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RESEARCH ARTICLE

Preferences for deinfibulation (opening) surgery and female genital mutilation service provision: A qualitative study

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Abstract

Objective: To explore the views of female genital mutilation (FGM) survivors, men and healthcare professionals (HCPs) on the timing of deinfibulation surgery and NHS service provision.

Design: Qualitative study informed by the sound of silence framework.

Setting: Survivors and men were recruited from three FGM prevalent areas of England. HCPs and stakeholders were from across the UK.

Sample: Forty-four survivors, 13 men and 44 HCPs. Ten participants at two community workshops and 30 stakeholders at a national workshop.

Methods: Hybrid framework analysis of 101 interviews and three workshops.

Results: There was no consensus across groups on the optimal timing of deinfibulation for survivors who wished to be deinfibulated. Within group, survivors expressed a preference for deinfibulation pre-pregnancy and HCPs antenatal deinfibulation. There was no consensus for men. Participants reported that deinfibulation should take place in a hospital setting and be undertaken by a suitable HCP. Decision making around deinfibulation was complex but for those who underwent surgery it helped to mitigate FGM impacts. Although there were examples of good practice, in general, FGM service provision was suboptimal.

Conclusion: Deinfibulation services need to be widely advertised. Information should highlight that the procedure can be carried out at different time points, according to preference, and in a hospital by suitable HCPs. Future services should ideally be developed with survivors, to ensure that they are clinically and culturally appropriate. Guidelines would benefit from being updated to reflect the needs of survivors and to ensure consistency in provision.

KEYWORDS

deinfibulation, female circumcision, female genital cutting, female genital mutilation, qualitative research, sound of silence

1 | INTRODUCTION

Globally, at least 200 million women and girls have experienced female genital mutilation or cutting (hereafter 'FGM').¹

FGM is a global health concern and an important healthcare challenge in countries with large FGM-affected diasporas, such as the UK.^{1,2} The UK NHS offers a range of support services for women and girls with FGM, costing ~£100 million

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each year.³ The NHS will be required to provide culturally acceptable and safe evidence-based care to growing numbers of FGM survivors. However, there is evidence to suggest that current care is sporadic, suboptimal and may not be culturally sensitive or appropriate.^{4–6}

FGM involves the partial or total removal of, or injury to, the external female genitalia without medical reason.⁷ The World Health Organization (WHO) has categorised FGM into four types (types 1–4).⁸ The extent of genital tissue cut generally increases from type 1 to type 3, with type 3 (infibulation) being the most extensive and potentially requiring surgical intervention (deinfibulation).⁷ Deinfibulation is a surgical procedure, typically undertaken by a midwife or obstetric and gynaecological medical staff, to release the narrowed vaginal introitus and/or the obstructed urethra in women and girls with type 3 FGM. There are no health benefits of FGM.⁹

Deinfibulation, one of a range of support services available to survivors, is associated with improved health and wellbeing.¹⁰ Currently, there is no consensus for the optimal time when women and girls could be deinfibulated should they wish to be.^{10,11} The Royal College of Obstetricians and Gynaecologists (RCOG) guidelines suggest that deinfibulation can take place at a number of different time points in a woman's life: prior to pregnancy (preferably before first sexual intercourse), during the antenatal period, in the first stage of labour, at the point of delivery, or as part of a caesarean section procedure.¹² The WHO FGM clinical handbook states that women and girls with type 3 should be counselled, as early as possible, around deinfibulation, including before and/or during pregnancy to support informed decision-making about whether and when to have the procedure.⁹ In addition to the lack of clarity about optimal timing, there is a lack of evidence that focuses on preferences for timing and experiences of deinfibulation from the perspectives of a diverse range of stakeholders, including survivors, men and healthcare professionals (HCPs).^{4,11,13}

The aim of the FGM Sister Study (FGMSS) was to explore and understand the views of survivors, their male partners (hereafter 'men') and HCPs on the timing of deinfibulation and how NHS services can best be delivered to meet the needs of FGM survivors and their families.

This aim was addressed through two work packages (WPs). The aim of WP1 was qualitatively to explore and understand the timing preferences for deinfibulation and how FGM services could be improved for type 3 survivors, men and HCPs. The aim of WP2 was to use established techniques with survivors and wider FGM stakeholders to test and ratify the findings from WP1, inform best practice and policy recommendations around deinfibulation and service provision, and identify future actions.

2 | METHODS

This study is registered as International Standard Registered Clinical/soCial sTudy Number (ISRCTN) 14710507¹⁴ and

further methods information can be found in the protocol¹⁵ and the associated extensive FGM Sister Study funding report.¹⁶

2.1 | Study design

This qualitative study was structured around the Sound of Silence framework (hereafter 'SSF') (Supporting Information Figure S1).¹⁷ The SSF is underpinned by social constructionist worldviews and is useful for researching sensitive issues and the healthcare needs of marginalised populations.¹⁸

2.2 | Study setting

The study was undertaken across multiple regions, settings and services in the UK to capture variation in experiences. We sought to purposively recruit survivors and men from the West Midlands, London and Manchester where there is a diaspora who practise type 3 FGM. HCPs and wider stakeholders were sought from across the UK.

2.3 | Eligibility

Survivors were eligible if they had experienced FGM, were ≥18 years, UK residents, spoke English, Somali, Arabic or French, and gave informed consent. We excluded those where it was judged by the trusted advocate doing the initial recruitment and/or the research team that the survivor might not be able to provide informed consent and/or it was believed that the survivor's participation might risk or worsen their wellbeing. Men were eligible if they had a partner/spouse or family member who had experienced FGM, were ≥18 years, UK residents, spoke English, Somali, Arabic or French, and gave informed consent. HCPs and stakeholders were ≥18 years, spoke English, gave informed consent, and were involved in FGM service provision.

2.4 | Sampling and recruitment

In WP1, we used maximum variation techniques¹⁹ to increase diversity from a range of type 3 FGM-affected communities, locations, ages and education levels. FGM survivors were purposively sampled within four groups including those who had: (1) not had a deinfibulation procedure; (2) a deinfibulation procedure for health and/or personal reasons; (3) a deinfibulation procedure antenatally; and (4) a deinfibulation procedure during labour or at the point of birth. Survivors and men were recruited via trusted advocates in seven NHS Trusts, voluntary and community organisations, advertising and snowballing.²⁰ HCPs and stakeholders were recruited via social media, research team networks and snowballing.²⁰

2.5 | Data collection

WP1 data were collected via semi-structured interview conducted either face-to-face or phone by one of six researchers, supported by trained interpreters. Of the six researchers, five identified as female and one as male. Two researchers were midwives, one was a philosopher and qualitative researcher, and three were applied qualitative health researchers. WP2 workshops were run in partnership with the National FGM Centre at Barnardo's.²¹ Workshops were held face-to-face and included facilitated discussions. Background questionnaires allowed us to describe the participating samples. Discussion guides (Table 1) were developed iteratively based on interviewer field notes and reflections, early analysis and regular discussion. Given the sensitive nature of the discussions and the potential for disclosures that might indicate risk of harm, we had distress and safeguarding pathways in place. The adequacy of the sample size was monitored to ensure that the overall sample and associated data had sufficient information power to develop new knowledge in relation to the research questions.²²

2.6 | Data analysis

Interviews and workshops were audio recorded and transcribed. A random sample of translated transcripts were checked to ensure interpretation was capturing the nuances and depth of responses. Data were analysed using a novel hybrid framework method which was an alignment of both the SSF¹⁷ and the Framework Method (Supporting Information Figure S2).^{23,24} This involved five cyclical stages of analysis: compiling, disassembling, reassembling, interpreting and concluding. Themes, sub-themes, cross-cutting themes and silences were interpreted across the data. Extensive information about the development and application of the novel hybrid framework method can be found in the FGM Sister Study funding report.¹⁶ WP2 data were used to confirm and/or challenge the findings from WP1 and identify any new lines of enquiry or interpretations of the data that might have gone unnoticed initially. Relevant WP2 data were incorporated into the final analysis and presentation of the data.

Two researchers (ED and BDC) led the analysis, with oversight from LLJ. Initial coding, thematic maps and interpretations were presented regularly to the wider team at study management meetings, and to our PPI survivor group, throughout the analysis period. Their views were incorporated as the analysis developed until the final models and interpretation was agreed. The range of researcher worldviews and lenses through which the data were interpreted provided investigator triangulation²⁵ and validation of findings. We were particularly mindful that as a team we might hold 'Western societal' and health/social care focused views on the practice of FGM, and so this was discussed and reflected on throughout the study.

TABLE 1 Key discussion points explored in interviews with FGM-survivors, men and healthcare professionals

Survivors and men

- Preferred terminology around FGM and opening surgery (deinfibulation)
- Understanding of FGM as a practice
- Experiences and impacts of FGM (e.g. personal, partner, wider family)
- Culture of and attitudes around FGM and opening surgery within their community/home country and in the UK (including FGM laws)
- Views on and experiences of opening surgery
- Experiences of and influences on decision-making around opening surgery
- Preferences for timing of opening surgery (e.g. when, where, who)
- Experiences of accessing FGM-related care (including opening surgery in home country in UK/receiving country)
- Awareness of local (UK) FGM services
- Facilitators and barriers for accessing FGM-related care (including opening surgery)
- What services/support/interventions should be offered to FGM-survivors and their families (e.g. what, where, who)
- How current local FGM services could be improved

Healthcare professionals

- Awareness and knowledge of terminology around FGM and deinfibulation
- Understanding of FGM, FGM types and deinfibulation
- Understanding of culture and attitudes around FGM and deinfibulation within the UK and FGM-affected countries
- Understanding of impacts/consequences of FGM for survivors and wider family members (e.g. male partners and children)
- Awareness and attitudes towards FGM law in the UK/protection orders (including influence on practice)
- Awareness and knowledge of local, national, international FGM guidelines/policies
- Personal views on deinfibulation
- Understanding of the outcomes of deinfibulation for FGM survivors (and partners)
- Preferences for timing of deinfibulation (e.g. when, where, who)
- Experiences of providing FGM-related care (including deinfibulation)
- Awareness of local (UK) FGM-related services (including outside of their own experiences both NHS and non-NHS)
- Views on current UK services/support/interventions offered to FGM-survivors and wider family (e.g. what, where, who)
- Perceptions around the facilitators and barriers for survivors and their families to accessing FGM-related care (including deinfibulation)
- Thoughts on what services/support/interventions should be offered to FGM survivors and their wider family (e.g. what, where, who)
- View on whether UK FGM services could be improved to better support FGM survivors and their families
- Views on whether the UK FGM Law/Protection Orders need to be changed

2.7 | Patient and public involvement

In addition to a survivor representative on the study steering group, a group of four type 3 FGM survivors were pivotal across all aspects of the study. Further extensive information about PPI can be found in the FGMSS funding report.¹⁶

3 | RESULTS

One hundred and one interviews with 44 survivors, 13 men and 44 HCPs were conducted, supplemented by two workshops with affected communities (participants, $n = 10$) and one workshop with stakeholders (participants, $n = 30$). Tables 2 and 3 provide sample characteristic summaries. In this paper, we present three themes: (1) preferences for deinfibulation; (2) choice and decision-making around deinfibulation; and (3) FGM support and provision.

3.1 | Preferences for deinfibulation

3.1.1 | When

There was no clear consensus about when deinfibulation should be undertaken for women and girls who may wish to be deinfibulated. However, there were nuanced preferences within cohorts. Survivors expressed a preference for deinfibulation pre-pregnancy; HCPs preferred antenatal deinfibulation, but with the caveat that it should be the survivor's choice, taking wider risks into account; and there was no consensus among men.

Before pregnancy, before I have intercourse, before even I get married, I had it [deinfibulation], so even when I get married it was easy process for me. I didn't struggle because when you get married you will struggle.

(Survivor 16)

In the second trimester it's ideal timing unless [the] women decides that it's better to have it done at delivery or even in the first stage of labour [...] depending on the situation and [the survivor's] preferences really.

(HCP 37)

There was a narrative around 'emergency' and 'planned' deinfibulation procedures, influencing the preference for antenatal deinfibulation for some survivors and most HCPs. Planned antenatal deinfibulation was understood to mean that the 'right person' would be available to perform the procedure, in contrast to intrapartum deinfibulation, when a suitable HCP might not be available. This was also seen as minimising potential complications arising from deinfibulation.

TABLE 2 Survivors, men and community event participant characteristics

Characteristics	Survivors $n = 44$ (%)	Men $n = 13$ (%)	Community event participants $n = 10$ (%)
Age (years)			
18–29	21 (48)	2 (15)	1 (10)
30–39	19 (43)	5 (39)	5 (50)
40–49	3 (7)	5 (39)	3 (30)
≥50	1 (2)	1 (8)	1 (10)
Employment status			
House maker	11 (25)	—	—
Employed (full or part time)	20 (46)	8 (61)	5 (50)
Student	7 (16)	1 (8)	1 (10)
Looking for work	2 (5)	4 (31)	—
Unemployed	1 (2)	—	4 (40)
Other	3 (7)	—	—
Relationship status			
Married/civil partnership	32 (73)	11 (85)	6 (60)
Partner	4 (9)	2 (15)	2 (20)
Separated	4 (9)	—	1 (10)
Single	4 (9)	—	1 (10)
Country of origin			
Eritrea	1 (2)	—	1 (10)
Guinea	5 (11)	2 (15)	—
Mali	—	1 (8)	—
Sierra Leone	1 (2)	—	—
Somalia	27 (61)	3 (23)	—
Saudi Arabia	—	—	1 (10)
The Gambia	5 (11)	4 (31)	—
The Sudan	5 (11)	3 (23)	3 (30)
Zambia	—	—	1 (10)
Type of FGM/Partner's FGM			
Type 1	3 (7)	1 (8)	1 (10)
Type 2	7 (16)	2 (15)	1 (10)
Type 3	22 (5)	3 (23)	3 (30)
Type 4	—	—	1 (10)
Other	1 (2)	1 (8)	—
Unsure/not specified	11 (25)	6 (46)	3 (3)
Deinfibulated/partner infibulated			
Yes	31 (70)	4 (31)	3 (30)
No	10 (23)	4 (31)	0 (0)
Unsure/not specified or applicable	3 (7)	6 (46)	7 (70)
Number of children			
0	13 (30)	3 (23)	2 (20)
1–2	13 (29)	7 (53)	2 (20)
≥3	16 (36)	3 (23)	6 (60)
Not specified	2 (5)	—	—

TABLE 3 Healthcare professional and stakeholder event participant characteristics

Characteristics	Healthcare professionals <i>n</i> = 44 (%)	Stakeholder event participants <i>n</i> = 30 (%)
Gender		
Female	41 (93)	28 (93)
Male	3 (7)	2 (7)
Age (years)		
18–29	3 (8)	4 (13)
30–39	10 (23)	8 (27)
40–49	14 (32)	8 (27)
≥50	17 (39)	10 (33)
Profession		
General Practitioner	3 (7)	—
Health Visitor	2 (5)	—
Hospital doctor	13 (30)	—
Midwife	20 (45)	—
Physiotherapist	1 (2)	—
Practice Nurse	1 (2)	—
Psychologist/therapist	4 (9)	—
Professional group		
Medical	—	4 (13)
Charity/third sector	—	9 (30)
Medical academic	—	1 (3)
Midwifery	—	8 (27)
Police	—	2 (7)
Policy Maker	—	3 (10)
Safeguarding	—	1 (3)
Social care	—	2 (7)
Region of UK where participant works		
East Midlands	2 (5)	2 (7)
East of England	—	1 (3)
London	9 (20)	10 (33)
Nationwide	—	8 (27)
North East	9 (20)	—
North West	3 (7)	1 (3)
Scotland	2 (5)	—
South East	—	1 (3)
South West	5 (11)	—
Wales	3 (7)	—
West Midlands	11 (25)	5 (17)
Not specified	—	2 (7)
Reported FGM prevalence in region where participant works		
High	33 (75)	18 (60)
Low	(23)	4 (13)
Unsure	(2)	8 (27)

We would prefer her to have it done antenatally just so that we know that we've got a consultant there [with] experience [of] doing deinfibulation rather than doing it in labour [...] we would try and say to have it done antenatally, you're going to have better outcomes.

(HCP 5)

3.1.2 | Who

Participants expressed a preference for HCPs to undertake deinfibulation. They reported that any suitably trained, knowledgeable, experienced or qualified HCP (hereafter 'any suitable HCP') could undertake deinfibulation:

Someone with the appropriate skills, expertise and setting. I think it could be a GP in a community clinic, I think it could be a midwife, I think it could be an obstetrician or gynaecologist, but I think the important thing is not who they are but that they have the support around them and the appropriate setting and the appropriate skills.

(HCP 27)

The experience, expertise, knowledge, and skillset of a HCP was more important than their title, position or typical clinical remit:

From my personal experience it was great having my midwife do it, but I am sure under different circumstances where you are not in labour a doctor could have just done the job... or even a nurse. I just think it depends on experience and the qualification that person has.

(Survivor 54)

3.1.3 | Where

A strong preference across all cohorts was expressed for deinfibulation to be performed in hospital. Survivors and men believed that hospitals were 'clean' and 'safe' environments. There was a requirement to be able to prevent and deal with any potential medical problems arising from deinfibulation:

In hospital because it's the best place to do [deinfibulations]...I, because [in case] something is happening with you [...] [or] your baby, like maybe you will get bleeding sometime, and when you are in hospital you are in exactly the place [to get help so] that you [do] not [need to] worry about it.

(Survivor 88)

Survivors stated that attending hospital for FGM consultations and deinfibulation provided a level of anonymity otherwise unavailable in other settings. They worried about their community 'discovering' that they had been deinfibulated for fear of judgement. This was important for women who were seeking deinfibulation outside of marriage, because they may be perceived as deviating from a perceived cultural norm:

In my opinion a girl that is not married yet there is that shame that if she goes and gets the opening [deinfibulation] ends up saying oh you have been with somebody else before [...] because the man expects you to be... to not be opened basically.

(Survivor 15)

3.2 | Choice and decision-making around deinfibulation

Participants identified many routes to, and influences on, decision-making related to deinfibulation. There were complexities around decision-making, including: who was or should be involved; the role of HCPs, and the type and quality of information and advice they provide to survivors; and, ultimately, who makes the relevant decision. Types of decision-making included: intra-marital or with their partner; survivor-only; survivor-HCP (at different stages and with various HCPs); involving family, friends or peers in their community; and a range of other processes.

Men were sometimes excluded from decision-making by the survivor or HCP, but equally men self-excluded:

He wasn't involved in any discussion, and at one point she [HCP] told him to leave the room, which I am sure that's the protocol...

(Survivor 4)

When it came to identifying who ultimately made decisions, most survivors agreed that the decision to be deinfibulated was ultimately their choice, with most feeling as though they had made an informed decision:

I didn't mind the midwife to be honest, she was very professional, she was very compassionate, she was very... wasn't making decisions for me, she was listening to what I wanted and when I wanted it.

(Survivor 54)

However, there appeared to be some circularity in decision-making and uncertainty around who makes the decision to be deinfibulated. Although HCPs reported that it was ultimately the survivor's choice, some survivors reported feeling pressured or heavily influenced by HCPs:

[The HCP] was very unhappy with me when I decided to have it on the day [of birth] instead

of before. [...] If I wasn't let's say a hard-headed person myself, I think she could have easily persuaded me [...] she was very adamant that I have it done before.

(Survivor 4)

While some survivors spoke of feeling pressured or influenced by HCPs, others spoke positively of their interactions with HCPs and of shared decision-making with HCPs:

[The HCP] was so welcoming, and she would assure you [...] So she makes you welcome, accepted in the state that you are in, and reassure you that everything would be fine [...] it was like oh yeah you can rely on her.

(Survivor 47)

3.2.1 | FGM support and provision

The type, level, accessibility and appropriateness of FGM support and provision featured heavily in most discussions. Services were sometimes inaccessible to survivors and their families due to geographical restrictions, for example, only being available to residents of a certain region or due to being unable to travel to access support outside of their local community. Even when similar services were available in two different locales, the pathways (e.g. via self-referral having found information on the internet, GP, midwife, community and voluntary sector organisations) to accessing these services were often different.

Survivors reflected that they felt that some services operated in a way that was insensitive to the cultural needs of survivors and functioned in a way that potentially reinforced stigma in their community, thereby placing themselves and others in a difficult position and/or making them anxious about accessing these services. For example, survivors often did not know that there was FGM service provision, including deinfibulation, outside of pregnancy. They highlighted the importance of transparent service provision and the need to improve access to this support. This was most noticeable in the ways in which FGM services were predominantly, and in some cases exclusively, oriented around provision via maternity services. Survivors who sought FGM services, including deinfibulation outside of pregnancy and/or marriage, were often 'forced' to access care via these maternity services. This was perceived by some survivors as culturally insensitive because many of their cultural traditions and norms include the view that sex outside of marriage is wrong:

If I get my FGM reversal done before I get married my husband will automatically say that I have been out doing things with other men, because that's what we are told when we are younger.

(Survivor 62)

Participants reported that current services predominantly focused on physical health and that there was a gap in provision related to mental health for both survivors and their families. For example, mental health services to address trauma for survivors were specifically identified as a missing but key area of provision:

When I went to my surgery [deinfibulation] yes, we will fix the scars, but it wasn't a discussion of how does it affect your life for the last 10 years, how it affected your life. It was just like why do you want it open? ...If someone is going through trauma and hardship and pain and infections and they will have a lot more to deal with, and I think they need someone to be able to tell all these things, someone to explain how it affected them.

(Survivor 76)

Another area of missing provision, particularly identified by men, related to social and relationship support, including counselling. Some participants thought that more and better support for couples could positively impact on the wellbeing of survivors and men and on their relationship:

[W]hen I've looked after women in labour or have participated in any care of women antenatally with FGM they are very often nervous, or scared, or frightened of any physical examination or physical touch, and I think that would have a massive [impact] on their psychosexual relationships with their partner.

(HCP 28)

4 | DISCUSSION

4.1 | Main findings

There was no clear consensus between groups on the optimal timing of deinfibulation. However, within groups, survivors expressed a preference for deinfibulation prior to pregnancy; HCPs preferred antenatal deinfibulation, with the caveat that it should be the survivor's choice; and there was no consensus among men. There was agreement that deinfibulation should take place in a hospital setting and be undertaken by a suitable HCP. Decision-making around deinfibulation was complex. Deficiencies in professionals' knowledge impacted on the provision of appropriate care. Although there were examples of good practice and positive care interactions, in general, service provision was opaque and remains suboptimal, with deficiencies most notable in mental health support. The way in which services are planned and provided can silence the perspectives and preferences of survivors and their families.

4.2 | Strengths and limitations

As far as we are aware, this is the largest cross-culture and multi-language qualitative exploration of survivors', men's and HCPs' views around deinfibulation and NHS FGM service provision in the UK. We undertook a rigorous and methodologically robust qualitative study with 141 diverse stakeholders, including 54 women and 13 men affected by FGM. We successfully recruited seldom heard populations and discussed the challenging topic of FGM in depth.

We have reflected on the potential limitations of the study. Of the six interviewers, only one could be perceived as a cultural insider,²⁶ the rest of the interviewers and wider research team were cultural outsiders. There are potential benefits to being outsiders, as our PPI group highlighted that given the stigma that surrounds FGM, talking to outsiders was perceived as safer than talking to insiders who may have connections within their FGM community and thus potentially share information about participation.

We attempted to recruit survivors, men and HCPs through various pathways to reach a diverse range of participants. However, most survivors (75%) and HCPs (50%) were recruited via NHS Trust maternity units, which might have shaped views and preferences around antenatal deinfibulation, as it is likely to reflect the direct experience of the participants. The other potential limitation of the survivor sample was linked to their difficulty in knowing what type of FGM they had. This was not unexpected, and some are not aware that they have FGM at all. However, this meant that some of the survivors who were not type 3 and/or had not been deinfibulated found it more challenging to explore their preferences for deinfibulation as the questions were hypothetical rather than experiential. We may have also benefitted from greater diversity in the HCP sample, including more male HCPs and wider professional groups involved in FGM care provision such as social workers and school nurses. Recruiting men was particularly challenging and we had limited success with snowballing from survivors.

4.3 | Interpretations

Deinfibulation can be undertaken at any point during a survivor's life; however, the evidence-base around optimal timing is limited and ambiguous¹¹ and there are currently no agreed standards of care regarding the timing. There are two main suggested deinfibulation time points: (1) outside of pregnancy and (2) during pregnancy.⁹ However, there is considerable variation between and within clinical guidance.^{9,10,12} HCPs' preferences for mitigating the potential risks of intrapartum deinfibulation, but undertaking an elective planned procedure, aligns with the wider literature, which suggests that there are compelling reasons, particularly around minimising risk, to undertake deinfibulation antenatally.^{10,12,27,28}

The finding that survivors had a preference for deinfibulation pre-pregnancy and specifically prior to marriage was contradictory to previous research which has shown that this was 'an unusual choice' and that the majority of women have a preference for being deinfibulated in labour.^{4,6} A qualitative evidence synthesis reported that survivors' preferences around deinfibulation were influenced by cultural norms, making it difficult for some women to seek deinfibulation outside of marriage.⁶ The FGM community clinics established in 2019 do specifically offer care for non-pregnant survivors²⁹ but these are based in the community, which goes against the preferences of the participants that deinfibulation should be undertaken in hospital settings. Our findings suggest that there is a need for the provision of services and care pathways for non-pregnant survivors to facilitate choice, which aligns with 2018 NHS England commissioning guidance.²⁹

Decision-making around deinfibulation was complex, with multiple routes to and influences on the process, including at what point the survivor presented to the NHS and what services were available to them. There was evidence of circularity in decision-making, with the HCP suggesting that it was ultimately the survivor's choice but the survivor also seeking guidance and advice from HCPs. The guidance and advice given in some cases appeared to be suboptimal, with survivors reporting feeling pressured or influenced by HCPs. This is supported by wider evidence which suggests that survivors can be persuaded by HCPs to change their preferences around when they would prefer to be deinfibulated,^{30,31} and that they often report a lack of choice, control and ability to provide voluntary consent to intervention, particularly in maternity settings, leaving them feeling vulnerable and disempowered.⁴ Overall, this may be indicative of unequal power dynamics between HCPs and survivors and thus current FGM services and care pathways may not be culturally safe.³² There is a need to redress this power imbalance to facilitate shared decision-making. Cultural safety requires HCPs and the organisations within which they work, to examine and address how their cultural attitudes and potential prejudice can impact healthcare interactions and service delivery.³³ This can be challenging, as it requires self-reflection and individual and organisational accountability for delivery of culturally safe FGM care.³³ To improve cultural safety and competency, there is a need to improve the clinical FGM knowledge of HCPs working with survivors and there are likely unmet HCP training needs, as highlighted in other studies.^{4,34–38}

FGM remains a global health concern and is an important healthcare challenge in the UK.¹ FGM survivors and their families may face complex challenges as part of their adaptation and assimilation to UK culture, specifically within healthcare.^{39,40} These cross-cultural challenges can influence and impact all those involved in the receipt, delivery and/or configuration of healthcare services.^{41,42} The NHS is increasingly required to provide evidence-based,

culturally appropriate, competent and safe care to FGM survivors and their families; however, evidence suggests that current FGM care may be neither culturally sensitive nor appropriate.⁴

5 | CONCLUSIONS

In general, FGM service provision remains suboptimal and, in some cases, does not consider the perspectives and preferences of survivors. Deinfibulation services need to be widely advertised. Services should ideally offer deinfibulation in a hospital, outside of maternity settings, by suitable HCPs, and at a range of time points to facilitate choice for survivors who wish to be deinfibulated. Future services should ideally be developed with survivors to ensure that they are clinically and culturally appropriate. Guidelines would benefit from being updated to reflect the needs of survivors and to ensure consistency in service provision.

AUTHOR CONTRIBUTIONS

LLJ was primarily responsible for, with support from ED, KJ, AB, PL, MF-W and JT, the conception of the study, obtaining funding, planning and delivery of the study. AA, HA and HA are patient partners and have been involved in the study since its conception. LLJ, BDC, ED, JC and FC-S contributed to data collection. BDC, ED and LLJ were responsible for data analysis. All authors contributed to interpretation of the data. LLJ, JT, BDC and ED wrote the first draft of the paper. All authors read and approved the final article. LLJ is the guarantor.

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CONFLICTS OF INTEREST

None declared for all authors other than PL. PL declares that she has received an honorarium from Gideon Richter to deliver a lecture to GPs about the menopause.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS APPROVAL

The study has received a favourable opinion from the Northwest Greater Manchester East Research Ethics Committee (18/NW/0498) and approval from the Health Research Authority. Voluntary informed consent to participate and be audio-recorded was gained from all participants.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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