Improving specialist services for FGM

Juliet Albert explores a new project, ACERS-UK, which is currently underway and aiming to improve specialist service provision for survivors of female genital mutilation

Female genital mutilation (FGM) is when the female genitals are deliberately cut or injured without medical reason. It is a form of gender-based violence, deeply entrenched in gender inequality and a violation of the human rights of women and girls. The practice is illegal in at least 59 countries, including the UK. Globally, an estimated 200 million women and girls, (5% of the female population) live with the consequences of FGM (World Health Organization (WHO), 2023a). Furthermore, it is anticipated that, as the world population grows, the number of women with FGM accessing services in the UK will increase (Jones and Albert, 2021).

In 2015, it was estimated that 137 000 FGM survivors (1.5% of women giving birth), predominantly from Black, Asian and minority ethnic communities, live in England and Wales (MacFarlane and Dorkenoo, 2015). NHS England Digital (2024) identified more than 85 000 FGM healthcare attendances between 2015 and 2023, 80% reported through maternity services (NHS Digital, 2021; Karlsen et al, 2022). FGM survivors have multiple disadvantages as women predominantly from minoritised ethnic communities who have suffered a serious sexual assault, usually during childhood. A high proportion are vulnerable refugee or asylum seekers and are therefore at increased risk of experiencing other forms of intersectional gender-based violence and socio-economic deprivation (Wikholm et al, 2020).

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FGM produces a range of lifelong negative impacts, including urinary tract and genital infections, dysuria, dysmenorrhea, sexual health problems, such as decreased desire and pleasure, dyspareunia, decreased lubrication, reduced frequency or absence of orgasm, excessive scar formation, obstetric complications and psychological problems, including post-traumatic stress disorder, anxiety and depression (WHO, 2023b). FGM is a traumatic event and adverse childhood experiences are associated with increased healthcare costs and use. FGM consequences are estimated to cost the NHS approximately £100 million annually, with the psychological care of women representing 64% of NHS expenditure (Hex et al, 2016).

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In the global north, specialist services have been established in many countries to treat the consequences of FGM. These were often set up on an ad hoc basis, as an adjunct to maternity services (Albert and Wells, 2020). Guidelines introduced by the WHO (2016) recommend that all FGM survivors have access to deinfibulation, mental health support, sexual counselling, education and information. In spite of this, in many countries, services frequently remain orientated primarily towards physical care in preparation for childbirth, and psychological support is rarely integrated into care pathways. When it is, care is usually trauma focused rather than providing holistic care, including psychosexual assessment and treatment (Johansen et al, 2018; Albert et al, 2023).

Two main surgical procedures, deinfibulation or reconstructive surgery, may be offered to women who have suffered FGM, depending on the type. Deinfibulation opens the sealed vulva and exposes the vaginal opening and urinary meatus for women who have type 3 FGM. This can be performed on non-pregnant women, or pregnant women during pregnancy or childbirth, by suitably trained midwives, nurses or doctors. FGM reconstructive surgery aims to restore original genital appearance by revealing any remaining clitoral tissue and/or rebuilding the clitoral glans, clitoral hood and/or labia. This can be performed on non-pregnant women with type 1,2 or 3 FGM by either plastic surgeons, urologists, uro-gynaecologists, or gynaecologists. Other surgical interventions may also be required to address voiding dysfunction, scarring and cysts secondary to the adverse effects of FGM (Johansen et al, 2018).

Reconstruction has been available since 1998 and is now available in several countries in Europe (including Germany, France, Switzerland, Sweden, Netherlands, Belgium, Italy and Spain), and parts of Africa (Burkino Faso, Kenya and Egypt) and the USA. Several studies have evaluated safety and clinical effectiveness (Foldès et al, 2006; 2012; Abdulcadir et al, 2012a, b; Mohamed et al, 2020; Bah et al, 2021; Christopher et al, 2022; Manin et al, 2022; Tognazzo et al, 2023) and there is increasing evidence that clitoral and/or labial reconstruction can help treat genital

pain, improve sexual pleasure, and help with body image concerns which may in the long term improve marital/sexual relationships, quality of life and reduce psychological problems.

In the UK, women can access vulva reconstruction surgery for conditions such as lichen sclerosis or post-cancer surgical reconstruction, men can access gender reassignment surgery to become women and labiaplasty (labial reduction surgery) is available for women diagnosed with mental health problems (Royal College of Midwives, 2024). Furthermore, designer vagina/cosmetic surgery is available in the private sector. However FGM reconstruction surgery is not available through the NHS. This could be considered a social injustice that discriminates against FGM survivors and an example of a health inequity.

ACERS-UK (advocating for access to clitoral reconstruction and emotional support within a research framework) is a voluntary collective of FGM experts including survivors/women with lived experience, specialist FGM midwives, urogynaecologists, gynaecologists, plastic surgeons, gender reassignment surgeons/urologists, GPs, academics, specialist trauma therapists, psychosexual therapists, health advocates, film makers, Royal College of Midwives FGM policy advisors, and charity/non-governmental organisation members.

The project was co-founded by FGM specialist midwife Juliet Albert and consultant uro-gynaecologist Professor Soheir Elneil in March 2021. The aim is to establish a National Centre of Excellence providing FGM reconstruction surgery and psychosexual therapy as a treatment option for FGM survivors. There will be a co-designed holistic care package delivered by a multidisciplinary team with patient and public involvement and engagement at its core. Surgery would be the final option after careful psychosexual assessment, education and offer of treatment alternatives. This will be carried out as part of a clinical trial to ensure that robust safeguards are in place and so that the project contributes to the development of new evidence in this important area of healthcare research.

Box 1. Phase 1 of the project

We are grateful to The Urology Foundation for providing funding to support Phase 1 of this project:

- Development of a web page (https://fgmnetwork.org.uk/)
- Conducted a scoping review of the evidence surrounding reconstruction surgery (in press, to be published in British Journal of Obstetricians and Gynaecology)
- Conducted patient and public involvement consultations
- Launch of a parliamentary petition
- Four members of the team attended a female genital mutilation reconstruction masterclass in Geneva (two online attendees), meeting international teams from Geneva, France, Belgium, Netherlands, Egypt and the USA
- Collaborated with other leading female genital mutilation charities including FORWARD-UK, The Dahlia Project (Manor Gardens), Sister Circle, Midaye, IKWRO, INTEGRATE-UK, Oxford against Cutting, NESTAC and the Vavengers
- Partnered with Oxford Surgical Trails Unit to develop research funding proposal
- Team members visited a reconstruction clinic in France run by Dr Pierre Foldes
- Presented at the Zero Tolerance to FGM day national stakeholder event and at the British Journal of Midwifery conference in April 2023, planned presentation to the Global Surgery Umbrella collective in May 2024

The team believe that although not all women with FGM will want or benefit from reconstruction surgery, women should be able to make an informed decision to access this if they wish. They also believe that the NHS should be funding research in this area, so that in the future this type of surgery can be offered to FGM survivors.

All members have significant experiences caring for women with FGM and/or have had FGM themselves or come from an FGM-affected community. The team works collectively and collaboratively with the voices of FGM survivors at its core. **BJM**

Please sign and share the petition to show your support: https://petition.parliament.uk/petitions/655651

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