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The experience of maternity care for migrant women living with FGM: A qualitative synthesis

Abstract

Background: Increasing numbers of childbearing women with a history of female genital mutilation (FGM) are accessing maternity services in high-income countries across the world. For many of these women, their first contact with the health services in their host country is when they are pregnant. While the clinical consequences of certain categories of FGM are well documented, how high risk maternity services – designed to mitigate the obstetric consequences of FGM – impact upon women's experience of childbearing is less clear. **Methods**: Using a meta-synthesis approach, this paper synthesizes 12 qualitative research papers, conducted in 5 high income countries, to explore how migrant women with a history of FGM experience maternity care in their host countries. **Results:** One over-arching theme and four discrete sub-themes of migrant women's experience of the maternity services in their host country were identified: Feeling of alienation; fatalism and divine providence, positive and negative feelings about maternity care, different understandings of the birthing process, and feelings about FGM. **Conclusion:** The findings illustrate that migrant women with a history of FGM, frequently encounter negative attitudes when accessing the maternity services in their host countries. The women's experiences suggest a concerning absence of sensitive and empathetic care; a more woman centered approach is recommended.

Keywords

Female Genital Mutilation; Maternity care; meta-synthesis; systematic review

Introduction

Immigrants from non-European countries represent one of the fastest-growing groups resettling in many high-income countries across the world.[1] Furthermore, the proportion of women in these migrant populations is growing. The need to provide appropriate and sensitive maternity care for vulnerable migrant women has become increasingly important in all host countries.[2] This need is more pressing when women have a history of female genital mutilation (FGM), as migration from countries where the cultural practice is prevalent steadily increases.[3,4]

FGM refers to 'procedures that intentionally alter or cause injury to the female genital organs for non-medical reasons'.[5] It is important to note that the degree of severity of FGM varies considerably. According to the WHO classification, there are four major types of FGM which range from pricking and piercing to full infibulation - involving the removal of all the external genitalia and the narrowing of the vaginal opening through the creation of a covering seal.

Concerns relating to FGM in part stem from the potential physical and psychological complications that the practice can cause, especially in relation to reproduction.[2,6] There is a consensus of clinical opinion that women who have undergone FGM should be classified as high risk during pregnancy and birth.[4,6] In many high-income countries, this translates into the clinical recommendation of hospital-based obstetric-led care. This recommendation is made despite evidence suggesting this care pathway may not be in the best interests of these women[7] and a

paucity of evidence on which women from this group would actually benefit from such care.[8] Furthermore, the clinical recommendation is based upon little understanding of how this group of women feel about childbirth and what their preferences for maternity care may be. This paper presents a systematic review of the literature on how migrant women with FGM experience their maternity care. In this review we have synthesised the qualitative research with the aim of capturing the lived experience of the maternity service provision available to these women. The purpose of this synthesis is to strengthen the voice of these women in the evidence base that can be used to plan and deliver their maternity care.

Methods

Before commencing the search, the Cochrane Library, the Campbell Collaboration, along with the International Prospective Register of Systematic Reviews were all accessed to establish whether this review was required. Once the need was confirmed, the search strategy was commenced. Due to our research interest in the lived experience of maternity care, only studies that reported qualitative data were included.[9] The research question that was used to guide the search strategy was: How do women living with FGM feel about the maternity care services provided in their host countries?

Electronic Databases

A systematic search was carried out in order to identify peer-reviewed, primary research using the two international literature platforms: EBSCOhost (CINAHL, Medline, PsycINFO, SocINDEX,) and Ovid Online (Embase, Cochrane Central Register of Control trials, Global Health). The selected databases used within the platforms provided access to relevant clinical and health care journals.[10] The search was broadened to incorporate a multidisciplinary perspective on the research problem by the

inclusion of two further databases - Web of Science and Google Scholar both recognized for their multidisciplinary research capacities.[11] Further hand searching took place using forward and backward referencing,[12] along with individual searches (using the same search terms) of relevant academic/professional journals: *Midwifery*; *British Journal of Midwifery*; *Birth*; and *Maternal and Child Health Journal.*

Search terms were developed from the research question using an adapted PICO approach where C for comparison was removed due to irrelevance to the research question.

Table 1: Search terms

The Boolean operator 'or' was applied for within PIO category searches (terms in the same columns in table 1). These searches were then combined using 'and' for the across PIO category searches. Wild cards and truncations were used to ensure a sufficiently broad search.

Criteria for inclusion

The studies included in this review were all:

- Empirical studies published between 2000 and mid-March 2017;
- Contained qualitative data;
- Focused upon migrant women's experience of maternity care in high-income host countries;
- Participants were women with a history of FGM;
- Primary research.

Criteria for exclusion:

- Not English (no French papers fitting the inclusion criteria were identified in this search);
- No maternity service focus;
- Exclusively quantitative research design;
- Broad sample including migrant women whom did not have a history of FGM and non-migrant populations;
- Discussion papers or grey literature.

All studies identified were screened individually to check for relevance to the research question. Screening was carried out by the two researchers to ensure validity. Following detailed reading, the final papers were summarized and appraised using the ten items Critical Appraisal Skills Programme appraisal tool for qualitative research.[13]

Data extraction and synthesis

Detailed reading of each of the papers enabled data to be extracted according to Noblit and Hare's concept of constructs and included the collection of both first- and second-order interpretation data.[14] Priority was given to first-order interpretation data: the participants' own words. Where this was inadequate to capture the experience of the participants, second-order interpretation data that was presented under the findings section of the papers were also included.

All data were inputted into NVivo Version 11.3.2. and analysis and synthesis were conducted in the first instance independently by both authors and finally collaboratively. A three-step process was followed starting with the reading and re-reading of all the data in order to identify key metaphors, phrases, ideas and concepts. This analysis was carried out independently. Identification of commonalities across all

of the data was the next step which was done collaboratively. Out of this work emerged the four sub themes outlined in figure 2. Finally, the sub themes were integrated and synthesised to provide a core theme – the first level interpretive synthesis.

Results

Out of a total of 131 primary research papers retrieved, 12 were deemed to fit the criteria for the review. A PRISMA diagram (Fig. 1) and summary table (Table 2) as recommended by Moher, et al. are included to provide an overview of the search strategy and outcome.[15]

All but two of the 12 papers were deemed to be reliable, valid and significant, and of sufficient quality according to the CASP criteria.[16] Despite being considered valid, it was not possible to score the Essén et al[17] and Bulma and McCourt[18] papers against all of the appraisal criteria as insufficient research design information was provided. Despite this however, both papers offered rich descriptions that were highly significant to the review's aims and were therefore still included.

Study characteristics

All of the studies included in this review presented qualitative data but were heterogeneous in their research paradigm and study design. All were carried out in high-income countries (2: UK; 2: US; 1: Australia; 1: Switzerland; 3: Sweden; 2: Canada; 1: Norway) with migrant populations, with a total of 609 women involved from Somalia, Eritrea, Sudan, Ethiopia and Liberia. Two of the studies also included health professionals in their sample frame (data excluded from sythesis). Eleven of the papers included participants with a history of Type-III FGM (infibulation). Only one study included in this review reported having participants with other types of FGM. All but one of the papers included in this review were published before 2010.

Interpretative synthesis

One overarching meta-theme emerged out of the analysis of the 12 papers, along with four sub themes. Starting with the meta-theme, this section of the paper describes each of the sub themes (as seen in figure 2) in turn.

Feelings of alienation (n=12)

All of the studies included in this review described the migrant women making sense of their maternity care in ways that were often at odds with those of their care providers. Importantly, while these women's lived expereinces included understandings of FGM, they were not necessarily defined by this experience[19]. Rather, FGM had become part of their way of life:

> 'In our homeland, it is so common with circumcision. All women are circumcised, so no one thinks that anything will happen. When we come to Sweden, we meet people who say that female circumcision causes risks during childbirth, but we don't think so much about it'[17]

The women reported being shocked by the over-inquisitive attitudes of their caregivers towards their FGM. For example, one participant explained:

> 'All of them just wanted to look at me. I didn't understand why and nobody asked me, but I thought that they found it exciting to see when I was cut open'[20]

Another participant from a different study gave a more gruelling account of a similar experience:

> 'My genitals were on display. A group of white-coated staff will come and look and talk to each other with disgust' [21]

The loss of agency that arose out of such encounters with the maternity services created feelings of alienation[19]. Fertility, for example, interpreted as a gift by the

women, could be seen as a sign of weakness or inconvenience by staff. As one participant from study described:

> 'Before and at my first two deliveries the health personnel were very nice, but then there was like a change in attitudes. I remember when I came for my third delivery and a midwife said, 'Are you here again already? We'll probably see you here next year and next year again.' Then when I came back, I didn't feel good' [20]

The women described having their personal autonomy curtailed by health professionals' clinical decision making. As these first-order data illustrate:

> 'When I go there, I feel like a small girl that they are going to take care of. They do their work in a good way, but you also feel that they want to decide everything on your behalf' [18]

> 'You say, 'Oh yes, yes,' although you are not answering the questions, you just say yes' [22]

> 'They had tied this belt so tight around my belly, it pained me and I tried to pull it away. I tried to tell the nurse, but she didn't listen. She was angry and yelled at me' [23]

Several of the papers included in the review described women's feelings of disenfranchisement resulting directly from the attitudes of the maternity care staff they encountered.

Fatalism/Divine providence (n=11)

> 'I think that in American culture you put a lot of trust in science. In the Somali culture, we put our trust in Allah' [24]

Eleven out of the twelve papers included in this review reported on their participants' experience of religious belief and how this belief influenced the way they

made sense of their reproductive experiences. Participants reported that belief in God affected their decision making during pregnancy and childbirth. This sense of faith among the participants tended to introduce a sense of fatalism that provided comfort and resolve, as the following quote illustrates.

> 'The child is a gift from God. If anything went wrong during delivery, I would never accuse anyone because we know that no one wants a bad outcome. If something does go wrong, it is God who has decided the child's fate…'
>
> 'It is God who knows if the pregnancy is going well. We do not know. If the baby kicks, we are not worried' [17]

Positive and negative feelings about maternity care. **(n=12)**

Two concordant ideas ran through the research reviewed for this project in relation to the women's attitudes and feeling towards their maternity care. On the one hand, several of the studies included described the women's sense of gratitude for the maternity they received (n=7). For example, participants' contrasted their host countries midwives, who were described positively, with midwives from their home country who were notoriously brutal and harsh, some even hitting the women during childbirth. [20,25] This sense of appreciation was particularly evident when participants felt that their carers were experienced in managing FGM.

However, a more densely populated construct centred around feelings of being disrespected and inability to trust their maternity care provider's competence (n=12). For example, health professionals' lack of knowledge, skill and sensitivity in relation to managing FGM during labour and birth, as these data illustrate:

> 'I had a lot of questions during my pregnancy. I had the feeling there was nobody whom I could have really asked. I missed a traditional midwife as we have in Somalia' [26]
>
> 'She looked really panicked when she tried to, um, to deliver the baby, and she didn't know what to do, but I had my niece to tell her quickly that she can cut….

> I felt I was different because of the female circumcision I had and wasn't really sure. I felt so embarrassed the whole time that I was at the hospital' [22]

Feelings of re-victimization appeared under the negative feelings about the maternity services interpretation. For example, Berggren et al found that 'the memories of the primary FGC (Female Genital Cutting) experience were reawakened in situations with gynecological examination and delivery.' [20]

> 'In my dreams, my delivery and my circumcision are sort of mixed up. I am lying there pregnant, but only six years old, as I was at my circumcision, and there are people around me with knives cutting me up everywhere. It is just awful' [23]

> 'I became a victim in Sudan already when I was 4 years old; I had no choice. Now I have to become a victim again after delivery, when the midwives refuse to resuture me. I just ask for a few stitches; not to have an open wound' [20]

The gender of the health care professional was also seen as being problematic in several of the studies, and there was concurrence across all the papers that unfamiliarity with language and culture, as well time constraints, all operated to negatively impact upon the women's experience of maternity services.

Different understandings of the birthing process (n=10)

> 'Over there, it seems a pregnancy is a very natural experience; it's not like seen as a big, big thing like here. Like a woman has to have a baby and that's natural. Their body can handle it' [24]

How the women perceived pregnancy and childbirth impacted upon their understanding of the maternity services they accessed in their host countries. Many of the women migrated from areas where pregnancy and childbirth were seen as a natural

and normal part of everyday life rather than something that should be medically managed[27].

The routine scrutiny of antenatal care is alien within such a cultural context and deemed unnecessary by some. In the ontological framework where birth can be thought of as a natural physiological process – a routine part of a married woman's life – FGM is simply positioned as being part of that routine. When understood in this way, FGM excited relatively little attention and was not necessarily interpreted as an obstetric risk by the women. Chalmers and Hashi, for example, reported that the majority of women involved in their study did not believe FGM had much or any impact upon birth.[21] Provided the women were confident that their birth attendants were competent in the management of FGM, it was not necessarily considered to be a problem.

Despite being seen as natural, childbirth was not necessarily thought of as something that was safe. Several of the papers described the women's feeling of fear around birth, even fearing death:

> 'I thought of her actually coming throughout you know from there. I thought it was strange and awkward. Would I, you know, bleed, I dunno. I was scared of it because of the, you know, because it was closed for so many [years] …it was terrifying, yeah.' [28]

> 'Childbirth is like going into a tunnel, and you never know whether you are coming out alive' [23]

> 'The only thing I thought about delivery was fear of dying. I remember my pregnancy in Somalia. I had dinner with a pregnant friend of mine. Suddenly, she started to feel labour pains and went to the hospital. She and the baby died that day' [17]

Although many of the participants talked about home birth being the norm in their countries of origin, seven of the papers reported women stating that, in their host

country, hospital birth was safer than home birth. Commitment to the medicalization of birth, however, was far from absolute. For example, all but one of the papers included presented evidence of a strong resistance to caesarean section. Caesarean section was feared by many of the participants more than birth itself[27]. This procedure was not perceived as a way to avoid maternal and neonatal death so much as a potential cause of it. Wishing to avoid caesarean section and preferring vaginal birth was a construct that ran across all the papers and, in some instances, the fear of having this preference ignored was enough to drive women away from the maternity services entirely.

> ‘I avoid going to hospital when my waters break because of C-section. The doctor frightened me by saying you may not have a healthy or live baby as a result of your FC. I told him I believe in Allah who determines my baby’s life… I was very scared and afraid’ [21]

The post-natal period was also a time when tensions between the migrant women and their maternity care providers could arise, particularly when the women chose to follow traditional lying-in practices, resting to recover from the hard work of childbirth. This was perceived by some practitioners as troublesome and evidence of laziness or even arrogance.

> ‘When I asked the nurse to hand me my baby she said ‘I am not your servant’. [29]

Feelings about FGM (n=12)

Ways of knowing about FGM were complex and in some instances contradictory. FGM was at once seen as a cause of significant harm and suffering, while simultaneously, it was seen as something that traditionally preserved social coherence and feminine dignity.

> ‘If you are not married, you have problems with your menstruation. If you are married and you want to have sex with your husband you suffer from pain. If you want to deliver your baby, it is difficult. This is terrible!’ [26]

Positive descriptions of FGM were associated with stories about the women's countries of origin, where FGM was described as a kind of purge, protecting a girl's dignity, purity and virginity before marriage[24]. Feelings of pride and excitement accompanied FGM[21] and the consequences of not being cut could include social isolation and ostracization.[20]

When de-infibulation should be offered to women with Type-III FGM/C was inconsistent, with some papers strongly suggesting that women expressed a preference for pre-labour de-infibulation,[20] while other papers suggested that the procedure carried out during labour would be the most culturally appropriate option.[26,28]

Discussion

Genital cutting, in the absence of medical indication, is a widespread practice that is undertaken on both males and females worldwide. Attitudes towards this practice vary according to ethnicity, gender and age with the genital cutting of girls exciting a range of cultural responses ranging from abhorrence and criminalization to veneration.[31–33] The diversity of attitudes towards FGM is corroborated in the findings from this literature review. Importantly, this diversity of positioning to this cultural practice exists, not simply between different cultural groups – for example, between maternity caregivers and care receivers – but within the same group. Women who have undergone FGM can at once feel culturally dignified and at the same time emotionally horrified by their experience. It is crucial therefore that maternity care providers respond appropriately and sensitively to such complexities.

FGM is one, rather private, element of a rich cultural heritage that women bring with them when they migrate to different parts of the world. The evidence presented here suggests these women may experience their practitioners' preoccupation with their FGM as being disproportionate. Worryingly, this preoccupation on the part of

practitioners can create tensions which erode other crucial aspects of safe and effective maternity care such as sensitivity, kindness and compassion.

The strength of the study is that it provides a perspective on FGM and maternity care that is under represented in the literature – the women's perspective. This perspective is not straightforward nor is it necessarily consistent; however women's feelings about their care are important. In synthesising this literature, we have been able to explore how migrant women with a history of FGM feel about their maternity experiences in their host countries and how having FGM can impact negatively on the care they are able to access. The review has several limitations. Firstly, we acknowledge that this paper echoes the over representation of infibulation apparent in the FGM maternity care literature. Just 1 of the 12 papers reported including women with a history of other types of FGM, despite the fact that the less severe types of modification purportedly account for the majority of cases of FGM across the world.[34] A second limitation is that the majority of the papers included were published more than six years ago. Some notable differences in the later paper - published in 2016 - could indicate that attitudes towards this group of women are softening as the migrant communities align themselves with their host's positioning towards FGM eradication. Without further investigation however, this supposition must remain speculative. A third limitation of this paper relates to the quality of the papers that were included in the review. Two of the 12 papers included did not provide the necessary information to score against some of the CASP appraisal questions. Furthermore, 6 out of the 12 had sample sizes below 20. Finally, due to the nature of the papers retrieved, we included both first and second order data. Around 30% of the data were second order interpretation findings. Although we were careful to ensure that all of these data were

lifted from the findings sections in each of the papers, we acknowledge that inclusion of both first and second order data could potentially introduce some bias.

Conclusions

Some women who have undergone FGM will suffer obstetric and psychological complications due to their surgery; clinical recommendations are clear on that point.[35] The evidence presented in this paper however indicates that precautionary, high-risk approaches to care can operate to amplify FGM in ways that are incompatible with the needs of the women. These vulnerable women, more than anything else, need to be treated with dignity and respect. Their wishes and preferences, as well as their physical bodies, should be at the centre of their care. To achieve this quality of care, migrant women who have a history of FGM need to be heard in ways that can unsettle some of the unhelpful attitudes of some clinicians towards the appearance of their genitals.

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