QUALITATIVE EVIDENCE SYNTHESIS

**Health information interventions for female genital mutilation**

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**Synopsis:** This qualitative evidence synthesis highlights poor communication between women living with FGM and healthcare providers, and signals a need for health education and information interventions.

**Abstract**

Providing information and education to women and girls living with female genital mutilation (FGM) could be an important influence on their healthcare-seeking behavior. Healthcare providers also need adequate knowledge and skills to provide good quality care to this population. Recent WHO guidelines on managing health complications from FGM contain best practice statements for health education and information interventions for women and providers. This qualitative evidence synthesis summarizes the values and preferences of girls and women living with FGM, and healthcare providers, together with other evidence on the context and conditions of these interventions.

The synthesis highlights that healthcare providers lack skills and training to manage women, and women are concerned about the lack of discussion about FGM with providers. There is a need for more training for providers, and further research to understand how health information interventions may be perceived or experienced by women living with FGM in different contexts. **1. Introduction**

Providing information and education to women and girls living with female genital mutilation (FGM) is in line with international human rights, can be empowering, and can be an important influence on the healthcare-seeking behavior that this population exerts. Such interventions, which include information on women’s health as well as the health effects of FGM, can also have positive effects on women, girls, and other community members by reducing the willingness of women to recommend FGM for their own daughters and helping to overcome the shyness among women to discuss the procedure.1 Specific information about interventions used to treat complications of FGM (e.g. deinfibulation) can help women to better understand the procedures and their benefits and harms, and help them to make more informed decisions. In the absence of direct evidence of the effects of such interventions, the newly published WHO guidelines on managing health complications of FGM issued two best practice statements suggesting that: (1) information, education, and communication (IEC) interventions about FGM and women’s health should be provided to women and girls living with any type of FGM; and (2) health education and information on deinfibulation should be provided to girls and women living with type III FGM.1

Different cadres of healthcare workers in both high-prevalence and high-income countries encounter women and girls living with FGM, who may present with a range of health complications associated with being cut. Healthcare providers need adequate knowledge and skills in order to provide good quality and timely care to women and girls. Equally important is providers’ ability and confidence to handle discussions about FGM, and convey information to women in a way that is readily understood, so that they can make informed decisions and feel at ease during health service encounters. Over the last decade countries have started to develop information interventions to improve the knowledge and attitude of healthcare providers, and their ability to manage and care for women and girls with FGM. The WHO guidelines located one systematic review and one quasi-experimental study evaluating the effects of providing information to healthcare providers, but the evidence is of low quality and insufficient to make clear recommendations. However, the guidelines include several best practice statements relating to information interventions, which should encourage countries to continue to invest in pre- and in-service training and capacity strengthening programs as a means of improving the quality of care provided to women and girls living with FGM.1

The best practice statements included in the WHO guidelines are made based on practical judgment, supported by human rights and equity principles, and consideration of available evidence on values and preferences of girls and women living with FGM, and healthcare providers. This commentary summarizes those values and preferences, along with other evidence on the context and conditions that may be required to implement health information and education interventions, derived from a systematic review of the available qualitative research.

**2. Summary of the evidence**

Eight studies were included in the qualitative synthesis (detailed methods described in Stein et al.2 All were conducted in high-income countries: US (n=3), Sweden (n=2), Finland (n=1), Norway (n=1), and multiple settings (n=1). The majority of studies were conducted with providers and were concerned with their experiences and educational needs (n=4),3,4,5, 6 while the others documented women’s needs and encounters with the health system (n=2),7,8 women’s views of patient–provider communication on FGM (n=1),9 and providers’ use of a publication on FGM (n=1).10 We found no studies relating directly to health information interventions for women or providers in high-prevalence countries.

**3. Context and conditions of implementation**

3.1. Providers’ experiences

Evidence from studies included in this review suggests that health workers in high-income settings find caring for women with FGM both stressful and emotional. Midwives, doctors, and nurses in one study in Norway4 described their encounters with circumcised women as “emotionally and ethically” difficult. They explained how they avoided discussing FGM as an expression of “respect” for what they considered a “taboo” and “sensitive” subject, to the extent that very little communication happened between midwives and women. Health workers reported suppressing their feelings and remaining “silent” in order to appear professional and not let their emotions affect their work, thinking it best to “pretend nothing was wrong.”4

Midwives in Sweden6 and health workers in Norway4 expressed anger and strong feelings of aggression and hatred toward the culture, and the patriarchal structure, that they felt was responsible for the practice of FGM. For example, Swedish midwives described the situation as difficult because “you’re so angry. You get so…enraged at the whole situation, at the whole culture…how the hell can they subject women to that…I become furious at men….” These feelings seemed not to be directed toward the woman herself, but towards “tradition, religion, men and more specifically, the husband….” Most of the midwives said they tried to conceal these aggressive feelings. Some felt this was possible to do, although others acknowledged that it was difficult.6 Alongside these feelings midwives expressed deep empathy for women living with FGM, a desire to treat them with “extra care,” and need for more understanding to enable better care.6

Despite the desire to better relate to women living with FGM, providers appear to lack the training and skills to do so. Across several high-income settings, providers described a lack of formal training on management of women living with FGM prenatally and in childbirth, as well as lack of awareness of clinical guidelines. As Swedish midwives explained, “to put it simply there’s a gap in our education...since we have such an amount of immigration from FGM practicing countries, it’s very important for midwifery to learn about it...the more knowledge and information you have, the better it is both for yourself and the patient.”6 Doctors and nurse midwives in the US,5 health workers in Norway,4 and midwives in Sweden 6 all reported never having received any formal training on the management of these women, but had rather learnt “on the job” or from more senior or more experienced colleagues. Providers’ awareness of clinical guidelines also appears to be low. In some high-income settings formal protocols on management of women living with FGM do not exist5 or national guidelines had not yet been published at the time of the study.4 One review including research conducted in high- and low-income countries concludes that it is not clear whether doctors are unaware that guidelines exist, or whether the guidelines were not well circulated by the hospital or health authority in which they worked.3 Across all studies in high-income settings, providers expressed a need for more information on how to relate to these women,4 greater depth in the content of professional training programmes,6 and increased competence to talk about FGM with women.4

3.2. Health system and service context

In relation to the context of care provision for women living with FGM, providers in high-income settings commonly reported difficulties when trying to converse with women.3,4,5,6 There is evidence that language and communication barriers exist, to the extent that providers are “completely reliant” on interpreters.5 However, providers found working through interpreters frustrating and challenging,5, 8 especially if communication was abdicated to male partners, since this was thought to deprive women of “autonomy” and not reflect “her own wishes.”5 For example, as obstetricians and nurse midwives in the US explained, “it may be that the husband or the family member is doing the interpretation…it is impossible to know exactly who is making the decisions…she could be saying ‘no. I don’t want that’ and he is saying ‘we will have it’…and you don’t know what she said…so you just take him at his word.”5

Providers also expressed discomfort and difficulty in communicating with women about FGM. Some explained this in terms of differences in language and sentence structure,5 while others explained they were simply unsure how to approach the subject of FGM with women.6 However, providers seemed to develop ways of dealing with communication problems, for example providers in the US reported that “there are circumstances where a patient will ask questions and somehow open the door for me and then I feel more comfortable, but I don’t really know how to communicate about that effectively…”5 and Swedish midwives explained how they would simply ask women “bluntly” if they were “circumcised” and by doing so it showed women that they were “not afraid.”6

Women expressed similar views on poor communication with providers. It appeared to be a common concern across several settings, which often heightened women’s fear and anxiety when seeking care in formal health services. Women living with FGM giving birth in maternity services in Sweden and the US explained how they were not asked if they had undergone FGM, and providers infrequently acknowledged or discussed FGM in the context of childbirth.7,9 Many women wished their providers had discussed their FGM,9 and women giving birth in Sweden explained that generally women would prefer to be cut open before delivery, without hurry, to ease delivery, but they did not perceive that the caregivers listened to them.7 As a result of poor communication between providers and women, and in many cases complete silence and absence of discussion, women living with FGM experience feelings of insecurity, helplessness and vulnerability,7 fear and anxiety,9 and misunderstanding and uncertainty4 at the time of birth. Alongside these emotional reactions and frustration at the lack of communication, migrant women accessing maternity care in high-income settings experience feelings of shame and inferiority brought about by provider behavior and response to FGM. Women accessing services in Sweden describe being “stared at” and “looked down on” by providers whose attitude made them reluctant to return for prenatal care,7 and in the US women did not want to appear “strange” or “different” because of their FGM.8

**4. Conclusion**

Our synthesis of qualitative research provides insight into the context of healthcare provision for women living with FGM accessing services in high-income settings. It highlights that providers lack skills and training to manage women, and that their encounters with women can be distressing and highly emotional. Even more concerning is that providers appear to lack basic communication skills to allow them to exchange vital information with women. At the same time, women are concerned about the lack of discussion about FGM and the negative reactions of healthcare providers who they expect to take proper care of them, especially during childbirth. While the review found no studies relating to health information interventions for women or providers in high-prevalence settings, our findings on the complex context and conditions of care for women in high-income settings do have implications for the development of such interventions.

The fact that providers lack skills and competence to handle discussions about FGM with women, and women report concern about the lack of communication, signals an unmet need for more information and training for providers. This could be provided through improved opportunities for in-service capacity strengthening, but also by incorporating in-depth information on FGM and its consequences into core curricula for professionals in training. There have been attempts to develop academic curricula in high-income and high-prevalence countries, but this takes time and there are often significant costs associated.

Given the challenges providers face in communicating with women, academic curricula should be balanced with practical skills in conversing with women and their families, including making more effective use of available interpreters. Improving communication between women and providers offers the chance for greater exchange of information and is an important step toward informed decision-making for women, and improved quality of care. As the best practice statements contained in the WHO guidelines begin to inform the development of information interventions for providers, it will be important to conduct rigorous evaluations to ensure interventions are effective in improving provider knowledge, attitude and practice and appropriate in different contexts.1

We did not find any qualitative studies on health information interventions for women or girls living with FGM, either IEC on FGM, or specific health education about surgical procedures to facilitate informed decision-making. We therefore have little understanding of how such interventions, or their outcomes, may be perceived or experienced in different contexts, and these are priority areas for future qualitative research. As the best practice statement contained in the WHO guidelines suggests, the content of such interventions needs to be carefully designed to avoid unintended adverse effects including recreating trauma in women already experiencing FGM-related post-traumatic stress and other anxiety disorders.1

**Contributions**

HS designed the qualitative synthesis, led the data extraction, analysis and interpretation of the data and wrote the manuscript. KS contributed to data extraction, analysis and interpretation of data and commented on drafts of the manuscript.

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**Conflict of interest**

The authors declare that they have no conflict of interest.

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