What women want: A reflexive thematic analysis of the healthcare experiences of women with female genital mutilation/cutting in South Australia

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ABSTRACT

Background: Global migration has seen an increase in female genital mutilation/cutting (FGM/C) cases observed in countries where it is not part of the cultural norm. This shift has led to many healthcare professionals (HCPs) reporting a lack of knowledge and skills necessary to support the needs of women with FGM/C.

Aim: To explore the experiences and needs of women with FGM/C accessing women’s health services in South Australia.

Methods: Women with FGM/C were recruited through purposive and snowball sampling to participate in one-to-one semi-structured interviews. The voice recorded interviews were transcribed verbatim, coded, and analysed using Braun and Clarke’s reflexive thematic analysis to determine themes.

Findings: Ten migrant and refugee women living in South Australia, were interviewed. Four themes and 13-sub-themes were identified. The main themes were, 1) the healthcare experience, 2) cultural values shape the healthcare experience, 3) speaking up about female genital cutting and 4) working together to improve healthcare experiences.

Discussion: Women’s cultural needs, not their health needs, play a fundamental role on how women experienced healthcare services. When women’s cultural values and traditions are acknowledged by HCPs, they are more likely to trust and feel confident to engage with services and seek medical support. Areas identified for improvement included access to the right interpreters, having more time during appointments, opportunities for continuity of care and the inclusion of family in care and treatment decisions.

Conclusion: Women with FGM/C have specific health and cultural needs that can be met through education and provision of woman-centred care.

1. Introduction

Female genital mutilation/cutting (FGM/C) is an ancient cultural tradition, that despite significant health risks, continues to be practiced globally [1]. FGM/C is defined as any non-medically indicated procedures, and/or deliberate injury, to the external female genitalia and is classified into four types (1–4) dependent on the degree of damage caused [2].

Despite numerous campaigns to end FGM/C in the last three decades, increased rates of global migration has seen the practice in countries where it is illegal, such as Australia [3]. Reasons given for the continuation of FGM/C today are a combination of cultural, religious, and social factors including but not limited to, safeguarding girls’ future through social acceptance, hygiene, and aesthetics, family honour,
preventing promiscuity and a rite of passage into womanhood [2]. However, several authors and civil rights advocates argue that continuing the practice is patriarchal control of girls and women [1]. As such, the World Health Organization (WHO) denounces FGM/C as a form of gendered-based violence, that infringes on the human rights of millions of women and girls worldwide [2].

FGM/C can cause significant immediate and lifelong biopsychosocial implications for girls and women [4]. These implications are further compounded by resettlement challenges (e.g., displacement, low socioeconomic status, limited social and family support, trauma and intersectionality), often faced by women from culturally and linguistically diverse (CALD) backgrounds in host countries [5]. Yet, for many women with FGM/C, these issues are first identified when they engage with sexual health and maternity services. Thus, healthcare professionals (HCPs) are in an ideal position to identify, manage and support the health needs of women with FGM/C; however, they often report a lack of awareness and confidence to discuss FGM/C in a culturally safe manner [6].

Research on the experiences of women with FGM/C and HCPs who provide care has predominately come from countries with high prevalence of FGM/C, or where there are significant investments in education and prevention of the practice [7–9]. In Australia, most of the FGM/C research has sought to understand HCPs knowledge and attitudes and health outcomes for women with FGM/C [10–15]. Only one study explored the experiences of women with FGM/C accessing maternity services, in a setting with well-established services for migrant and refugee communities [16]. Therefore, this study addresses an identified deficit in current literature.

1.1. Aim

The aim of this study is to explore the experiences and needs of women with female genital mutilation/cutting accessing maternity, gynaecological and sexual health services in South Australia (SA).

Research questions:

1. What factors affect the experiences of women with FGM/C accessing maternity and gynaecological services in SA?
2. What are the needs of women with FGM/C in SA?

2. Methods

2.1. Qualitative research design

A qualitative research design utilising semi-structured interviews and a reflexive thematic approach to explore the lived experience of women with FGM/C [17].

2.2. Research paradigm

Interpretivism is a paradigm used to understand how individuals perceive the world based on their experiences, circumstances, and culture [18]. Reality is relative, truth is subjective and always evolving, and constructed by people through meanings they form from their experiences in the world [18,19]. Interpretivism guided in-depth exploration of the lived experiences of women with FGM/C accessing women’s health services, in a flexible and reflexive manner [18].

2.3. Researchers’ characteristics and reflexivity

All four authors are either nurse/midwives or midwives with clinical and research experience working with women from culturally and linguistically diverse backgrounds including women with FGM/C. None of the authors had any relationships with the women interviewed in this study. The authors adopted a cultural relativism stance where one cannot evaluate the beliefs, customs, and standards of one culture using the beliefs, customs and standards of another [20].

2.3.1. Minimising biases

Community engagement was essential to establish cultural protocols for engaging with women and FGM/C practicing communities. Therefore, a cultural advisory group was set up and comprised of two Sudanese community leaders, two refugee/migrant health clinical nurses and a bicultural health worker. The advisory group informed cultural customs of key communities, appropriate language to use when discussing FGM/C, recruitment strategies, community engagement and study design.

2.4. Context

The South Australian healthcare system supports a population of 1.8 million people with approximately 25% from migrant and refugee backgrounds [21]. South Australia currently, does not have a policy framework that supports the needs of migrant and refugee people [22] though, the State’s health plan recognises the disparities in health status for these populations [23]. Furthermore, South Australia has no formal processes for reporting FGM/C cases observed in clinical practice and, unlike other States and Territories in Australia, there are no known specialised community-based FGM/C clinics to support women with FGM/C, or FGM/C education for HCPs [24–26].

2.5. Sampling strategy

Purposive sampling was used to recruit women with FGM/C in this study. Once interviews began snowball sampling occurred, as women referred other women to participate. Sampling saturation was determined when the researchers were unable to identify new codes and themes [27,28]. In our study sampling saturation occurred after the seventh interview, though a further three interviews were conducted to confirm this.

2.6. Recruitment

Posters and postcards in English and translated into Swahili, Somali, French, Tigrinya, Amharic, and Arabic, (languages commonly spoken by FGM/C practicing communities) were used to provide information about the study with links to the study’s website and contact details for the principal investigator (MD). Information was displayed at two metropolitan hospitals and a community health clinic in SA; posted on social media and emailed to several agencies and individuals working with migrant and refugee women. To increase awareness of the study, information sessions were provided to staff at participating venues. Participants were provided with a $50 gift voucher to cover costs associated with participation.

2.7. Ethical considerations

Ethics approval was obtained from the Women’s and Children’s Health Network (2021/HER00156) and University of South Australia (ID:204096) human research ethics committees (HREC).

All recruited women were given a participant information sheet and provided written consent prior to interviews taking place. Inclusive and culturally appropriate language was used to help women feel safe and empowered to speak about their experiences. Women could choose to either have the interview face-to-face, or via telephone or video conferencing, at a time and place most suitable to them. All participants chose to be interviewed face-to-face at their residences. Women were able to have a trusted person (friend or family member) during the interviews. A support protocol was available, in the event the interviews triggered any distress for the women [29,30].
2.8. Data collection methods and instruments

Semi-structured interviews were conducted using an interview schedule adapted from previous research that investigated concepts explored in this study, to guide each interview [16,31]. The interviews were audio recorded, and then manually transcribed by the principal investigator within 48 h. Pseudonyms were used to anonymise women and identifying markers were removed from transcripts before entered into NVivo Microsoft Windows software for data management and content analysis. Transcriptions and data analysis took place between October 2021 and April 2022.

2.9. Participants

Women who had experienced female genital mutilation/cutting, lived in SA, and met the inclusion criteria: 1) > 18 years; 2) identified as having FGM/C (Type 1–4); 3) had accessed women’s health service (i.e., maternity, gynaecological or sexual health) in SA in last five years; and 4) consented to an interview being audio-recorded. Interpreters experienced in a healthcare context were available for women who did not speak English.

2.10. Data processing

Constant comparative method (CCM) was used to analyse and generate codes after each interview [32,33]. This method enabled investigators to identify areas that required more exploration in future interviews, thus providing a collection of more explicit data [33]. The investigators used Boeije’s [32] epistemological approach for CCM as it supported the emergence of meaningful theories as interviews occur, rather than after all interviews had taken place.

2.11. Data analysis

Interviews were analysed and coded separately by two investigators (MD, AB) using Braun and Clarke’s ‘six-step for reflexive thematic analysis’ as a systematic way of identifying themes and preserving trustworthiness of the study [17]. Codes were added to a master list and reviewed after each interview; any new concepts that required further exploration and/or clarifications. Purposive sampling supported the emergence of meaningful theories as interviews occur, rather than after all interviews had taken place.

2.12. Techniques to enhance trustworthiness

Credibility was achieved by consulting with the cultural advisory group and reflections on potential biases by the investigators. Concepts that arose during the interviews were cross-checked in two ways: 1) the interviewer performed a ‘member check’ with each woman by summarising the conversations back to her to confirm the information was being accurately interpreted by the interviewer [35], and 2) another investigator took notes during the interviews to identify any concepts that required further exploration and/or clarifications. Purposeful sampling supported the transferability of findings by including women with similar characteristics to better understand the topic under investigation [36].

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Opening recruitment to women across SA who had accessed public and private health sectors promoted the participation of migrant and refugee women from five different countries thus capturing a wider range of ethnic groups. Investigators met on a regular basis to discuss each stage of the study. Information discussed and decisions made that influenced the dependability of the study were recorded via minutes as an audit trail [36]. To enhance data collection and confirmability of findings, two investigators independently coded transcripts using the CCM and reflexive thematic analysis which were then reviewed by the whole research team.

3. Findings

3.1. Participant Characteristics

Ten women, from five countries, were interviewed. Five required an interpreter. All women chose to be interviewed in their homes and had a support person present. The length of the interviews ranged from 25 to 46 min. Table 1 summarises participants’ demographic characteristics.

3.2. Themes

Four main themes and thirteen subthemes were identified (see Table 2) to describe the experiences of women with FGM/C accessing health services in SA.

Theme 1. : The healthcare experience.

Nine out of ten women described positive experiences with healthcare services, they felt that HCPs treated them well and with respect and provided sufficient information about their care. Women expressed complete trust in doctors stating they were the ‘experts’. They also identified the importance of communication during their interactions and the inclusion of families.

Subtheme. : ‘They treated me well’.

Women with FGM/C reported being generally satisfied with the care they received particularly, women who had accessed maternity services.

‘…. treatment in the hospital itself, it was good. They treated me really well … The good thing I’ve noticed [is] that when you need them to look after you for certain things, they really look after you and care for you …’ (P4).

This was further reinforced when women reported they felt

<table>
<thead>
<tr>
<th>Participant characteristics</th>
<th>Frequency (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Country of birth</td>
<td></td>
</tr>
<tr>
<td>Indonesia</td>
<td>2</td>
</tr>
<tr>
<td>Kenya</td>
<td>1</td>
</tr>
<tr>
<td>Liberia</td>
<td>1</td>
</tr>
<tr>
<td>Somalia</td>
<td>1</td>
</tr>
<tr>
<td>Sudan</td>
<td>5</td>
</tr>
<tr>
<td>Primary language</td>
<td></td>
</tr>
<tr>
<td>Malay</td>
<td>1</td>
</tr>
<tr>
<td>Indonesian</td>
<td>1</td>
</tr>
<tr>
<td>Arabic</td>
<td>5</td>
</tr>
<tr>
<td>Kissi</td>
<td>1</td>
</tr>
<tr>
<td>Somali</td>
<td>2</td>
</tr>
<tr>
<td>Type of FGM</td>
<td></td>
</tr>
<tr>
<td>Type 1</td>
<td>1</td>
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<tr>
<td>Type 2</td>
<td>4</td>
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<tr>
<td>Type 3</td>
<td>1</td>
</tr>
<tr>
<td>Not stated</td>
<td>4</td>
</tr>
<tr>
<td>Employed (including volunteering)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
</tr>
<tr>
<td>Highest education level reached</td>
<td></td>
</tr>
<tr>
<td>No schooling</td>
<td>1</td>
</tr>
<tr>
<td>Primary</td>
<td>2</td>
</tr>
<tr>
<td>Secondary</td>
<td>2</td>
</tr>
<tr>
<td>Tertiary</td>
<td>2</td>
</tr>
<tr>
<td>Certificate/ diploma</td>
<td>2</td>
</tr>
<tr>
<td>Not stated</td>
<td>1</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>26 – 56 years (42.1 years)</td>
<td></td>
</tr>
<tr>
<td>Length of time living in Australia</td>
<td></td>
</tr>
<tr>
<td>9 – 19 years (14.7 years)</td>
<td></td>
</tr>
<tr>
<td>Number of children</td>
<td></td>
</tr>
<tr>
<td>1-8 children (5 children)</td>
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</table>
supported during hospital admission and when provided with ongoing care:

‘They treated me really well, and even they continued their visits after they discharged me at home … I received the best care and treatment …’ (P3).

Being informed about all aspects of care contributed to a positive healthcare experience for women. As one woman recalls her experience with deinfibulation:

‘… they knew that I had the circumcision before, and they did what they needed to do. Yes, they explained ‘we need to do a cut that will help you practicing your life with your husband’ and at that time they said after the first child ‘we will insert IUCD so that will help with future pregnancies’ as well, so yes, they did provide me with information’ (P1).

Some of the women noted that they did not question the decisions doctors made about their care because they were female and, therefore felt unable to determine what was best for their health. As one woman stated:

‘… because doctor he has more experience than us, yeah … you know, we are human being, we are female, and sometimes we [are] shy and we don’t know what’s good for us and our body’ (P8).

Subtheme. : Importance of communication.

Communication was a valuable aspect of women’s healthcare experiences and was responsible for both positive and negative encounters. For example, being heard enabled women to feel respected and empowered. One woman recalls having the opportunity to speak to HCPs about a previous negative experience with the birth of her first child. This was important for her because she did not want to relive the same negative outcomes.

‘They gave me time to talk about my experience back in (city name). So, I explained to them what happened to me, the infection, [and] the … pain and they were recording. Yeah, and … I did not need any more for what happened there to happen here …’ (P4).

However, this is not always the case, as one woman recalls her experience with a GP where she felt her concerns were not heard.

‘… so, I used to see this GP, but I felt like my needs wasn’t met because she wasn’t really listening to what I was suffering … I kept on telling her I feel some sort of pain …, and she’s brushed it off by saying it could be gas, so that was my last straw with that GP. I went to another one and I told her everything … it turn[ed] out I had a cyst.’ (P5).

Four women reported a lack of communication between service providers and families, one woman recalled that her husband was upset that he was not informed that she had experienced a post-partum haemorrhage during the night and had been moved to another ward for closer monitoring.

‘… [child’s name] was born Saturday and then I had the bleeding Sunday night, yeah and it was quite a lot … they had to take me back to the labour room at that time … and then in the morning … he [husband] called me, and I said oh, I’m not on the ward, I’m in delivery room. ‘What happened?’ he [asked and was] quite upset because no one tell him …’ (P6).

Being unable to speak and understand English confidently, posed a significant barrier to accessing health services particularly when interpreters were unavailable:

‘… they call the interpreter, but the interpreter doesn’t come … I don’t know why, but I have another friend from Indonesia she very good English. She translated for me then after that …’ (P7).

Subtheme. : Including families.

The inclusion and support of husbands and families was integral for enriching women’s healthcare experiences. Women explained that having the support of families or friends meant a better birth experience. This was especially important for women who did not have immediate family support in Australia.

‘… yeah, most of us like family … my husband is Sudanese, so I have help, I mean I have [a] friend to help me … but because they are Sudanese, they just do their culture. To me it’s ok because I don’t have family here …’ (P6).

One possible way to include families following birth was suggested by one woman:

‘… they should be allowed family members to sleep over, at least one to two people, you know, because … if she couldn’t sleep that whole last night or it was a bad birth, of course, she would need extra support …’ (P5).

Theme 2. : Cultural values shape the healthcare experience.

Several women correlated positive healthcare experiences when their cultural needs were met by healthcare services, for example when they were able to discuss their concerns with female HCPs and when they were supported to undertake some of their traditional birth practices.

Subtheme. : a woman’s body is women’s business.

Women were most comfortable speaking with female HCPs, because they deemed women’s health issues as women’s business. A few reported health services were often unable to fulfil their requests for a female doctor, leaving them feeling uncomfortable and conflicted.

‘… sometimes is hard specially because we need to see a woman and sometimes when I go to the doctor, they tell us … we don’t have any doctor woman, we have only men, and as part [of] our religion we need only [see] female [doctors]’ (P8).

Women discussed how this inhibited them from expressing their health concerns freely and were scared or embarrassed, especially if it meant they would be required to undress for a physical examination.

‘… then the family planning caused that bleeding, and she never [went] back to the doctor … and when I [asked her] … ‘why you

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub Themes</th>
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<tbody>
<tr>
<td>The healthcare experience</td>
<td>• They treated me well (n = 9)</td>
</tr>
<tr>
<td>Cultural values shape the healthcare experience</td>
<td>• Importance of communication (n = 7)</td>
</tr>
<tr>
<td>Speaking about female genital cutting</td>
<td>• Birth traditions: the first 40 days (n = 4)</td>
</tr>
<tr>
<td>Working together to improve healthcare experiences</td>
<td>• Cultural misunderstandings (n = 5)</td>
</tr>
</tbody>
</table>

Table 2

Themes and subthemes (n = frequency).

Women and Birth xxx (xxxx) xxx

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Women and Birth xxx (xxxx) xxx
didn’t come to doctor?’ She said, ‘no, I was thinking [too] shy to [go to] the doctor to explain’ because, yeah, especially when a woman [has been] bleeding a lot, they [don’t] go to the doctor … and sometimes the GPs you can’t get the female [doctor], it’s very hard to get the GP female’ (P9).

**Subtheme. : Birth traditions: the first 40 days.**

Birth traditions were described by several women as essential to continue in their adopted countries to enhance positive birth experiences. As one woman explained:

‘… we consider birth, like a secret society, is not something that is talked about too much, it’s only with all the women, so men are not allowed to be there, and even after birth you go to either your mothers’ or mother-in-law’s place and stay there for probably seven days … when I came to Australia, my first child, my husband wasn’t present, because he still want[ed] to maintain that culture, even though he was at the hospital but not in the birthing room. I had to get some older women from the community to be with me as a support person’ (P9).

The first 40-days after birth was often deemed a sacred time, essential for healing, where other women take care of the mother and child to promote time to heal.

‘… I don’t know about other cultures but with my culture like I just said, 40 days in bed and she does nothing, and she gets looked after, and there are certain things they prepare for her like perfumes, and like … the burning of incense, those kind of things [are] prepare for her’ (P5).

Food was another element of healing that was important for some women, particularly eating specific foods such as rice or other permissible or ‘Halal’ foods to meet religious beliefs, as one woman explained:

‘In Indonesia we have to eat rice three times a day. I think a thing like that is important. Because … every time I go there [the hospital], I have [to] bring food, because I don’t like to eat the food [from the hospital] … [I] worry because [we] have to eat Halal food … so … every time we visit someone in hospital, we always bring food’ (P6).

**Subtheme. : Cultural misunderstandings.**

Cultural misunderstandings sometimes occurred when women did not understand why certain things were undertaken in relation to their care, for example mobilising 24 h after a caesarean section:

‘I had a caesarean … I had him around 2 am on a Saturday and then the next day the midwife expected me to walk down the hallway to get my lunch, and I felt like ‘oh my God what?’ Especially in my culture, you have to like, for 40 days you don’t do anything for yourself, people do it for you. And it’s not just that, but in general, I wouldn’t let someone who just had caesarean walk down the hall to get their lunch … ’ (P5).

**Theme 3. : Speaking up about female genital cutting.**

While women were not asked about their FGM/C experiences, nine out of the ten women felt that it was important to speak about it as it impacted their healthcare experience. Their discussions centred around knowledge of what FGM/C meant to them, not knowing they had been cut or the type they had. They spoke about the practice as an unwanted tradition and felt relieved that their daughters were safe in Australia.

**Subtheme. : Religious vs Pharaonic.**

World Health Organization classifies FGM/C into four types; however, most women only spoke of two; type 1 was referred to in three ways ‘just cut a bit’ or ‘the other one’ or done for religious reasons, and type 3 was known as ‘Pharaonic’.

‘So, the kind of circumcision in our country differs, there are two kinds of them, the Pharaoh one when they stitch everything and then the other one, the religious one where they take just a little bit of it. So, I have the second one’ (P2).

Women who discussed the FGM/C types described type 3 as the ‘worst’ that caused ongoing health problems, and type 2 was considered ‘normal’ and less of a problem.

‘… because there are two types of circumcision back there [home], so I got the normal one but the other one is worse’ (P5).

**Subtheme. : Disclosing FGM/C to healthcare professionals.**

Women who had type 2 FGM/C did not think it was necessary to report their FGM/C status to HCPs as they did not believe they had any related health concerns.

‘I think it’s not important for them to know because I’m fine, you know, it didn’t really affect me in any way’ (P5).

One woman reported she did not disclose her FGM/C status to her HCP because ‘they never asked’ (P6) and she did not understand the differences between someone who had been cut and someone who was not, therefore, she did not think it would cause any concerns for childbirth. When asked if she had any concerns about her FGM/C status for the birth of her child she responded:

‘Not really because actually, I don’t know the difference between the person that’s been circumcised or not, and I think, according to my husband maybe the difference only but when you do like sex, that’s the only different’ (P6).

Others did not disclose their FGM/C status because they felt embarrassed to speak about the topic, as one woman explained:

‘You know some people they [do] not tell you, … some people when they [are in] labour and you [HCPs] start checking, you only see (the circumcision) then. And when you try to [ask] them [about it] they are shy, they can’t say anything … If the midwife, ask[s] you ‘what do you have?’ [the woman] can’t say anything because she’s shy’ (P8).

Some women reported that they did not know that they had been cut till they were older, this was a common theme among women who were cut during infancy (before 4 years of age).

‘… that was the thing we learn in the school, and then I asked my dad ‘did you do this procedure to me?’ and he said ‘yeah’ … we just cut a bit’ (P6).

Other women remained unaware of their FGM/C status until they were adults and had their first encounter with women’s health services. One woman recalls the moment her friend found out she had been circumcised:

‘… the doctor was [showing] two pictures and the doctor said point. And she point[ed] this one’, and the doctor [asked] to explain, she said I can’t explain, ‘because my mum do like that’, she said she only saw the pictures, but whatever [type] they done she doesn’t know’ (P8).

**Subtheme. : Living with FGM/C is hard.**

All women regardless of the type of FGM/C they had, agreed that living with FGM/C was difficult, as one woman explained ‘heaps of people there (country of origin), they suffer from this practice’ (P2).
Others described aspects of their lives that have been affected by FGM/C, including intimacy and childbirth.

The experiences of intimacy varied among women, for some it was a traumatic and painful experience.

‘…the problem I faced just on the day of marriage was because the kind of circumcision I had is the Pharaoh one, so it was hard to practice sex at that time. It was difficult to practice sex, I tell them I needed to go to the hospital just to do a cut’ (P1).

For others, intimacy with their husbands was a time of discovery, particularly, when they had no other sexual experiences to compare to and relied on their husbands for information to understand their experience.

‘… when you do the intimate thing with your partner, that’s the time you can feel the problem, according to him. I don’t know’ (P6).

One woman believed that FGM/C affected sexual desire for some women and was one of the reasons some marriages failed.

‘That’s an issue in marriages now. Because most of the women that are circumcised, they don’t have the sexual desires sometimes, sometimes they have them and sometimes they don’t, so [it’s] becoming an issue within some marriages, and cheating …’ (P9).

Women with FGM/C reported childbirth was difficult, especially for women with type 3. FGM/C was linked to labour and birth complications ‘… in general woman during pregnancy and birth they have lots of complications because of that procedure’ (P4), and painful procedures such as episiotomies.

‘… because I had the caesarean, I didn’t have any problems during the delivery of the baby, but I’ve heard stories from other friends, they say that delivering [was] a bad experience, [and] is very hard because they needed to have a cut there [perineum] to make it easier for them to deliver the baby’ (P1).

However, despite all health concerns, some women felt that if FGM/C was not performed, families would be socially isolated, which was considered far worse than being subjected to the procedure.

‘… it was part of the culture, that if you don’t do it, you would become talked about in the community. So, it’s not something I would say I blame my parents or my father or my mum for that, but it was an experience. So, I went through it … even though it’s not a good practice, I’m not here to judge anybody for doing that to me…’ (P9).

Subtheme. : Daughters are safe.

There was a strong view amongst most of the women interviewed that they did not wish for their daughters to be cut. They felt that the centuries old tradition no longer served them and being in Australia where FGM/C is illegal made them feel safe.

‘Thank God that we are here. We feel safe that my girls, they don’t need to go through this practice the same as us’ (P2).

Furthermore, women felt positive about the practice becoming illegal in more countries, meaning that their daughters will no longer have to worry about being forced to have the procedure.

‘… now it’s illegal in Sudan to do circumcision, so the new generation coming to Australia they don’t have this issue, they are not circumcised, and our daughters here they are not which is, it’s something we feel they are in a safe environment’ (P4).

On the same token, women with FGM/C who lived in Australia and were from countries where FGM/C was still legal, felt strongly the practice should be discontinued as they observed ongoing health implications women experience.

‘… circumcision for my kids I don’t like it because it’s so hard. It’s a part of our tradition but when you see the problems that the ladies getting that’s, I don’t want that anymore for my kids’ (P8).

Theme 4. : Working together to improve healthcare experiences.

Women with FGM/C identified several areas that women and HCPs needed to work on to improve healthcare experiences. These included having more time to discuss concerns; access to continuity of care; provision of translated information and education; providing culturally safe, respectful, and non-judgemental care; encouragement to speak up about their health needs and empathy for new migrants.

Subtheme. : Having healthcare choices.

Some women expressed their wish to have more time to speak about health concerns with HCPs and more opportunities for continuity of care. One woman described an experience where she felt a lack of understanding and patience from her midwife as she hurried to discharge her before her baby had been medically cleared.

‘… I felt at the time they [the midwife] didn’t give enough attention and they didn’t have enough patience … my baby was a girl, and I was waiting for the paediatrician to come and see her and check her, but the nurse kept saying ‘no, you need to leave the hospital, we need to discharge you’. But at that time the paediatrician came, and he test the baby and she needed to stay in hospital because of some issues with her breathing’ (P1).

Access to ‘continuity of care’ was a service that some women identified as important, especially during pregnancy and childbirth. Women felt that having to repeat the same information to various health providers was exhausting.

‘… the only problem is I keep changing the doctor, yeah … That’s why the last (pause) the year [of my] … third pregnancy, I think, I do [sic] the shared care with my GP, so I prefer [it], I like it because I’m still [seeing] the same person, so they don’t keep asking me the same question, yeah’ (P6).

Subtheme. : Improving health literacy of women with FGM/C.

Women reported health education was key to gaining confidence to make informed decisions about their health, such as accessing routine screening services like pap smears, which are often avoided as they do not understand the purpose of the test and/or they feel embarrassed about undergoing the procedure:

‘Pap smears. Especially that one, the community doesn’t like that one because they feel shy. Yeah, they [don’t] know anything about pap smears …’ (P8).

Four women stated they would like to have access to relevant health information and education that has been translated into their own language to promote health autonomy and be delivered in various formats, as some women do not read or write in their own languages.

‘… me I don’t know how to read, but some people they know how to read, how to read Somali [but] they don’t know to read English. But if you bring [information in] Somali, they can read and they can understand all the things’ (P8).

Another suggestion was that education sessions need to be delivered face-to-face to be effective and meet the needs of their target audience, as some women find technology difficult ‘… [education is] more effective face-to-face. Some people they don’t even know how to use their mobile [phone]’ (P8).

Conversely, another woman suggested providing a safe space to talk, suggesting group information sessions might not work for all women, as
some do not feel confident to speak up in a large group, out of fear it might get back to other members of the community.

‘… but when you do one-on-one [sessions] sometimes you can be lucky to get more information from women than when you do it in a group because they will be thinking ‘oh this one is sitting there she’s gonna hear my story and it’s gonna be another talk in the community’, so, this [type of] talk … make women to draw back a bit that want to talk, so if you can get one-on-one [sessions] with some of them, some of them will open up to you’ (P9).

One woman proposed in relation to childbirth and the postpartum period to have a wall of stories about various cultural traditions to help educate others.

‘… you can have a wall of stories about how women give birth and afterwards what they do to the lady. I mean it would be interesting, for example, … I know a lot of women struggle for milk to come out, that could be a good idea, [to see] what other women can try too, you know when they read … it could work for them. It will be interesting’ (P5).

**Subtheme. : Caring with empathy for new migrants.**

Women with FGM/C want to be treated with respect and kindness, more specifically they wanted HCPs to understand they felt alone and at times scared in Australia, having left most of their family and support structures overseas.

‘… first of all, to deal with us with respect, to provide support, because we are coming from another country, we have no family support, and we miss that. The husband sometimes he might provide support but most of the time he’s working … I expect to be treated respectfully and [with] kindness. Just need, [someone] to say, ‘oh it’s ok, it’s ok’. It helps a lot. In general, I’m not complaining, because I lived good experiences in the past, but there are things [that] can be done just to be[ing] kind with these women is essential because they are by themselves here’ (P1).

Furthermore, women do not want to be judged about their FGM/C status, they want HCPs to understand that the procedure was done to them, and not something they had a choice in. Women also want HCPs to be aware of their body language and facial expressions when they see FGM/C as this can be an indicator that they are being judged.

‘… sometimes facial expression can tell you that they (HCPs) are already judging … need to be aware that, these things were done to women back then, is not that they wanted to, but they had no choice …’ (P9).

Women felt that HCPs could provide them with the confidence to speak up about their health issues by building trust and rapport, by creating a safe space and speaking in a culturally sensitive manner especially when discussing FGM/C.

‘… maybe at the first initial stage of their [antenatal] assessment … maybe bring [FGM/C] up … they will feel comfortable talking about it before their due date. So that whoever is going to be looking after them, that midwife will already have the knowledge to say, ‘okay she’s that’, and then make a plan and tell her that, yeah, and just give her that reassurance’ (P9).

Lastly, women with FGM/C wanted to be treated with understanding and empathy. For most women, leaving their country of birth was not a choice and they may struggle to adjust to live in the adoptive country.

‘… the other thing we need to understand that all the people when they come to the country they come with new transition and experiences … some people … they miss their home, and their parents, everything, they (HCPs) need to be like kind with them’ (P1).

**4. Discussion**

This study sought to understand factors that affected healthcare experiences and health needs of 10 migrant and refugee women with FGM/C accessing women’s healthcare services in SA. Findings suggest that women’s cultural needs, not their health needs, played a fundamental role in how they experienced healthcare services. Communication, access to continuity of care, cultural empathy, and psychosocial implications of FGM/C, were expressed as the determinants of positive and negative experiences. The issues raised were similar for all women regardless of their country of origin. These findings provide deeper insights into the needs of women with FGM/C living in a country where FGM/C is not a cultural norm and where there are no FGM/C specific support services.

Many women in this study felt they were ‘treated well’, and for most part, with respect by HCPs. Being ‘treated well’ was linked to care that was seen as respectful, supportive, and when information regarding care and treatment was provided to make informed decisions. This is consistent with findings from previous studies that identified that positive healthcare experiences are essential for women with FGM/C to feel safe and supported and to promote trust between women and HCPs [8,9,16,37]. When trust is fostered, women with FGM/C are more likely to connect with healthcare services and engage in routine health screening thus improving the health outcomes of women [7,37]. Women who feel respected and safe are also more likely to feel confident to advocate for their own care [7,37]. This is important when women do not believe they have the knowledge to make informed choices and do not question the advice or treatment they receive, as reported by some women in this study. When women believe that ‘doctor knows best’, they are essentially dismissing the value of their own knowledge and experiences. Previous research found that this value is most common amongst older CALD women and those that feel disempowered to speak up, which is consistent with those identified in this study despite participants being younger [38]. HCPs who are aware of these issues can advocate for women by including them in decisions pertaining to their care, and providing opportunities to discuss questions and concerns, thus facilitating woman-centred care [7,37].

Being heard and understood is necessary for effective communication and the development of trusting relationships that foster autonomy [16]. Not being heard makes women feel frustrated and disappointed leading to disconnections between women and health services [8], as was the case for several women in this study. Previous studies have identified that women from CALD backgrounds are more likely to experience miscommunication and anxiety with HCPs due to language barriers and cultural misunderstandings [8,9]. Miscommunication is further reinforced by time limits applied to consultations, which do not take into consideration language and communication challenges for women from CALD backgrounds. [7] The current study supports these findings, with several women reporting being rushed during appointments and not being heard by HCPs. Additionally, women indicated that having information translated into other languages was helpful, but many did not read or understand English therefore presenting information in other formats was needed (e.g., diagrams and video). Similarly, other studies have recommended the need to have accessible information for women who do not read or write [7-9]. A simple solution may be to present information through pictures, diagrams and videos in translated languages, which have been shown to improve health literacy among CALD communities [39].

Access to accredited interpreting services is an important requirement to ensure women have a voice and can participate in their own care. However, accessing interpreters for less common languages can be problematic as they may not be easily accessible, furthermore, the interpreter may be known to the woman. Possible solutions for these issues may be the inclusion of a community health worker during appointments [40], implementing continuity of care models [8], and including families [7]. Several studies have demonstrated that
community health workers are vital for supporting CALD women and can aid in translation, understanding cultural customs, and provide a bridge between healthcare services and the community [7,24,40–42]. Moreover, community health workers have been shown to be a cost-effective intervention when compared to standard care [43]. This approach together with a continuity of care model, whereby the person has the same known HCP each time they access a specific service, will enable the development of trust and rapport between women and services [16].

Understanding the vital role families play in CALD women’s healthcare decisions was considered important to the provision of holistic care [7]. All women interviewed in this study had strong bonds with their families and relied on them and their community for support. Therefore, it is imperative to ask women their wishes regarding family involvement and facilitate the inclusion of family support in healthcare decisions when women request it.

Every contact a girl or woman with FGM/C has with healthcare services is an opportunity for HCPs to identify her health needs and provide her with the necessary information to make informed choices about treatment and care options [7]. Women with FGM/C are more likely to experience significant adverse health outcomes in pregnancy and childbirth because of their FGM/C status than women who have not had FGM/C [4,44]. However, as the women interviewed recognised, speaking up about FGM/C is difficult particularly when they may not be aware they have had FGM/C or understand the differences between the types, or implications FGM/C has on their care. As such HCPs need to understand the concerns women have regarding disclosing their FGM/C status and discuss care needs, this is particularly important for women accessing maternity and gynaecological services.

Upholding cultural traditions was a significant determinant of the healthcare seeking behaviours of women interviewed in this study. Most women conveyed strong connections to their culture and a need to maintain traditions, especially those pertaining to pregnancy and childbirth and having a female HCP. Cultural traditions help women feel safe and connected to values that are inherent to their identity; when these are not acknowledged by HCPs, women lose those connections and in turn their autonomy [7]. Consequently, women are left feeling scared and disrespected, which places them in a dangerous position whereby they may avoid seeking vital medical support [7,8]. Ways in which healthcare services can support women in a culturally safe manner include; partnering with FGM/C affected women and their communities in the development, design and implementation of cultural education for HCPs [45]; facilitating access to female HCPs whenever women request it or, including husband/ partner or, a female community health worker during consultations and examinations; and implementing individualised healthcare plans to meet the specific health and cultural needs of women [46–48].

5. Strength and limitations

A major strength of this study was the involvement of a cultural advisory group in the development, recruitment, and implementation stages of this research. The cultural advisory group provided the investigators with key insights for maintaining cultural safety and minimising biases. Additionally, the recruitment of women with FGM/C from five African and South Asian countries enabled the investigators to capture a wide range of stories not limited to one continent, supporting the fact that FGM/C is practiced globally. Furthermore, women who did not speak English were able to share their experiences with the support of an interpreter.

Snowball recruitment process meant some women knew each other and therefore lived and interacted together in the community and may have had similar views or experiences and therefore could be seen as a limitation of this study. Additionally, some responses may have not been a true representation knowing that the interviewer was a midwife working in SA despite being informed that the information they provided would remain anonymous.

6. Conclusion

Quality of the healthcare experiences for women with FGM/C accessing maternity, gynaecological and sexual health services in SA is predominantly determined by the ability of services to meet their cultural needs. Women in this study identified several barriers to accessing quality care which may be improved through cultural education and development of services that include the voices of women with FGM/C and their communities. Future research needs to explore the effectiveness of cultural education for healthcare professionals that incorporates the voices of women and engages with the community to enable culturally safe woman-centred care.

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Declaration of Competing Interest

None declared.

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