

FGM (Female Genital Mutilation) Health Support for Non-Pregnant Women: Evaluation Findings From the NHS Pilot Programme

Louise Warwick-Booth¹ and Louise Starks²

¹Centre for Health Promotion Research, Leeds Beckett University, UK

²Starks Consulting, UK

l.warwick-booth@leedsbeckett.ac.uk

louise@starksconsulting.co.uk

Abstract: NHS England funded eight pilot Female Genital Mutilation (FGM) clinics for non-pregnant women across England from 2019 to 2021, with our evaluation exploring how best to meet the health and wellbeing needs of non-pregnant women who had experienced FGM. Prior to these clinics, there had been little progress in meeting the needs of non-pregnant women with FGM seeking medical help in England. Our evaluation commissioned Starks Consulting, Ecorys and Leeds Beckett to evaluate documented service delivery across the eight pilot sites. Within this we explored the importance of delivering clinics within community settings. The evaluation tested how effective/capable these clinics were in meeting the health and wellbeing needs of women accessing them. We also examined the effectiveness of various staff roles (lead clinician, health advocate and therapist) to understand the service delivery approach. We captured the views of a small number of service users through individual interviews, gathering their lived experiences of FGM and clinic attendance. The main aim of the evaluation was to determine whether the clinics improved the health outcomes of non-pregnant survivors of FGM. This paper presents findings from the qualitative component of the evaluation; interview data from 42 professionals and 12 service users. We detail the model of support (community service delivery, with trusted professionals, creating a safe space) and the learning gained from the pilot implementation. Positive outcomes include improved health and well-being for women (mental and physical health improvements). Challenges in service delivery included language barriers, how professionals reach into communities, the stigma associated with FGM as an experience, and mental health problems arising from FGM.

Keywords: Evaluation, FGM (non-pregnant women), Women, Health service pilot, Models of practice

1. Introduction

Female Genital Mutilation (FGM) is defined as the partial or total removal of the female genitalia for non-medical reasons, and is recognised as an act of violence against women and girls (WHO, 2022). FGM is performed mostly in Africa, carried out on young girls in the main. There are four different types of FGM which vary in severity. Type I usually involves the removal of the clitoral foreskin, type II is the removal of the clitoris with partial or total excision of the labia minora. Type III is more extreme type as the clitoris, labia minora and majora are removed and then the vaginal opening is sewn, leaving a tiny opening for urine and menstruation blood. Sometimes, FGM involves pricking, and/or piercing of the clitoris or vulva, and scraping of the vagina, which is defined as type IV (Utz-Billing & Kentenich 2008).

FGM is performed for a variety of reasons such as to control the moral behaviour of women and girls, to ensure beauty, as a form of birth control, and to guarantee faithfulness to husbands (Utz-Billing & Kentenich 2008, WHO, 2022). A wide range of cultural factors underpin the continuation of FGM (Waigma et al 2018), including patriarchal systems and gendered social norms, resulting in complex family relationships supporting FGM as a practice. Both men and women support FGM, which remains of social value in several countries despite increased understandings of the health issues associated with the practice (Akweongo et al, 2021). FGM has no medical benefit, is usually performed by traditional practitioners in communities and has immediate consequences such as pain, bleeding, swelling, infections, shock and death. Longer term consequences include urinary problems, infections, scar tissue, sexual problems, issues with conception and childbirth, as well as psychological trauma (WHO, 2022). Survivors suffer from gynaecological, urological and obstetric problems, as well as long-term mental health and emotional problems (Utz-Billing & Kentenich, 2008). There is emerging evidence of the profound effect of FGM on women's sense of identity, self-esteem, personal relationships and family life (O'Neill & Pallitto, 2021). Despite these complications many women are prevented from seeking treatment for FGM complications due to stigma (Waigma et al, 2018), and traditional gender roles limiting their agency (FGM Sister Study, 2020).

FGM has been made illegal in a number of countries, including the UK. However, it is estimated that over 200 million girls and women are alive today who are suffering as a result of FGM (World Health Organisation, 2022). Global migration from areas where FGM is practiced also means that FGM remains a worldwide health

concern (UNICEF 2016). Furthermore, It is estimated that treating survivors of FGM, costs the NHS approximately £100 million pounds per year (Hex et al, 2016). Therefore, minimising the costs by treating symptoms early is a major driver for the NHS. In addition, the evidence base lacks research about the successful management of FGM within primary care (Dixon et al, 2021).

2. NHS Service Specification (Pilot Clinics)

In 2019, NHS England launched a pilot scheme of eight specialist Female Genital Mutilation (FGM) clinics for non-pregnant women. These clinics provided services and support for non-pregnant women over the age of 18 who were living with the consequences of FGM. Pregnant survivors have been historically treated within maternity services, however no provision has existed in the UK, for women with FGM who are not pregnant.

The NHS service specification for the pilot clinics outlined that they should provide a form of tripartite support including basic medical treatments provided by a specialist midwife or nurse; counselling for mental health concerns, and advice from a health advocate on health and wellbeing needs for example. Clinics were to be located in community settings for ease of access. The remit of the clinics was gender-specific focusing upon treating survivors only, and the model of care was trauma-informed, with a focus on holistic support, working in patient-centred ways, as well as the prevention of re-traumatisation (Lurie et al, 2022). The service specification (NHS England, 2018) drawn up by NHS England stated that women should expect to receive the following:

- Health care including assessment of needs, FGM diagnosis, simple de-infibulation with local anaesthetic (where needed), cervical smear testing
- Access to consultant gynaecology and urology for assessment and treatment if required
- Offer of a smear test
- Safeguarding assessments and personal education about FGM, consequences and illegality, exploring attitudes and perceptions
- Access to a specialist counsellor (up to six sessions)
- Access to an FGM Health Advocate providing advice and support
- Referral to other voluntary and community sector specialist support as needed.

3. Methodology

The key aim of our evaluation was to determine whether the clinics improved the health outcomes of non-pregnant women with FGM. Within this overarching aim, key evaluation objects were identified:

- To determine whether the pilot services adhered to the original service specifications and where there may be deviations, to understand which specifications are crucial to improving the health and well-being of women
- To explore the importance of the clinics being in a community setting
- To provide an understanding of the dynamics played by having a health advocate and a counsellor involved in the service and how this benefitted service users.

Our evaluation adopted a mixed-model approach generating qualitative and quantitative data, with this paper reporting on our qualitative findings. We conducted semi-structured interviews with 42 professionals involved in the delivery of the clinics; one commissioner and two voluntary organisations. Twelve women (service-users) who accessed the support also self-selected to participate in semi-structured interviews.

3.1 Interviews With Staff

We completed a total of 42 interviews with professionals either via telephone or MS Teams. One clinic was visited by both authors. Our sample of professionals included, 3 consultants, 1 General Practitioner, 7 FGM specialist midwives/nurses, 2 clinic management/administrative staff, 8 health advocates, 7 psychotherapists/counsellors, 2 voluntary and community sector service leads involved in delivering support as well as 1 commissioner. Interview schedules were developed tailored to each professional role but similarly covered the clinic approach, service delivery (model of support), its impact upon service users, partnership experiences, learning, and suggestions for service improvements. Detailed sampling information for professionals according to organisational belonging has been deliberately omitted, due to the small scale nature of this evaluation, and the need to ensure their anonymity in the reporting.

3.2 Interviews with women using the services

A total of 12 women who had used the clinics were interviewed via the telephone, or online (via MS Teams) subject to their preferences. The evaluators were advised of suitable women to interview via clinic staff, so our sample was made up of self-selected women who agreed to participate in an interview. We sampled drawing upon the experience of staff to select appropriate service users for inclusion, ensuring that we minimised the psychological impacts from women sharing their experiences. The service user schedule focused upon access to the clinic, experiences of support, outcomes for women as well as their suggestions for future improvements. The small sample of 12 was achieved despite extensive efforts towards recruitment. In addition, detailed demographic information for survivors was not gathered, as we allowed survivors to share information on their terms, given the sensitivities surrounding their experiences.

3.3 Analysis

Interviews were recorded and then transcribed. The data were analysed using Framework Analysis, with the initial framework drawn from the aims of the evaluation. Framework Analysis develops a hierarchical thematic structure to classify and organise data (Ritchie et al., 2003), with patterns and connections then identified. Themes were agreed by members of the research team. Internal monitoring data was also descriptively analysed and mapped for inclusion in final reporting.

3.4 Ethics

The evaluation received ethical approval from Leeds Beckett University. The following practices were adhered to:

- Informed consent: written or verbal consent was obtained from all participants in the interviews
- Safeguarding: given the sensitive nature of the topic being researched, attention was paid to risk reduction in data collection, with sensitive handling of service user and onward referral available should further support be required
- Confidentiality and anonymity: no personal identifying information has been used in reporting the data
- Secure information management: maintained through password-protected university systems.

3.5 Limitations

No service user outcomes tool were agreed by the clinics and no permissions were in place for evaluators to contact previous service users. Data on impact was only available through a limited number of qualitative interviews. The evaluation team were unable to interview any women who had not engaged with the clinic provision, following non-attendance. Our evaluation data did not capture experiences of women unable or unwilling to engage, or those who did not have their needs fully supported by the NHS pilot clinics. Given the challenges of complex need outlined by the women that we interviewed, it is unlikely that every woman who needed support could access it. There is a gap in the evidence gathered about survivor's partners views, as these were outside of the scope of this evaluation. These factors taken together have an impact on the robustness of the findings.

4. Findings

4.1 Evaluation Objective: To Explore the Importance of the Clinics Being in a Community Setting

Despite the specification stating that clinics should be delivered in the community, three of the eight clinics operated from within a hospital, and five from within community health centres or a GP surgery. The hospital sites were led by consultants with experience in delivering FGM services. Here, the model of delivery was extended to include the counsellor and health advocate. There were no reported disadvantages to providing the clinic in a hospital setting; staff agreed it was more about providing a sensitive and welcoming environment. There was evidence that extending holistic support in a hospital allowed easy access to other gynaecology services or urology services. In addition, hospitals could build on existing referral pathways established within their settings (e.g. GP referrals and consultants). However, not all hospital settings were successful in generating referrals. There was no evidence that the experience of women was affected by their attendance at the clinics in the hospital, rather survivors needed an environment that felt welcoming and trusting relationships with staff:

"I didn't mind it being in a hospital...they understand the background I come from. They were very informed, and I would say educated about the history of the survivors." (Survivor)

4.2 Referrals

Clinics provided data which showed that in total over a two year period, from 2019-2021, 578 women were seen. A key route into the service was self-referrals with 38.7% of women self-referring. A further 33.0% were referred by their GP. The three hospital sites accounted for 60% of all GP referrals. 1 community site received no referrals from a GP and another just 2 referrals. Health advocates accounted for approximately 1 in 10 referrals.

4.3 The Model of Support

Support for each service user in the clinics took similar pathways. The health advocate was the initial point of contact and was active in supporting women. Advocates were part of the initial assessment where additional needs such as housing, welfare needs, or support with refugee status, for example, were identified. A specialist midwife/consultant completed the FGM diagnosis and performed any clinical procedure as required (e.g. de-infibulation). They also assessed for any ongoing health care needs or complications which may need a referral to a consultant.. Counsellors and/or psycho-sexual therapists supported the women further to help them understand impacts on their mental health, emotional well-being and personal relationships. The input from each professional role was not necessarily sequential; some women accessed counselling support before any clinical intervention and continued with counselling after the clinical procedure. Some women did not access any counselling. Our evaluation found that the clinics provided services flexed to the needs of individual women, on a case by case basis.

4.4 The Significance of the Specialist FGM Midwives/ Consultants or Nurses

Specially trained midwives or consultants and nurses were responsible for completing the FGM diagnosis and any further procedures such as perineal repair and de-infibulations. They provided a high level of expertise when assessing the women's health needs and agreeing on a care plan. The FGM Clinics also provide treatment for other symptoms including urinary tract infections (UTIs) menstrual problems, or thrush for example,

"We have to look at the woman in her entirety, explore all of her symptoms and make sure we give her the best care we can while she is with us." (Midwife)

The second person in the room during the medical procedures was typically another midwife or a nurse. Clinics agreed that having a second midwife supporting the procedure enabled greater opportunities for learning and knowledge transfer,

"I feel that I need an experienced person with me because it's complex... and while I feel I am skilled, I like to have someone else around when I'm doing the procedure." (Clinic Lead)

4.5 The Role of the Counsellor

Speedy access to counsellors and psychotherapists was one of the most valuable forms of support for survivors. Evidence showed how valuable this support was for their recovery,

"The trauma that many of these women have gone through in their earlier life has been buried, but it manifests itself in many different ways...in their mental health, often how they feel about their sexuality, their identity...their ability to have positive relationships". (Counsellor)

Where women needed specific help with personal relationships and spoke of difficulties with sex, psycho-sexual therapists were available (in some clinics) to work with the women around intimacy and sex. Counselling was also delivered to partners in some limited instances, with survivors full consent to help them understand intimacy issues. Group sessions were run by one counsellor in a clinic which helped to break down the barriers in talking about FGM.

4.6 The Significance of the Health Advocate Role

Health Advocates were crucial to the effective running of the clinics. They supported the clinics by raising awareness of their services within local communities, contacting each service user before their appointment, and providing advocacy. Some managed the clinic's bookings, responded to telephone and email inquiries, and helped organise the clinic diary. Where health advocates were more active, non-attendance rates were

reduced. Health advocates tended to be from similar backgrounds as the service users, bringing cultural understanding. Some advocates were themselves survivors, recognising the benefit of sharing their personal experiences with service users, to engender considerable trust,

“She was amazing, she understood me... I trusted her, she was so kind”. (Mariam)

4.7 The Benefits of the Tripartite Support

The tripartite support ensured the women who accessed the services were able to move forwards more confidently. None of the women interviewed had previously spoken about their traumatic experiences and professionals agreed that they would not have accessed their clinic if the service was solely clinical,

“This is a challenge in itself to encourage them to talk to a professional about it... without this active engagement and support throughout their journey, they wouldn’t be here...the clinic opens the door to that conversation for the first time.” (Psychologist)

4.8 Challenges to Service Delivery

Most clinics reported challenges in establishing their service such as drafting operating protocols, purchasing suitable equipment, recruiting and retaining experienced staff, operating at capacity, gaining access to necessary medicines, collating and storing case data, and supporting women for whom English was not their first language. These challenges were not present in all clinics but were reported across several clinics. In addition, the pandemic resulted in some staff working from home, impacting the effectiveness of the tripartite support. There was a low level of management and supervision in some clinics, affecting the health advocates in particular. Key implementation lessons include ensuring that there was sufficient time allowed for the set-up of the clinics and greater consideration needed to be given to data management and information sharing across the teams to ensure that support was meeting all client needs.

4.9 Women’s Experiences of the Clinic

Women’s views of the support were very positive. They liked the ability to self-refer and were pleased with the timely response following initial contact. Clinics treated the women sensitively, providing a high level of emotional support. Women felt listened to and understood, which engendered trust. The diagnosis of their FGM was an important first step in their recovery,

“Now I know this, I can move forward...this is so empowering for me to understand what has happened. Now I can begin treating myself too.” (Kaya)

Women who had de-infibulations spoke of a change in their physical health but also optimism for their future, in particular with their relationships and intimacy; several women had come to the clinic in preparation for marriage.

The counselling and psycho-sexual therapeutic support had a significant impact on women’s self-awareness, and their understanding of how the trauma of FGM had affected them. For several women, this was the start of their journey and ongoing support was going to be needed, with some suggesting peer-to-peer support groups as helpful here, though this had not been implemented the time of the research. For most women, the memory of their FGM experience was still vivid despite the event being many years ago. Women interviewed were in their twenties, thirties and forties and were still dealing with mental, physical and emotional scars left by FGM,

“I have physical symptoms, the area is very sensitive, and I suffer from psychological trauma.” (Bintu)

Women reported feeling the team provided a responsive and supportive environment,

“I felt listened to at the first appointment in [name of clinic], and able to trust staff.” (Rana)

“Everything was carried out perfectly for me personally... a lot of support and greeted with a lot of understanding and care. I am very grateful.” (Fazia)

Women spoke of the benefits of the holistic support and a range of positive outcomes including health improvements, increased self-confidence and feelings of empowerment, improved mental wellbeing and improved relationships. Women reported improvements in their physical health, with reduced pain during menstruation and an end to urine infections. Women spoke about having a better experienced during

menstruation and being able to use tampons more effectively which helped them to feel cleaner. They spoke of connecting with their body for the first time instead of feeling alien to it,

"I feel like I am beginning to understand myself as a woman now." (Leila)

Although very few women opted to take a smear test, some said that they would now feel more confident in doing so. This was partly due to having had a de-infibulation, but also due to the support they had experienced from the health professionals and feeling more confident with their bodies,

"Now I know that they understand, I feel more confident talking about it with my doctor." (Mariam)

Others described how they felt empowered with the knowledge they now had about FGM and their related symptoms. They felt more able to look after themselves when they had completed their therapy sessions; they felt more positive from being heard,

"The benefit has been amazing. Very pleased with it. There are so many women out there that suffer in silence and if I can encourage them to speak about it it's been worth it..." (Sona)

Several women spoke about how the FGM clinics were a source of empowerment against the violence that had been done to them. For the first time they were felt supported by a community that was openly dealing with FGM,

"I feel like I am undoing all the wrong that was done to me, this is me beating back from all the hurt." (Leila)

Greater confidence with relationships and intimacy was frequently reported. One woman spoke about how she had come to terms with her own sexuality as a result of feeling more confident with her body and her emotions,

"Having this therapy has helped me explore my emotions and to admit what I feel and to come to terms with my bi-sexuality." (Bintu)

Women reported feeling more confidence with sex and having got a sex life for the first time as a direct result of the clinical intervention, the knowledge gained about their body and the psycho-sexual therapeutic support,

"...I am now able to touch myself.. and to be aware of how my own body feels...I feel less shame about this and in a much better place". (Fazia)

"...after like a year and a few months I was able to have a normal sexual intercourse after working on my brain and you know my thoughts... I spent years and years trying and it was impossible [prior to the clinic support]." (Rana)

"[If it wasn't for this clinic] I would still be the same...I have been through a lot, and I used to be crying thinking that I would be like this for the rest of my life, but I got rid of my vaginismus." (Hadiza)

The improved sense of mental wellbeing came as the result of talking about the problems to someone and understanding the cause of their low mental wellbeing and anxiety. Many spoke about feeling a sense of weight being lifted from their shoulders,

"I had twelve sessions...the impact of this support, opened me up to my whole experience...the FGM and abuse from my family...they helped me cope with my depression." (Casho)

5. Discussion

Our evaluation data illustrates that the NHS pilot clinics treating non-pregnant women with FGM, worked to effectively support them in achieving positive outcomes for both their physical and mental health. The tripartite model of support was important to address their needs holistically in a safe, and trusted space. These findings echo evidence about other women's services designed to address complex need. Thus, offering women-centred approaches to service provision is effective in meeting their needs. Using holistic, joined-up, women-centred, models of support is the best way to achieve positive outcomes for women with complex needs (Women's Aid, 2022). Women must be at the heart of the provision and supported in a holistic and gender-specific manner (Warwick-Booth and Cross, 2020). Service user outcomes detailed in our evaluation show the value of NHS services offering holistic, women-centred support in primary care. The relational methods used by the NHS staff in the pilot clinics formed the mechanisms by which trust is promoted, an essential component when working in a trauma-informed manner (Covington, 2007; Warwick-Booth & Cross,

2020; Lurie et al, 2022). However, the timing of deinfibulation remains a complex matter for survivors, with services needing to recognise that women require agency and choice in relation to procedures and their bodies (The FGM Sister Study 2020).

Cultural barriers and stigma however remain a challenge, creating significant barriers for women accessing services and support for FGM (Akweongo et al, 2021), with health education interventions seen as a promising tool to tackle such issues (Waigima et al, 2018). Health Advocates undertook some localised awareness raising, in line with existing evidence indicating that community based organisations play an important role in facilitating women's engagement with and access to health services (Connelly et al, 2018). Our evaluation data also illustrates the value of educating survivors at an individual level to enable them to understand the implications of the procedure, and start their journey to recovery. Stevenson & Kelly (2022) highlight that women and girls are often unable to accurately recall which procedure was performed. Indeed, the survivors interviewed in this evaluation all noted that they had not disclosed their FGM to anyone until they attended health appointments, indicating the prevalence of stigma as an ongoing challenge. Therefore, health care services need to operate carefully to ensure that they do not further stigmatise survivors and communities, nor retraumatise women seeking their support (Karlsen & Mogilnicka, 2019; Lurie et al, 2022).

Despite evidence of effectiveness, the pilot clinics were funded in the short-term for two years, and tasked with becoming sustainable via integration into local commissioning arrangements. Two of the eight clinics were not successful in gaining funding to continue to offer the tripartite model of care, but are still offering FGM treatmentservices. Time-limited funding does not always support sustainable service provision, and therefore the literature already notes that FGM specialist service clinics such as the ones discussed here, should be a resource priority (Dixon, et al 2020).

6. Conclusion

Our evaluation showed that the NHS pilot clinic approach for non-pregnant survivors of FGM was successful in delivering holistic, women-centred support, enabling positive outcomes for women who accessed the service. The provision was delivered in line with commissioning requirements, though this was not without challenges. Whilst the NHS pilot clinic funding enabled a new model of care to be implemented, ongoing work is needed due to the stigma surrounding FGM practices, with many non-pregnant survivors likely to be living with unmet needs as a consequence of their FGM.

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Appendices: Definition of Terms

Health Outcomes: in our evaluation we did not apply a specific definition of health outcomes from the literature, nor attempt to quantify these. Rather we qualitatively captured survivors and staff perceptions of health improvements resulting from the clinic support.

Health and wellbeing: again we had no quantifiable, nor measurable definition of health and wellbeing, intending to capture voices and views about what mattered in this area to survivors, enabling full exploration of impacts linked to the provision of holistic support.