Views of female genital mutilation survivors, men and health-care professionals on timing of deinfibulation surgery and NHS service provision: qualitative FGM Sister Study

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Declared competing interests of authors: Kate Jolly is part funded by National Institute for Health and Care Research (NIHR) Applied Research Collaboration West Midlands and is a subpanel chairperson of the NIHR Programme Grants for Applied Health Research programme.

Published March 2023
DOI: 10.3310/JHWE4771

Scientific summary

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Health Technology Assessment 2023; Vol. 27: No. 3
10.3310/JHWE4771

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Scientific summary

Background

Female genital mutilation (FGM) is a significant health concern, with an estimated 200 million women and girls affected globally. FGM comprises all procedures in which the external female genitalia are deliberately cut, injured or changed without a medical reason. The World Health Organization's joint statement has categorised FGM into four main types (i.e. types 1–4) (World Health Organization. *Female Genital Mutilation: A Joint WHO/UNICEF/UNFPA Statement*. Geneva: World Health Organization; 1997. URL: https://apps.who.int/iris/handle/10665/41903; accessed 14 January 2022). In general, the extent of genital tissue cut increases from type 1 to type 3, with type 3 (infibulation) being the most extensive and potentially requiring deinfibulation (opening) surgery. There are no health benefits of FGM and the practice is associated with a range of lifelong negative complications, including health, sexual, psychological and economic impacts. Deinfibulation is associated with some improvements in health and well-being. FGM is an important health-care challenge in destination countries such as the United Kingdom (UK) because of the rising levels of migration from FGM-affected countries. The current estimates of the prevalence of FGM in the UK diaspora may underestimate the true burden of FGM given the sensitive nature of disclosure, language barriers and often limited engagement of survivors in health-care services. The annual cost to the NHS to care for FGM survivors is £100M. Evidence suggests that FGM care provision is suboptimal in the UK and may not be culturally sensitive or appropriate. There is a need to further develop evidence-based care to improve outcomes for survivors, in particular outcomes around the preferred (or optimal) timing of deinfibulation.

Objectives

The overarching aim of this study was to explore and understand the views of survivors, men and health-care professionals (HCPs) on the timing of deinfibulation and how NHS FGM services can best be delivered to meet the needs of survivors and their families. This overarching aim was addressed through two work packages (WPs). The aim of WP1 was to qualitatively explore and understand the timing preferences for deinfibulation and how FGM services could be improved for type 3 survivors (WP1a), men (WP1b) and HCPs (WP1c). The aim of WP2 was to use established techniques with survivors (WP2a) and stakeholders (WP2b) to synthesise the qualitative research findings, inform best practice and policy recommendations around the timing of deinfibulation and care provision and identify future actions.

Methods

This was an exploratory qualitative study. The methods were structured around the Sound of Silence framework. Silences are areas of research and experience that are little understood or are unheard. This framework is also useful for researching sensitive issues and the health-care needs and perspectives of marginalised populations. Given that the nature of this study was to explore silent and marginalised discourse around the preferences for deinfibulation surgery and NHS service provision, the study was undertaken across multiple regions, settings and services in the UK to capture variation in views and experiences. Survivors live in every local authority in England and Wales, with the highest numbers of survivors living in inner-city areas. Birmingham, London and Manchester all have large diasporas of people from countries who practise type 3 FGM and so we purposively sought to recruit survivors and men from these three regions. HCPs and wider stakeholders were sought from across the UK. A range of recruitment pathways were employed. Survivors and men were recruited through trusted advocates in seven NHS trusts, charity/third-sector organisations, advertising and culturally sensitive snowballing.

HCPs and stakeholders were recruited using social media, personal and professional networks and snowballing.

Data in WP1 were collected through semistructured interviews, conducted either face to face or over the telephone, and supported by trained interpreters as required (e.g. who speak Arabic and Somali). The community and stakeholder events were run in partnership with the National FGM Centre at Barnardo's (Ilford, UK). Events were held face to face and included facilitated discussions in small and large groups. Interviews and events were audio-recorded and transcribed by a specialist company. Voluntary informed consent was received from all participants prior to participation. The study received a favourable opinion from the North West Greater Manchester East Research Ethics Committee (18/NW/0498) and approval from the Health Research Authority. Given the nature of the discussions, a distress pathway was embedded within the study protocol and followed where necessary.

Data were analysed using a novel, hybrid framework method that was an alignment of both the Sound of Silence framework and the framework method. This involved five cyclic stages of analysis: compiling, disassembling, reassembling, interpreting and concluding. Subthemes, overarching themes, cross-cutting and silences were interpreted across the data. There was an intrinsic relationship and crossover between the themes and silences, although these were interpreted through different lenses. WP2 data were used to ratify, refute and/or challenge the initial findings that were interpreted in WP1.

A total of 101 interviews were undertaken in WP1. A total of 44 survivors were interviewed, the majority of whom were recruited in London, of Somali origin, married, aged <40 years, reported having type 3 FGM and had been deinfibulated. Of the 13 men interviewed, the majority were recruited in Birmingham, were from The Gambia, were aged 35–49 years, were employed and were unsure of or did not specify the type of FGM that their partner/spouse had experienced. A total of 44 HCPs participated in an interview; the majority were female, were aged ≥35 years and were either a midwife or hospital doctor working across the UK in high-prevalence settings. Three events were run as part of WP2: two with survivors (n = 10) and one with national stakeholders (n = 30).

Results

Reaching an overall consensus across the groups on the optimal or preferred timing of deinfibulation was challenging. However, there were clearer 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. There was no consensus among the men, but some indicated that deinfibulation should be performed as soon as possible. There was consensus across the groups that deinfibulation should take place in hospital, as the hospital environment was perceived as sterile, clean and safe. In addition, other professionals would be available in the hospital if anything were to go wrong during the procedure. There was also agreement across groups that any suitable HCP could undertake deinfibulation surgery. Suitability was primarily guided by the experience, expertise, knowledge and skillset of a HCP, rather than their job title or typical clinical remit. However, in many services, there was a limited availability of suitable HCPs with the appropriate clinical and cultural knowledge to engage with and provide support to survivors and men. This was linked with a narrative around planned (typically antenatal) and emergency (typically intrapartum) deinfibulation, where a planned procedure increased the likelihood of access to a suitable HCP in a hospital setting.

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. Deficiencies in awareness, knowledge and understanding presented and manifested in different ways, and resulted in potentially important and clinically salient impacts related to decision-making, consent, engaging in discussions around FGM and providing appropriate care.

Although there were examples of good practice and positive care interactions, current service provision was, in general, opaque and remains suboptimal. There was significant geographical variation in awareness of and access to FGM services for some survivors and men. These restrictions in accessing support, overlaid against a lack of nationally consistent care pathways to and provision of FGM services, were a barrier to supporting survivors and their families effectively. The specific deficiencies in service provision were most notable in mental health, well-being and counselling. These deficiencies were important given the numerous physical and emotional impacts of FGM reported by survivors and men in our study. The most salient of these were the impacts on psychological well-being, sexual health and intimate relationships. Deinfibulation reportedly helped to mitigate and/or alleviate some of these affects.

Interactions between survivors and HCPs were disproportionately framed around the law, influencing trust and future help-seeking behaviours. Some HCPs reported that legislation shaped their discussions with survivors. The perceived risks related to legislation and safeguarding around FGM were of concern for many professionals. There was a difficult balance between discussing the law/safeguarding with survivors and men and fostering a safe and inclusive environment to facilitate open discussion and shared decision-making. Although the legal framing of discussions was problematic, survivors and men were themselves reluctant to engage in help seeking for a number of reasons. For example, men held the perception that FGM is ‘a women’s issue’ and women reported the stigmatisation of both being a survivor and potentially needing help for their mental health. Survivors and men were both concerned about the risks associated with discussing their experiences, opinions and care needs because of the perception that this might lead to the involvement of agencies such as the police and social services.

Underlying much of the narrative around providing effective, culturally competent and safe care was the need to improve FGM knowledge through education and training. There were gaps or deficiencies in knowledge of survivors, men, HCPs and wider stakeholders, including the public. Many survivors and men thought that support and services, especially in the community, needed to be co-led or at least involve survivors; the idea of survivor-led support during FGM education was strong. Without appropriate clinical, legal and cultural knowledge, there was a risk of HCPs providing advice that did not meet the needs of survivors and men, or providing advice that did not fully respect or acknowledge the personal or cultural needs of survivors and men. From a clinical perspective, suboptimal knowledge might have an impact on a HCP’s ability to provide the right care at the right time.

Silences were rooted and manifested in cross-cultural discourse throughout the interpreted themes, which has led to the misinterpretation and misrepresentation of information. There was a reported lack of appropriately trained and skilled HCPs to interpret the information to create knowledge, and thus disseminate this information as part of providing appropriate care to survivors and men. As a result, the voices of survivors and men may have been silenced by the cultural, ideological interpretation that privileges a Western societal lens. Current services often silenced the experiences, perspectives and preferences of survivors and their families. Intermarital silence between husbands and wives was also interpreted, particularly in relation to sexual intimacy.

Conclusions

To the best of our knowledge, this is the largest cross-culture and cross-language qualitative exploration of survivors’, men’s and HCPs’ views around deinfibulation and NHS FGM service provision in the UK. A total of 141 diverse stakeholders participated, including 54 women and 13 men affected by FGM; interviews were conducted in three languages. We managed to successfully recruit marginalised populations and discuss the challenging and often unheard topic of FGM in depth. We found evidence of good practice, including positive experiences and interactions with providers and the health system. However, despite the concerted multiagency effort around FGM service provision in recent years, our study has shown that, in general, current UK service provision remains suboptimal and, in some cases, does not meet the minimum service requirements set out in commissioning guidance (NHS England. *Commissioning Services to Meet the Needs of Women and Girls with FGM 2018*. URL: www.england.nhs.uk/wp-content/uploads/2018/04/commissioning-services-to-meet-the-needs-of-women-and-girls-with-fgm-1.pdf; accessed 9 August 2021). In addition to this, we have shown that current FGM services may silence the experiences, perspectives and preferences of survivors and their families.

Core implications for policy, practice and education

- Deinfibulation service provision needs to be transparent regarding what is available and offer the procedure in hospital settings, performed by suitable professionals at a range of time points (in particular, pre pregnancy) to facilitate choice for survivors. When possible, this should not be performed in a maternity setting given the potential stigma for women seeking deinfibulation outside marriage/pregnancy. Survivors may also benefit from additional psychological support or counselling when considering and undergoing deinfibulation.
- Care pathways for survivors outside maternity settings need to be evaluated and further developed in both high- and low-prevalence settings. Prototype service models should be formally tested using appropriate study designs.
- Development and testing of effective training is needed to increase and support the generation and maintenance of FGM knowledge across all NHS staff, with further specialist training, including competency-based training around deinfibulation, developed for the FGM-specific workforce.
- Development of trust, a shared cultural understanding and open communication between survivor and HCPs is key to survivors feeling physically and psychologically safe when accessing services.
- Interactions between survivors and HCPs should not be framed around the law/legal aspects of FGM; this should form a minor part of the discussion unless immediate risks and concerns are identified.
- Survivors and the wider FGM-affected community must be involved in future planning, commissioning and provision.

Core recommendations for future research

- Undertake a comprehensive mapping exercise of UK FGM service provision at the local, regional and national level.
- Explore and better understand the experiences and needs of girls (aged <18 years), younger survivors (aged 18–24 years) and unmarried survivors, men and a wider range of professionals in the delivery of care.
- Use rigorous qualitative methods to explore the psychological and sexual health information and support needs of survivors and men at different time points throughout their lives.
- Establish the training needs of professionals involved in the provision of FGM care and use these data to inform the development and testing of education packages.
- Undertake primary data collection and/or analysis of pre-existing large data sets to better understand surgical risks and outcomes associated with deinfibulation at different time points.
- Evaluate how best to facilitate partnership working between FGM-affected communities and stakeholders in relation to FGM service design and provision.

Trial registration

This trial is registered as ISRCTN14710507.

Funding

This project was funded by the National Institute for Health and Care Research (NIHR) Health Technology Assessment programme and will be published in full in *Health Technology Assessment*; Vol. 27, No. 3. See the NIHR Journals Library website for further project information.

Health Technology Assessment

ISSN 1366-5278 (Print)

ISSN 2046-4924 (Online)

Impact factor: 4.014

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The research reported in this issue of the journal was funded by the HTA programme as project number 16/78/04. The contractual start date was in May 2018. The draft report began editorial review in November 2020 and was accepted for publication in May 2021. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

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