

# Improving care for women and girls who have undergone female genital mutilation/cutting: qualitative systematic reviews

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## Scientific summary

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# Scientific summary

## Background

The UK is in a period of 'super-diversity', which is characterised by high rates of migration from countries all over the world (rather than mainly from former colonies as in previous decades). As a result, there are growing numbers of women living in the UK who have experienced female genital mutilation/cutting. Hence, the need to address female genital mutilation/cutting within the NHS is already significant and is expected to increase.

The UK has initiated a range of policy and legal interventions over the last 5 years focused on female genital mutilation/cutting prevention and safeguarding, supported by increased staff training and systems to enable accurate reporting and recording. However, health-care provision for those affected by female genital mutilation/cutting is reported to be fragmented and variable, focused predominantly within maternity services, lacking clear referral or care pathways and difficult for women/girls to access. There is an ongoing need for culturally appropriate service development, informed by the best available evidence.

Existing evidence syntheses around female genital mutilation/cutting have focused primarily on maternity care, prevention, sociocultural transitions, clinical interventions or female genital mutilation/cutting in a global rather than specifically a UK (or high-income country) context. This project sought to add to this evidence base by synthesising research that could illuminate women's and health professionals' experiences and preferences in relation to care-seeking and care provision that would include, and could be transferable to, a UK context and that would go beyond maternity care to include all health-care settings and contexts.

## Objectives

To undertake two systematic reviews of qualitative evidence to illuminate the experiences, needs, barriers and facilitators around seeking and providing female genital mutilation-/cutting-related health care from the perspectives of (1) women and girls who have experienced female genital mutilation/cutting (review 1) and (2) health professionals (review 2).

## Methods

Comprehensive literature searches were undertaken in 16 electronic databases (including grey literature sources) from inception to December 2017. These were supplemented by reference list searches and suggestions from an expert reference group.

The reviews focused only on qualitative research in order to provide an in-depth understanding of care experiences. The reviews included evidence from only Organisation for Economic Co-operation and Development countries as, like the UK, these are common 'destination' countries for female genital mutilation-/cutting-affected migrant populations and face a common challenge of needing to adapt health services to increasingly diverse population groups. The reviews included research from any clinical setting or context, in any language and from any date.

Included papers were quality appraised using the Joanna Briggs Institute Qualitative Assessment and Review Instrument, and were also assessed for richness and relevance. Data on study characteristics were extracted using a Joanna Briggs Institute template. The reviews followed a well-established thematic synthesis methodology. PDF (Portable Document Format) files of the included papers were imported into

NVivo 11 (QSR International, Warrington, UK) in which study findings were coded and analysed using inductive thematic analysis to generate descriptive themes, which were then synthesised into higher-order analytical themes. Both review findings were then juxtaposed and analytically integrated into a combined overarching synthesis.

The level of confidence in the review findings was evaluated using the Grading of Recommendations Assessment, Development, and Evaluation – Confidence in the Evidence from Reviews of Qualitative Research (GRADE-CERQual) approach. All steps of the review process involved two or more reviewers working with a team that included community-based experts and clinicians. A national stakeholder engagement event was undertaken to consult on the final review recommendations and conclusions.

## Results

Out of 59,459 records screened, 78 papers (representing 74 distinct studies) met the inclusion criteria for both reviews: 57 papers in review 1 (55 distinct studies) and 30 papers in review 2 (28 distinct studies). Nine papers were common to both reviews and 10 papers were in languages other than English.

### Review 1 (women's experiences)

The 57 papers in review 1 represented 14 different countries ( $n = 18$  from the UK), with over half ( $n = 29$ ) published since 2011. One-third of the papers focused on maternity care contexts, whereas others pertained to cervical screening, psychological issues, primary care and 'other'. There were no papers on the experiences of girls. Seventeen descriptive themes were synthesised into five analytical themes:

1. communication is key
2. access to care – influenced by an interaction of multilevel community and health service processes
3. cultural and bodily dissonance – striving for cultural and bodily integrity
4. disempowering care encounters
5. positive care encounters.

The findings revealed limited awareness among affected communities of where or when to seek help related to female genital mutilation/cutting. Women's female genital mutilation-/cutting-related health-care experiences were shaped by silence, stigma and stereotyping, which hindered care-seeking and access to services. Language barriers exacerbated existing cultural taboos and impeded women's ability and confidence to talk about female genital mutilation/cutting. Many studies reported negative and disempowering care experiences, attributed to clinical interventions being experienced as another trauma and to receiving care from providers who appeared to lack the requisite skills/confidence. Such situations left women feeling distressed, anxious and vulnerable. There were many examples of disrespectful care. Descriptions of 'good' care had two elements: (1) achieving a trusting relationship with a culturally sensitive, knowledgeable provider, and (2) engaging communities in care delivery.

Confidence in the Evidence from Reviews of Qualitative Research assessments of confidence in the descriptive themes evaluated 10 findings as high confidence and seven as moderate confidence.

### Review 2 (health professionals' experiences)

The 30 papers in review 2 represented nine different countries ( $n = 5$  from the UK), with two-thirds ( $n = 20$ ) published since 2011. The majority of papers focused on midwives and doctors (or both), with an emphasis on the maternity setting; however, the papers also included health visitors, school nurses, district/community nurses and counsellors. Twenty descriptive themes were synthesised into six analytical themes:

1. knowledge and training
2. communication is key

3. encountering the 'other' in clinical practice – negotiating cultural dissonance and achieving cultural understanding within health-care relationships
4. identifying female genital mutilation/cutting
5. clinical management practices – inconsistent and variable
6. optimal service development.

The findings highlighted that providers often lacked knowledge and/or felt uncomfortable talking about female genital mutilation/cutting, leading to missed opportunities to identify female genital mutilation/cutting and/or suboptimal clinical management. Language barriers and challenges with interpretation posed significant obstacles to care. Papers reported variable levels of confidence and skill in the clinical management of female genital mutilation/cutting (particularly around deinfibulation), with some settings reporting no relevant guidelines or patchy adherence to guidelines and protocols. Providers across settings reported a desire for additional training. More positive experiences/practices were reported from contexts in which there was specialist service provision (or in which providers could access input from specialists) and in which there were clear organisational processes to address language barriers and to support timely identification, referral and follow-up.

Confidence in the Evidence from Reviews of Qualitative Research assessments of confidence in the descriptive themes evaluated eight findings as high confidence, 11 as moderate confidence and one as low confidence.

### **Overarching synthesis**

The two reviews had several common themes (e.g. communication challenges) but also had themes that were distinct. By juxtaposing the two sets of findings together, four interlinked syntheses were formulated that were able to take both women's and professionals' perspectives into account, thereby producing integrated and novel insights:

1. factors influencing health-care-seeking around female genital mutilation/cutting
2. identifying and talking about female genital mutilation/cutting
3. clinical management and care experiences
4. service configuration and resourcing.

The synthesised findings indicated that health-care-seeking relating to female genital mutilation/cutting was influenced by a complex set of cultural norms and taboos, by the woman's wider family and by the women's level of knowledge about services and female genital mutilation/cutting itself. Previous negative health-care experiences or more-pressing social problems hindered women from seeking advice or care. For all of these reasons, in many cases, care was mainly accessed during pregnancy and decisions such as timing of deinfibulation surgery were strongly influenced by the provider's confidence in talking about female genital mutilation/cutting and whether or not a woman was able to establish a trusting relationship with the health-care provider. Therefore, communication was key, yet effective communication around female genital mutilation/cutting was significantly challenged by language barriers and difficulties in accessing appropriate interpretation services.

A key finding was that women and providers both recognised that the onus of 'breaking the silence' lay with the provider, lending considerable support to the notion of routinising questions about female genital mutilation/cutting in key clinical contexts. Furthermore, utilising cultural brokers/community-liaison workers as interpreters seemed to be a promising strategy (in contrast to impersonal professional services or family members) as these could provide social and emotional support as well as language support. Another important finding was that even once identified, appropriate care related to female genital mutilation/cutting was not always provided owing to a lack of (or lack of knowledge of) relevant protocols, referral pathways or guidelines.

A central finding was that women's care experiences were shaped by feelings of stigma, stereotyping and shame. This was partly associated with an internal process of cultural dissonance whereby female genital mutilation/cutting began to be experienced as something 'abnormal' and 'different' once women started living in Western countries, but it was also associated with external processes, particularly reactions from health providers, which, in some cases, left women feeling humiliated, objectified and misunderstood.

An important finding was that women's care experiences were strongly shaped by their perceived sense of the provider's competence and confidence in managing female genital mutilation/cutting. Professionals generally reported a strong desire to provide person-centred and compassionate care, but also identified suboptimal care provision and anxiety caused by lacking the requisite knowledge and skills. When women lacked confidence in their providers or experienced disrespectful or poorly managed care, they felt fear, anxiety and vulnerability and lost faith in the system. Such negative experiences could lead to avoidance of future care and recommendations to others in their communities to avoid care.

Conversely, a key finding was that positive experiences, positive clinical outcomes and an ability to address sensitive issues, such as safeguarding of children, were reported from situations in which women and providers had been able to form trusting relationships and engage in shared decision-making. These processes appeared more likely to happen in situations in which providers were culturally sensitive, in which there was continuity of care and in which there was specialist service provision (or access to specialist advice). Both women and professionals called for greater engagement of communities in service development and delivery.

## Discussion

The review findings resonate strongly with the wider evidence base on health-care experiences of migrant populations in a context of super-diversity (e.g. language barriers, lack of familiarity with services and challenges in achieving cross-cultural understanding between providers and patients). However, the reviews show that female genital mutilation/cutting adds an additional layer of complexity for both women and providers, manifested through silence and uncertainty.

Almost one-third of the included papers were from the UK ( $n = 23$ ). The majority of these were in review 1, with only five in review 2. In terms of transferability to the UK NHS context, the Project Advisory Group and participants from the national stakeholder event suggest that the findings are highly relevant and do echo experiences around the country, especially in clinical settings (or low-prevalence areas) where there are no specialist female genital mutilation/cutting services. The review findings regarding providers are further backed up by several UK-based surveys that have been conducted among health professionals, which have also highlighted significant knowledge gaps and a perceived need for additional training.

## Gaps and limitations

The reviews show that there are gaps in the evidence base. In particular, there are:

- few studies exploring mental health impacts and no studies exploring experiences with mental health services
- no studies exploring women's views and experiences of surgical reconstruction following female genital mutilation/cutting
- no studies evaluating different models of service provision
- no studies that reflect the recent changes in UK policy regarding mandatory reporting and recording of female genital mutilation/cutting.

A limitation of the reviews is that they were unable to draw conclusions that were highly specific (e.g. to type of female genital mutilation/cutting, clinical intervention, symptoms, life course or community or professional group). This is because of the nature of the evidence base, which generally brought distinct groups or contexts together and made it difficult to undertake a more nuanced analysis.

## Implications for service development and training

The reviews suggest that there is a need to promote the development of (1) appropriate care pathways, (2) communication and (3) community engagement, all of which may require additional staff training.

### Care pathways

The focus of the reviews on all potential settings, not just maternity, has highlighted a range of challenges in care-seeking for women outside pregnancy or before marriage. These findings support recent NHS England commissioning guidance on the need to establish care pathways for non-pregnant women. For example, some midwifery services across England do now have systems in place to routinely ask women about female genital mutilation/cutting; however, routine discussions about female genital mutilation/cutting are not yet common in many other clinical settings (especially primary care). The reviews, therefore, suggest that routine provider-initiated discussions about female genital mutilation/cutting should be promoted and backed up by additional training for providers (including general practitioners, obstetricians, gynaecologists, health visitors and school nurses). Furthermore, both reviews highlighted a need for care pathways to include psychosocial support for some women.

### Communication

With respect to maternity care, the findings highlight a need for a person-centred approach based on greater communication, information giving and shared decision-making. Such an approach is particularly important for clinical interventions such as deinfibulation to ensure that women have the time and support to make informed decisions about where and when the procedure should take place. The reviews show that such shared decision-making is possible and appreciated, but requires continuity of care and trained and knowledgeable providers. Hence, the reviews suggest a need for women to have access to appropriate information resources and for providers to receive additional training.

### Community engagement

The reviews highlighted that community engagement is critical for culturally safe and culturally sensitive service development. The findings show that community engagement serves three important purposes: (1) to raise awareness of service availability, (2) to support service use and overcome cultural and language barriers (e.g. through the use of community-liaison workers) and (3) to establish trusting relationships between women and providers that can support open conversations around safeguarding and prevention of female genital mutilation/cutting.

## Recommendations for research

In the UK context, the reviews suggest that there is a need for research to:

- map and evaluate different models of service provision around female genital mutilation/cutting
- evaluate the most-effective models of training to enable providers to gain clinical as well as cultural competence in relation to female genital mutilation/cutting
- evaluate the most-effective approaches for identifying and supporting women who require additional psychosocial support
- explore women's information needs in relation to female genital mutilation/cutting at different points in the life course to support appropriate care-seeking and shared decision-making
- explore the impact of mandatory reporting and recording on care-seeking, patient-provider relationships and the ability to have open safeguarding discussions.

## Conclusions

This was an exceptionally comprehensive set of reviews. The reviews identify key challenges but also opportunities for the development of culturally appropriate and accessible services related to female genital mutilation/cutting.

## Study registration

This study is registered as PROSPERO CRD420150300012015 (review 1) and PROSPERO CRD420150300042015 (review 2).

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