"FGM is with us Everyday" Women and Girls Speak out about Female Genital Mutilation in the UK

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Abstract—There is inadequate information on the practice of female genital mutilation (FGM) in the UK, and there are often myths and perceptions within communities that influence the effectiveness of prevention programmes. This means it is difficult to address the trends and changes in the practice in the UK.

To this end, FORWARD undertook novel and innovative research using the Participatory Ethnographic and Evaluative Research (PEER) method to explore the views of women from Eritrea, Sudan, Somalia and Ethiopia that live in London and Bristol (two UK cities). Women's views, taken from PEER interviews, reflected reasons for continued practice of FGM: marriageability, the harnessing and control of female sexuality, and upholding traditions from their countries of origin. It was also clear that the main supporters of the practice were believed to be older women within families and communities.

Women described the impact FGM was having on their lives as isolating. And although it was clearly considered a private and personal matter, they developed a real sense of connection with their peers within the research process.

The women were overwhelmingly positive about combating the practice, although they believed it would probably take a while before it ends completely. They also made concrete recommendations on how to improve support services for women affected by FGM: Training for professionals (particularly in healthcare), increased engagement with, and outreach to, communities, culturally appropriate materials and information made available and accessible to communities, and more consequent implementation of legislation.

Finally, the women asked for more empathy and understanding, particularly from health professionals. Rather than presenting FGM as a completely alien and inconceivable practice, it may help for those looking into these women's lives and working with them to understand the social and economic context in which the practice takes place.

Keywords—Female Genital Mutilation, Female Circumcision/Cutting, Participatory Research, PEER method.

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I. INTRODUCTION

IN 2007, FORWARD undertook a prevalence study in the UK which suggests that over 24,000 girls under the age of 15 are potentially at risk of undergoing some form of Female Genital Mutilation (FGM) in England and Wales [1]. In fact, the populations born in practicing countries (primarily African countries [2]) and living in England and Wales exceed 174,000. The study also showed that the prevalence of FGM in the UK is on the rise. This indicates it is a serious issue in the UK that should be taken as much into consideration as have other harmful traditional practices considered denigrating to women, e.g. forced marriage and honor based killings.

Varying theories address the continuing practice of FGM including hypotheses surrounding marriageability and the self-perpetuation of gender specific traditions and myths [3], [4]. There is some anecdotal information on the continuing practice of FGM in the UK and there are often myths and perceptions within communities that strongly influence the effectiveness of prevention programs within communities that need to be defined and addressed. To this purpose, FORWARD undertook novel and innovative research using Participatory Ethnographic and Evaluative Research (PEER) to explore the views of women from FGM practicing communities.

The overall aim of this research was to gain some more insight into the perception of FGM by members of FGM practicing communities living in the UK. It attempts to answer a few important questions:

- 1. What is the continuing impact of FGM on the lives of affected women (sexual, reproductive and mental well-being)?
- 2. How do women affected by FGM perceive and interact with services (especially health services)?
- 3. How do women feel about the practice of FGM, for themselves and younger generations?
- 4. What are the ethnic variations with regards to the practice in different communities across the UK?

The research took place in London and Bristol, with some very useful, insightful and surprising results. This paper will present the results and findings from the study, outlining the women's views as relevant to service development and legislation implementation in the UK.

II. METHODS

A. The PEER Method

Participatory Ethnographic and Evaluative Research (PEER) is as the name implies a participatory, qualitative methodology that received ethical approval from the University of Swansea, Wales Ethics Committee in 2007. It is based on peer-to-peer interviewing (friends interviewing friends) to explore more sensitive issues in depth. The methodology is particularly suited to access hard-to-reach communities and to explore sexual and reproductive health issues [5]. It conveniently circumvents a lot of the barriers faced when researching minority or migrant communities as those targeted by this study, such as language for example. Lay persons from the local community are trained as PEER researchers and 'experts on their community' [5] to interview The methodology therefore friends and acquaintances. exploits the already established trust relationships between PEER researchers and their interviewees.

B. Study Areas and Demographics

FORWARD undertook two PEER studies on adult women over the age of 25 in London and Bristol, both large urban centers in the United Kingdom.

The initial research was based in the Borough of Westminster, Central London. FORWARD's main office is based at the uppermost tip of this borough, therefore the communities of women that FORWARD's work normally supports were reflected the research population: The participants were Sudanese, Somali, Eritrean and Ethiopian.

Approximately 230,000 people are thought to live in Westminster. It is considered an area of high mobility and has a larger than normal proportion of short term residents. In addition, the percentage of the population that is black and minority ethnic (BME) has increased from 21% in 1991 to 27% in 2001 [6].

2001 census data does not include reliable numbers for each of the relevant communities, but the proportion of the BME population that is 'Black or Black British' is 7%, and is likely to include Africans. The same census counted approximately 2,100 asylum seekers in Westminster, of whom significant proportions are African [6].

Bristol is a city of approximately 410,000 people. BME residents make up about 11.2% [7]. The participants in the Bristol research here were Somali and Sudanese women.

The majority of the Somalis, most having fled from the ongoing civil war in Somaliland, had been living in Bristol for over 10years and were more likely to be UK permanent residents. It is estimated that there are currently over 15, 000 Somalis living in Bristol [8].

In contrast to the Somalis, the Sudanese community is smaller and younger and most of the women have come to UK to join their husbands. They are newly arrived, predominantly refugees and less established.

Bristol's demographic make-up made some comparison between these two communities (Somali and Sudanese) possible.

C. Study Design

The London study was coordinated jointly with Options Consultancy Services ltd. who led on training and PEER methodology, with FORWARD providing the research questions and recruiting the women. The Bristol study was carried out by FORWARD only.

10 PEER researchers were recruited in London in comparison to 8 in Bristol. Recruitment was by 'snowball sampling'. The women in Bristol were exclusively Sudanese and Somali, whereas in London some were also Eritrean and Ethiopian.

Interviews were unstructured and informal. The women were asked to interview 2 or 3 friends (in Bristol or London respectively) on 3 main themes: Family Life; FGM; and the Wider Implications of FGM. PEER researchers defined and refined basic prompts for interviewing (bearing in mind the 3 themes) during training so they reflected the culture and language of their communities. They were also equipped with new skills including 'how to develop questions' and interviewing technique.

All interviews were in the third person ("What do people in your community think about....?") to avoid making participants vulnerable to their peers. Answering a general question was much easier and less threatening than a direct question. Within the interviews, women were also encouraged to narrate 'stories of someone they know' without mentioning any names. The resulting information described the daily lives, realities and perceptions of the PEER researchers' social worlds.

Outputs were a combination of notes from interviews (PEER researchers with friends and acquaintances) and transcripts from in-depth debriefings (FORWARD supervisors with PEER researchers). To triangulate results, some of the discussions during training were also transcribed and analyzed.

All the data was analyzed in two crucial steps: 1. Via a one day peer evaluation workshop, where researchers met with FORWARD supervisors and provided their own analysis of the data that they collected using various innovative methods such as role plays; 2. By the FORWARD research team, who filtered out the key issues, and defined the thematic codes and framework for full meta-analysis. The PEER researchers were consulted upon again at this latter stage if the need arose.

With all the cooperative work during training and analysis, the PEER process itself empowered the women by giving them ownership over content and methodology.

III. RESULTS

Within interviews the women talked a significant amount about the contextual issues surrounding family life. It was striking how intricately interwoven the impacts of FGM were with their daily problems and experiences: "Female Genital Mutilation is with us everyday" said one PEER researcher and

most interviews reflect this¹.

A. Perceptions through the Generations

The interplay between FGM and daily life was particularly apparent with regards to intergenerational relationships. A lot of women felt the need to pass on their culture and traditions to the younger generations but felt that there was a strong loss of cultural identity in their children, particularly the older and teenage youths:

"Maybe because my children are still young so [...] I am only really afraid about the little things. [...] But if they grow up and become teenagers my fears [are] that my children won't grow up with the same culture and traditions that we have as Sudanese. [...] So I really want to make sure that I take them to Sudan for holidays so they take some of our beliefs and ideas from our country." (Sudanese woman in Bristol).

There appeared to be a break in perceptions of FGM from one generation to the next. Therefore it was not surprising that almost all women interviewed regarded the older generation as the main architects in the perpetuation of the practice of FGM:

"It is a tradition. [...] we found our mothers did it because their mothers did it [to] them and they think FGM makes their daughters attractive to their men and protects their daughters from having sex before marriage." (Somali woman in Bristol).

B. The Continuing Practice of FGM

With the above statement this woman also succinctly defined the main reasons for the continuing FGM practice across communities that emerged from this research: marriageability, harnessing and controlling female sexuality, and continuing traditions. It was often made clear that all these reasons were primarily arguments given by the older generations to keep the practice going. Strikingly, none of the women mentioned religion as a reason, although it was often stated that the older generation used religion as a pretext for continuing practice.

There was also an interesting caveat in that women often perceived men as desiring circumcised women as 'marriage material' yet mentioned very often that they lived in the fear that their "husbands will leave them or find another woman who responds more to having sex with him". This contradiction indicates that men may not always support the tradition and older women seem to be the main perpetrators:

"I have an auntie who wanted this to be done [...] and she brought us all and they did for us the henna so that in the morning we could be taken to the circumciser [...] my uncle came unexpectedly back home [...] he was so angry that everyone defied him so fate helped us in not being circumcised." (Sudanese woman in Bristo)l.

Very often statements made by the women seemed to imply that the children belonged more to the community than to their parents, although some women said it was ultimately down to the parents to make a decision particularly now they live in the ΠK .

"Usually the person who has a say is the grandmother in addition to the aunts, although the whole community can actually voice their views. But the final decision is for the mother and father" (Woman in London).

C. Family and Daily Life

Most women felt FGM had a significant negative impact on their lives. They explored psychosocial effects in depth. Many experienced various forms of emotional distress, but also anxieties with regards to broken marriages, a disconnection from their children/the younger generation and the wider community, and a constant fear of actual physical pain (during sexual intercourse or otherwise).

"When the time came I felt a lot of pains but I could not speak to stop him or do anything, maybe because I was ashamed or I wanted to reach the end to feel relaxed because I know I have no choice and I felt like an injured bird. The only thing I did was cry and I hated everything in my life." (Somali woman from Bristol).

There were multiple factors related to FGM affecting daily living, sexuality, self-perception and confidence, health seeking behavior and community cohesion. Women felt isolated and alone ("Life in the UK is very lonely") – this was a strong recurring theme, which was repeatedly reflected in their feelings toward FGM, speaking out about FGM and sexuality, and the impacts FGM had on them. "Many women believe that they have to tackle any problems they may have or issues bothering and/or affecting them alone" said one woman from Bristol.

It was often repeated that FGM was "tradition [and] not allowed to be spoken about because it is a shame".

It was interesting to see that many felt feelings of underlying resentment towards family members who had pushed for FGM to be done or were present at their circumcision.

"I hated our tradition and I hated most my grand mum. But I didn't hate my mother because I know she didn't want to harm me but she could not do anything." (Somali woman from Bristol).

Women had an overwhelming sense of 'loss' as if 'something is missing' and they were 'not normal':

"You have the feeling that you have not been allowed to have something you should have by nature. It is something to do with pleasure. You hear about this pleasure, but you have never felt it. You don't know what it is. How would you know?" (Woman in London).

Some of them seemed to have only discovered this feeling of disconnect and 'being different' when they came to the UK, then realizing that FGM was not the norm and may be the root cause of many of their emotional and physical problems previously disregarded as 'normal':

"There is this woman who has Pharaonic type

¹ NB: All quotations in this section are taken from PEER interview notes or transcripts from debriefings with PEER researchers.

circumcision². When she went to the hospital, the trainee doctor who was treating her was very surprised when he saw her. He asked her if she had an accident and what happened to her. She told him she was circumcised and explained everything to him. He started to cry and she ended up feeling sorry for her self. It was the first time she felt she had a problem" (Researcher in London).

This realization was often described as traumatizing in and of itself, and only made the experience with UK health service providers more difficult:

"All of us feel embarrassed; especially when the doctor or the midwife asks us why we do that to ourselves! We do not know how to explain the real reasons to them." (Sudanese woman in Bristol).

D. Interaction with Health Services

Lots of 'stories' were of the first contact with UK health services (predominantly during pregnancy or at delivery), and can overwhelmingly be described as difficult at best.

An example:

"One lady in east London went to a hospital to deliver, there were two doctors and a midwife who had no idea what to do or how to deal with the situation, at the end they decided to do an emergency caesarean section on her, although it was unnecessary and she could have delivered by vaginal delivery." (Woman in London).

The majority of women had no information on specialist services (e.g. African Well Women Clinics³), nor how to get referred to them from generic services:

"I don't know of any of the health services. It is not advertised very well. Many people including myself are made to believe that there is no help available and if there is we are not really aware of it." (Somali Woman in Bristol).

This stood in direct contrast to the perception that "in general, health services in the UK are much more efficient" than in the women's home countries.

Most participants were embarrassed to speak about these issues and had to be prompted to explore FGM and sexuality in more depth.

"At first the women were hesitant to talk about FGM. One said that I was crazy; this is something we do not talk about in Somali culture. Even here, the women don't talk about it to their girls; they feel shy. I had to explain to them about the research and they eventually opened up." (Bristol Researcher from Somalia).

Lack of training and knowledge by health professionals, particularly when they react with insensitivity or shock, only exacerbated this feeling of inadequacy and hesitancy to speak about the issue.

"There is a woman who had some problems. She is not married. When she went to the doctor, he wanted to check her. She told him that she is a virgin and circumcised at the same time so he cannot check her. He did not treat her and told her that it is her responsibility and it is up to her." (Woman in London).

Another woman in London:

"During my pregnancy at Saint Mary's I had informed the midwife of my circumcision. On my due date, that midwife was not there. The new midwife took one look at me, and when she saw my circumcision she began screaming, saying 'Oh My God'. She even pressed the alarm."

None of these 'horror' stories that are obviously 'circulating' within communities would encourage trust in UK reproductive health services for these women (A few 'stories' appeared multiple times and from different women). In addition, although many seemed to be suffering from recurring traumas, depression and anxieties, in general they had neither access to nor had even considered any form psychological or mental support.

E. How will it End?

When asked about their projections for the future of the practice – the women saw it ceasing but only gradually:

"I think it will end, but it might take a long time and its effects would still be there." (Bristol researcher from Somalia).

In fact, they had concrete and insightful suggestions on how to improve awareness within their communities, education for health services, and implementation of legislation and policy. They also had good ideas about the best way forward, to end FGM in the long term.

- There requested more information on FGM itself, health services, legislation, and support: The general consensus was that information on FGM should not be labeled as such; should be available in various languages and in public places (community centers, libraries, doctors' practices, and on the internet) and in varying formats: "We know little about it; we need information about it. It is helpful if there are leaflets or websites to go to." (Sudanese woman from Bristol).
- They suggested community awareness raising; outreach; and campaigns.
- And were willing and eager to cooperate on all these issues with statutory partners via networks and consultations, indicating a lack of prior engagement.
- They were particularly adamant about training and awareness raising amongst professionals, especially for those working in healthcare.
- They called for a review of legislation and improved implementation: "In my point of view to protect girls from FGM we need to develop severe penalties for those who do this criminal act, even if a doctor or a

² Pharaonic or Type III FGM is defined by the WHO and UN agencies (2008) as the narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation) [2].

³ African Well Women Clinics are specialist reproductive health clinics that provide services for women who have suffered through FGM. There are 14 clinics across the UK; 11 of them in London; 1 each in Birmingham, Bristol, and Liverpool.

midwife." said one Sudanese woman in Bristol.

- And they suggested working across the board with communities (including all generations and both sexes) to end the practice of FGM in the long run: "We can only protect children if people have more knowledge and a clear picture that [prevention of FGM] is in the child's best interest. And people have to understand that there is a law and if they break the law they can get sentenced. We have never had someone sentenced here or back home!" (Sudanese woman in Bristol).

F. Information & Legislation

Within the interviews it became clear that the women had little or no information on details regarding the law, specialist services, or their rights as women. As one Somali researcher in Bristol put it:

"We know that in 1985 the UK passed a law against FGM but no one has ever been prosecuted. It goes on underground instead. Not many women speak up against FGM because we are made to believe that it's compulsory and the right thing to do, hence FGM going on for so long. I don't think most of the victims of FGM know of any laws."

Many mentioned that the law could be used to deter older people, particularly the more traditional and older women in the family, from pressing for daughters to be circumcised. But they also believed that if there were a will to do it and the mother of the girl was not assertive, or in a strong enough position to dissent, then there were ways to circumvent the law without severe consequences.

"She [interviewee] said 'How they will know I did that, even if they examine her [the daughter], I can even say that we went to a family in our country and they did it to her without my knowing. Who will they persecute then? Will they persecute my mother or my husband's mother back home?" (Bristol Researcher).

Many saw the UK law and its implementation as 'soft' and demanded for examples to be made. However they were very explicit that one community should not be singled out over another. They also all appealed for more information on the more recent legislation – the FGM Act 2003.

G. Variations – Locations and Communities

The views summarized above were shared across all women especially with regards to the psychological, emotional, sexual and reproductive health impacts, though there were some variances in knowledge and awareness of health services between London and Bristol. Some women in London were aware of specialist services and had had good experiences with health professionals – although many of them simply thought they had been 'lucky', i.e. it depended on who was on shift at the time and which area the woman lived in; whereas in Bristol, none of the women was aware of the specialist clinic in their area.

The demographics in Bristol also meant that the majority of participants were Somali and this meant that their views were particularly well represented. They were also the more established of the communities interviewed there. In Bristol in particular, deviations in overall stance within the two communities (Somali and Sudanese) towards the practice became apparent first during the debriefing process and later again throughout the analyses.

Many of the Sudanese who saw themselves as returning home soon, viewed the practice as compulsory in Sudan for social acceptance. They saw it as disadvantageous 'here but not there'. In comparison, the Somali communities were long-standing, a lot more established and a lot less accepting of the practice of FGM. These women believed the younger generation had no exposure or knowledge of FGM and would not be aware of the implications for older women. They believed the practice still continued 'underground' but stated that they were unwilling to subject their daughters to FGM.

Overall, women felt much less inclined to agree to the practice if they were well integrated in UK society.

Ultimately, the women were exceptionally motivated to continue working on the issue. The researchers in Bristol, in particular, expressed a strong desire to work with statutory partners within their communities as long as they were willing to approach them too.

"Whenever I knock on my friends doors after interviews had finished now, they are like: What again? FGM data? We all enjoyed it at the end of the day!" (Bristol Researcher from Somalia).

IV. CONCLUSION

The amount of daily life material collected in the interviews far surpassed any other material and showed just how much FGM affected the women. It was a constant thread running through their daily lives in a multitude of ways of which women were often not consciously aware. This calls for a lot more awareness raising amongst women and within communities using materials which are culturally sensitive and appropriate to the women's needs. Community engagement and outreach is clearly a priority.

It became very clear during the course of the research that the more empowered a woman felt, the more likely she was to withstand the pressures of older women, family, community and people 'back home' to circumcise her daughters. The research in itself seemed to galvanize and empower the women, and PEER may be a useful tool in future to initiate engagement with and empower women in various cities and communities. There is a clear need to further explore the lessons learnt from the PEER process, as an effective action and awareness raising tool to develop outreach models or women's leadership/championing programs within communities.

Integration and sense of belonging in the UK seemed to strongly correlate with the women distancing themselves from the practice of FGM. With more new migrant communities sprouting up across the UK following the new immigration policies of involuntary 'dispersal' of asylum seekers and refugees on a much wider scale, this is certainly an area to watch. The newly arrived are less likely to feel like they belong, are much more vulnerable to violence, face huge barriers to accessing health services (even more so when accessing specialist services), and often, as asylum seekers or refugees, experience social discrimination and isolation. They are also more likely to be associated with the continued practice of FGM on their children as they are more culturally isolated, less empowered and more likely to want to return to their home countries. It therefore becomes of paramount importance to address the issues surrounding FGM and asylum seekers/refugees if asylum seeking/refugee women contribute to an increase in the prevalence of FGM affected women in the UK; particularly, if the increase in numbers is in places where there are no appropriate services to cater for their healthcare needs. There is an apparent need for additional data on FGM prevalence, specifically amongst asylum seekers and refugees. This information would be relevant to long term specialist and generic reproductive health services' development.

Overall, material that was generated from this PEER research was revealing and thoroughly compelling. There are many new questions the have been asked following the collection of the views and perceptions of these women that would need further investigation:

- The true socio-economic cost to family if a girl child is not circumcised would be invaluable. This encompasses the perceptions of men and their preferences for marriage (as opposed to the perceptions of women)
- But there is also need for an investigation into men's awareness of the issues surrounding FGM, and their perception of its' impacts.
- Another relevant issue in need of further study are the differences in perception of FGM between generations.
 The London pilot presented so many challenges when including younger women that FORWARD was forced to explore the views of younger people separately in a further study at 3 sites across the UK the data are currently being analyzed.
- In addition, the FGM Act 2003, while seen as a convenient argument for women who are aiming to protect their daughters from being circumcised, is often disregarded as insignificant by those who still go ahead to mutilate their daughters. There was a clear call by the women for more information on the details of the FGM 2003 Act and its implementation. In the UK to date, not one prosecution has taken place that has led to a sentence for the practice of FGM on a girl child or woman. It would therefore also be desirable to see a review of policies and procedures in place in the England and Wales implementing the law.

Finally, the women overwhelmingly asked for more empathy and understanding, particularly from health professionals. Rather than presenting FGM as a completely alien and inconceivable practice, it may help for those looking

into these women's lives and working with them to understand the social and economic context in which the practice takes place.

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