaining 10% were born in the Middle East (n = 5; Iraq, Dubai, UAE and Saudi Arabia); Sri Lanka (n = 1) ; UK (n=4) and Europe (n = 5; Spain, Norway, Germany, France Netherlands).

Table 4 displays the age when women experienced FGM. The majority (n = 377; 47%) were between 5 and <10 years old. Eight women were over 18 years old. Several women reported being cut twice, and one woman recalled being cut three times, (because she had not been cut "enough" the first time). Several women disclosed they were already residing in the UK when taken on holiday abroad to be cut. Two women were cut in the UK, both more than 10 years previously . Neither wished to make a police report.

From 2015 onwards we began asking women who had carried out their cutting. 122 women said that they were cut in their own home by a traditional circumciser without pain relief. 35 women were cut by a healthcare professional. All 9 women born in Europe were cut between the ages of 5 and 15 years old.

Table 4: Age when experienced FGM

Age when cut	<1	1-<5	5-<10	10 - <15	15 - <18	18+	Not Cut	Don't remember	Not recorded	Total
N	25	60	377	93	6	8	2	55	182	808
%	3%	7%	47%	11%	1%	1%	0%	7%	23%	100%

Table 5 illustrates the age of women when they accessed the service. Most women, 163/808, (20%), were aged 25 - 29 years old. Four attendees were more than 60 years old. One 17-year-old pregnant woman attended for deinfibulation in 2011 (before the introduction of the Mandatory Reporting Duty). Although the clinic was essentially for non-pregnant women, 27 pregnant women self-referred. All were booked at local maternity hospitals. The majority said they were unable to access antenatal deinfibulation at their own hospital. We also saw several women with intact Type 3 who had previous caesarean sections without being offered deinfibulation.

Table 5: Age of women when they accessed the service

Age	Not Recorded	Under 18	18 - <25	25 - <30	30 - <35	35 - <40	40 - <45	45 - <50	50+	Total
N	159	1	147	163	123	107	55	31	22	808
%	20%	0%	18%	20%	15%	13%	7%	4%	3%	100%

310 (0.38%) women travelled 8km or less to attend the clinic (see Figure 3). Outside London, women travelled from all over the U.K. A cohort of women travelled more than 300 km (NB. Figure 3 does not include 140 women whose place of residence was not recorded; one woman who came from Germany; and another who came from Belfast).

Figure 3: Distance women travelled to attend the clinic

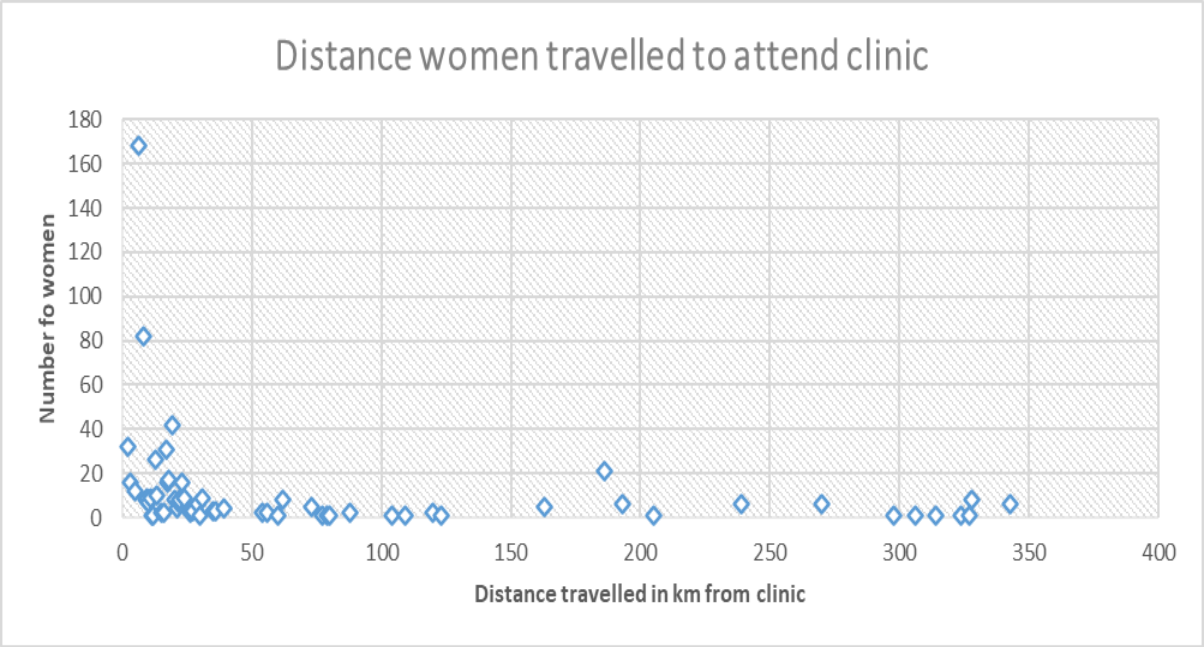


Table 6 denotes how long women had been living in the UK. Nearly half (46%) had been in the UK under 10 years; One third (30%, n=241) for more than ten years; and twenty-one (0.03%) for over 25 years. A small proportion had only been in the U.K. for a few months. Many women had lived in other countries 'en route' to the UK and had family members dispersed around the world. More than 10% of attendees were healthcare professionals. 5% were refugees/asylum seekers.

Table 6: Length of time living in the U.K.

No.of years	<1	1-5	6-10	11-15	16-20	21-25	26-30	30+	Born in UK	Not recorded	Total
N	23	151	193	122	67	31	18	3	5	195	808
%	3%	19%	24%	15%	8%	4%	2%	0%	1%	24%	100

Women found out about the service from multiple sources. A series of advertisements on Somali satellite television were shown twice weekly between 2009 and 2012 (until funding ceased). During March 2009 – Dec 2010, 375 phone calls were received with subsequent surges in clinic attendances.

The majority of women self-referred by phone call, email, WhatsApp, or text. 160 women were recommended by friends and/or family; 84 were referred by their General Practitioner (often for difficulties taking cervical smear tests), and 34 by other healthcare professionals; 60 said they had searched the internet. Often women mentioned more than one route of referral. Other sources included lawyers, social workers, and Non Government Organisation's(NGO's)/charitable organisations. For 258 the method of referral was not recorded. Many women said it had taken years to find help for their FGM-related symptoms.

From 2015 to 2019 we recorded the level of English spoken. Almost 1 in 8 (11.5%) had either basic English or none. Somali and Arabic were the most common first language. Nearly 50% said that they had never spoken in detail to a healthcare professional about FGM before and many women did not want appointment letters sent home or their GP's informed of their consultation.

Clinical Variables

In total, 541/808 women (67%) were diagnosed with Type 3 FGM. 104 (13%) with a history of/previous Type 3; 82 (10%) with Type 2; 26 (3%) with Type 1; and 6 (1%) with Type 4. In 49 cases (6%) no specific Type was recorded;

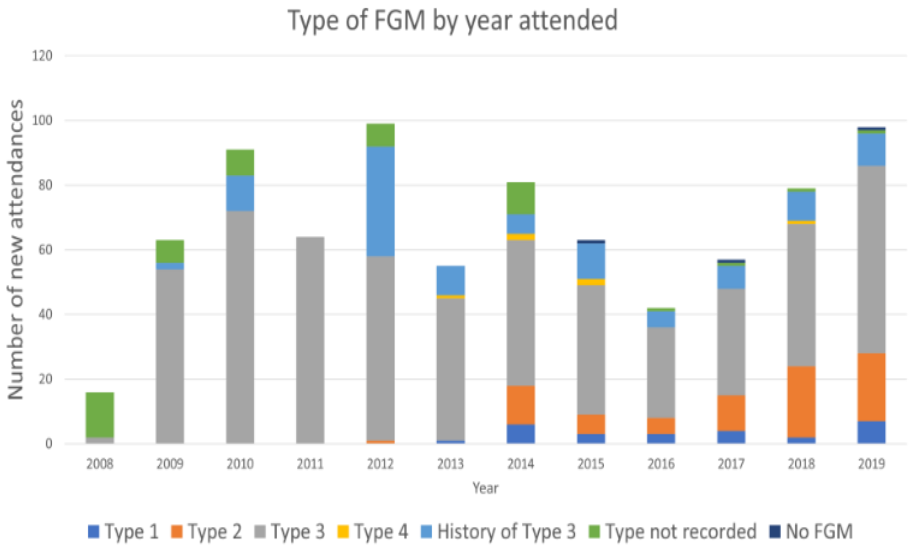
Female Genital Mutilation is classified into four types, depending on the varying levels of genital trauma (see Table 1).

Table 1: WHO Classification of FGM Types (7)

FGM Type	Description
Type I	Partial or total removal of the clitoral glans and/or the prepuce (clitoridectomy).
Type II	Partial or total removal of the clitoral glans and the labia minora, with or without excision of the labia majora (excision)
Type III or Infibulation	Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoral glans (infibulation).
Type IV	All other harmful procedures to the female genitalia for non-medical purposes, including pricking, piercing, incising, scraping and cauterisation.

After 2013 more women presented with Type 1 and Type 2 FGM, but there remained a high incidence of women with Type 3. Two women did not have FGM but were seeking proof of this. One was seeking asylum and feared being subjected to FGM if forced to return to her country of origin. The other woman had been raped, drugged, and beaten as part of ritual abuse and wanted to find out whether she had also suffered FGM. Several women who presented with history of/previous Type 3 said they had been partially "opened" by their husband. Figure 4 demonstrates the Type of FGM by number of women who attended each year.

Figure 4: Type of FGM by year attended



Women presented with a multitude of uro-gynaecological symptoms. The most common being:- dysuria, dyspareunia/apareunia, dysmenorrhea or recurrent infections. As seen in Table 7, those with Type 3 experienced the most problems and usually suffered from all four symptoms. Several women with history of/previous Type 3 presented with continuing uro-gynaecological issues despite having been deinfibulated and more than 30 women were found to have fused anterior scar tissue and could only be partially deinfibulated. In a few cases, where the labia majora had been cut and stitched, the clitoral glans, labia minora and prepuce were found to be fully intact beneath the scar. We also saw cases of labial elongation, tattooing, and two women with anal-vaginal fistulas.

Table 7: Uro-gynaecological symptoms reported

	Type 1	**Type 2**	**Type 3**	**History of / Previous Type 3**	**Total**
Dysuria	1	6	91	13	111
Dyspareunia or apareunia	7	28	180	18	234

Dysmenorrhea	2	4	246	14	268
Recurrent infections	2	6	95	15	119

For many women, penetrative sexual intercourse was not possible prior to deinfibulation, as the diameter of the introitus was less than 1cm. Several women described enduring years of painful, forced vaginal intercourse resulting in bleeding and perineal damage and a few disclosed experiencing anal intercourse. Often women reported being given repeated antibiotic prescriptions for recurrent urinary tract infections by their GP. Other recorded symptoms included: - clitoral or vulval pain, being unable to tolerate cervical smears, urinary incontinence, prolapse, lack of sexual pleasure; recurrent clitoral abscesses and cysts; and 3rd and 4th degree tears during childbirth.

Several women had been reinfibulated repeatedly during childbirth, some as many as 6 or 7 times, in countries such as Somalia, Sudan, and Saudi Arabia.

Therapeutic Variables

The primary reason women attended the service (86%, 452/526) was for deinfibulation under local anaesthetic (See Table 8). This was performed by the specialist midwives (or trainee Doctors or Midwives under their supervision). Some women attended a first appointment prior to deinfibulation whilst others (often if travelling from outside London) chose to be deinfibulated on the same day as walk-in cases. Over half of these (230/452) were about to get married or had just got married.

In one case, a woman suffered extreme pain post procedure caused by an exposed nerve-ending and required further surgery by a consultant uro-gynaecologist. This was the only serious reported complication since opening in 2008. Women rarely required antibiotics for

post deinfibulation infection, and emergency intervention during the procedure was never required.

Table 8: Therapeutic interventions

Management	Number of women
Deinfibulation under local anaesthetic	452
Referred for deinfibulation under general anaesthetic	22
Uro-gynaecology referral	134
Women had at least one Counselling session	90
Not recorded / Other management	68
Report for Home Office asylum application	44
Woman wants to know what Type of FGM she has	32
Women DNA deinfibulation appointment	17

Many attendees required more than one intervention. Almost all 44 women requesting clinical documentation to support their asylum application required a uro-gynaecology referral and/or wanted counselling. More than one third of these (17/44) were Nigerian. Other asylum reports were for women from Egypt, Eritrea, Gambia, Guinea, Iraq, Kenya, Senegal, Sierra Leone, and Sudan.

We began recording psychological symptoms from 2015. (See Table 9) Sixty percent of women who attended (n = 202/339) reported at least one, and often a combination of, symptoms including depression, PTSD, flashbacks, and nightmares. 129 women took up at least one counselling session.

Table 9: Most common psychological symptoms recorded from 2015 – 2019

	2015	2016	2017	2018	2019	Total
Symptoms of Depression/PTSD	23	11	19	32	44	163
Suffering flashbacks or nightmares	10	5	5	3	16	39

The average length of time from making contact to first appointment was two weeks. Consultations lasted on average 30 minutes to one hour, and longer appointments of approximately 1.5 hour were allocated for deinfibulations. Referrals to the link consultant for fast track deinfibulation under general anaesthetic were chosen/recommended for women with particularly traumatic memories, those suffering flashbacks or touch/needle phobia or with a complex presentation (e.g., epidermoid inclusion cyst). Surgery was usually performed within 4-6 weeks of referral.

Safeguarding

Three adult social care referrals, (all for domestic violence concerns) and nine referrals to children's social care were made. Three women disclosed that younger sisters, under 18 years old had FGM, and six mothers disclosed that their daughters, aged under 18, had FGM. Overall, there were three Mandatory Reporting Duty referrals (for those cases reported after the 2015 legislation was introduced) and two FGM Protection Orders were sought.

In 2011 two messages were left on the clinic answer machine from a man requesting FGM for his daughters. We informed the local Child Abuse Investigation Team (CAIT) team who were able to trace the family. The man was arrested and the daughters were temporarily placed into care. We also received one threatening letter and two threatening phone calls.

On occasion women disclosed rape, forced early marriage, domestic violence and abuse linked to faith or belief. Several women had been trafficked and/or subjected to modern slavery. Women from West Africa were more likely to have suffered other intersectional gender-based violence in addition to FGM, and many reported being under pressure from families “back home” to continue the practice.

Most women were adamant they would never subject their daughters to FGM having recalled traumatic cutting experiences and suffering the health consequences of FGM. They frequently said that FGM was practised for cultural reasons or tradition, but other justifications were mentioned. For example: - to “prevent women from being promiscuous” or stop the “clitoris growing until it reaches the floor”. Women often referred to Type 3 as “pharaonic” and used the word “sunna” to describe a less severe Type of FGM, implying some form of religious obligation. Furthermore, despite using the phrase sunna, women rarely said FGM was required by their religion. Although the majority of clinic attendees were Muslim, we saw women from other faiths, such as Coptic Christians from Egypt, and other Christian based faiths from Ethiopia and Nigeria.

DISCUSSION

These data illustrate that FGM is still a significant problem for non-pregnant women living in the UK. . Variations in attendance to the specialist clinic over the last 11 years may reflect changes in legislation, societal awareness and local advertising, but numbers averaged at 72 new appointments per year. In recent years, there has been an increase in:- referrals from healthcare professionals and charities/NGOs; ethnic diversity; women with Type 1 and 2 FGM; and requests for asylum reports and counselling. Notably, numbers of requests for deinfibulation under local anaesthetic have remained consistent. Nearly half of women who requested deinfibulation in 2019 were in the 18-25 age range, demonstrating that Type 3

FGM is still prevalent despite education and international attempts to stop the practice over the last 30 years.

The profiles of women attending the clinic were extremely varied reflecting the fact that there is no one homogenous FGM practising community. Women's ages ranged from 18 to post-menopausal, with some suffering symptoms for more than 40 years. (21) Some women were highly educated multilingual professionals whilst others spoke basic or no English. In particular the number of healthcare professionals and carers accessing the service was striking. (21)

Our findings corroborate previous research acknowledging the silence surrounding FGM (24)(12,22). Some women specifically asked to not see the Somali health advocate, as they preferred to remain completely anonymous and were fearful of FGM community members discovering that they had attended the service. Some women also reported community pressure to remain "closed" prior to marriage.

Worryingly, a small but growing body of evidence demonstrates that introduction of the 2015 Serious Crime Act legislation (17) and Enhanced Dataset Collection may have resulted in women being fearful of presenting to FGM services (19)(20)(21)(22).

The number of women who said that FGM took place whilst they were on holiday reinforces the relevance of the Serious Crime Act, which legislates that parents can be prosecuted for failing to protect their daughters from being cut by extended family/community members (17).

Clinical issues

Our data are consistent with WHO evidence that type 3 FGM is mostly practiced in the NE region of Africa (25) corresponding with high prevalence of Somali, Sudanese and Eritrean communities in West London. In our sample 71% (328/464,) of Somali women were cut between age 5 and 10 which correlates closely with UNICEF's 2020 country profile (26) reporting 82% of Somali women suffered FGM between age 5 and 9 years.(27).

The burden of symptoms experienced by women attending the clinic is consistent with that reported in other studies (28)(10) (29) (6,13,16). However, this may be an underestimation, as recent research from Norway highlights the complex factors involved for women to recognise that their symptoms are caused by FGM rather than believing them to be a "normal" consequence of womanhood (23). Furthermore, we noted many women with fused anterior scar tissue, where, even after deinfibulation, the introitus remained impenetrable for comfortable sexual intercourse. This is rarely discussed in any FGM literature but warrants further investigation (13).

The incidence of psychological symptoms, identified by previous research (30) (31), confirms the need for counselling provision in FGM clinics (34)(35). Women disclosed difficulties experiencing sexual pleasure, complained of not feeling 'whole' and, in recent years, increasingly requested clitoral and /or labial reconstruction. Previous UK care for women with FGM has focused on:- deinfibulation to prepare for childbirth and safeguarding assessments. Few clinics offer psycho-sexual support or long term counselling and there are no reconstruction services. Women spoke of their knowledge of reconstruction via social media, and some had either already had reconstruction or made plans to seek this surgery in Germany, France or Kenya.

Our data show that the uptake of one-to-one counselling increased substantially after 2015, correlating with an increase in attendees from non-Somali ethnic backgrounds. This may be because of a reluctance to seek counselling within the Somali community or may be an

indication that women who have suffered FGM with additional intersectional violence are more likely to seek this. This requires further exploration.

The majority of deinfibulations were performed under local anaesthetic as women often said they were “scared” of “having a needle in their back”. Gordon et al reported 90% of patients preferred the procedure under general or epidural anaesthetic (10) however our experience concurs with those of other UK services (28) (32,33). Over the eleven-year period only twenty-two women chose deinfibulation under general anaesthetic. One case, out of 452 deinfibulations, required an acute intervention the next day by a consultant gynaecologist. This suggests that simple deinfibulation under local anaesthetic in an outpatient or community setting is safe when performed by trained expert Midwives.

Many women travelled a long way to access the service. In 2019, the Acton clinic model became the prototype upon which NHS England based its new National FGM Support clinics (34) (13). These clinics, located in areas of high prevalence of FGM practising communities, should mean that women do not have to travel as far to access holistic multi-disciplinary care.

The implications of deinfibulation for later pregnancy and childbirth are not known. A number of women present every year to our pregnant women’s service who were deinfibulated by us prior to conception. No data capture how many of these nulliparous women go on to have a successful vaginal birth after deinfibulation. A longitudinal prospective study is needed to examine long term outcomes of deinfibulation and, in particular, childbirth outcomes in this population.

Several parous women with Type 3 described receiving a medio-lateral or bilateral episiotomy during childbirth (rather than an anterior incision to deinfibulate them). These

cut edges were then sutured together afterwards leaving them with intact Type 3 FGM. It is not known whether this persists in maternity units in the UK or whether improvements in the education of healthcare professionals have stopped this practice.

Limitations

Some data were missing or unretrievable from records prior to the relocation of the clinic was relocated. The methodology of a retrospective case note review means that it is not possible to establish cause and effect relationships.

Conclusion

This paper demonstrates that FGM specialist clinics (such as the one described) are providing a service that is not available within mainstream UK health system.

Despite worldwide attempts to eliminate FGM, the data suggests there remain a significant number of women with FGM in the UK, including many with Type 3 from a diverse age range.

Consistent attendance figures, women being recommended by family or friends, and positive feedback, all suggest a degree of service satisfaction. However, it is not known whether more women want/need help but do not know how to access it or perhaps even recognise they need help (30). The impact of policy and legislation introduced in 2015 has never been formally evaluated and it is unknown whether women may be too scared or ashamed to present to health services for fear of recrimination.

The success of the Somali satellite television advertisement, and the increasing use of modern media to make contact with clinic staff, indicates that Specialist services could use

innovative methods to publicise clinics. Research is required to investigate whether women would accept and benefit from being asked about FGM during routine gynaecology review, (in settings such as sexual health/family planning/GUM clinics/gynaecology appointments/Emergency Departments etc), and GP surgery new patient registrations. There are currently campaigners lobbying for this to become mandatory.

Clinical care has evolved as we learned more about women's individual needs and as the profile of clients diversified. Only one post deinfibulation clinical complication required consultant gynaecological intervention, suggesting that this midwife-led service model is cost effective, safe and acceptable. Furthermore, the high uptake of counselling demonstrates this could benefit women if available in all FGM clinics.

Sensitive safeguarding discussions and trauma-informed conversations around anatomy and physiology, sexual pleasure and education about the health consequences of FGM, require further investigation. This will help to inform how ideas of bodily integrity and negative cultural stereotypes affect women who have suffered FGM and may serve to support behaviour change and prevent FGM in the future

Declarations

Ethics approval and consent to participate

This study was registered as a clinical audit on 02/12/2020 (#562) by Imperial College Research Ethics Committee, and an ethics exemption was granted. Informed Consent was waived as data was accessed retrospectively and de-identified prior to analysis. The study was carried out in compliance and following the principles outlined in the Declaration of Helsinki.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

JA conceived, analysed and interpreted the patient data. CE and MW revised and edited the manuscript. All authors read and approved the final manuscript.

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