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ORIGINAL ARTICLE

Women survivors of female genital mutilation/ cutting: A collaborative process of engaging them as ambassadors of change in Hargeisa, Somaliland

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ABSTRACT

The overall question guiding this research was why after so many years of research and other forms of interventions to eradicate female genital mutilation, it persists. This article is about a special group of women who undergo medical surgery to repair the damage they had endured after genital mutilation/cutting (FGM) in childhood. The process describes how women are encouraged to reflect on their experiences before and after medical surgery and to engage in dialogue on how FGM can be stopped. The study builds on participatory action research aiming to generate knowledge while simultaneously attempting to change the system, or in this case, the attitudes to and reasoning around FGM. However, due to the outbreak of COVID-19, the entire process that should have lasted for at least three years, could not be implemented. This paper therefore covers only the initial process of reaching the affected women, whom we call ambassadors of change, and the organization of the first dialogue workshop. The process started with pre-dialogue mapping that involved visiting women who had received care through an NGO and interviewing them individually or in small groups about their FGM complications and their life after medical surgery. They were also invited to a dialogue workshop with other women and representatives from the government and civil society, to talk about FGM, their pains and how to stop FGM. A total of 34 women participated in the workshop where they discussed their experiences and exchanged views on how to end the practice. The use of participatory action research is discussed and the study indicates the need for using innovative methods to mobilize and engage community members and policy makers to end FGM.

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Background

The Network Against Female Genital Mutilation in Somaliland (NAFIS) started in 2006 focuses on empowering communities through information and awareness about the harm created by FGM. NAFIS is the only non-governmental organization (NGO) in Somaliland that offers counselling and medical services to girls and women suffering from FGM complications, thereby deepening the understanding of the harm FGM causes. This article describes the process of working with some of these women. The assumption was that their experiences, which often had changed their lives dramatically, would empower them to publicly talk about the link between their suffering and the severe consequences of FGM and to share their thoughts about what needs to be done to eradicate FGM.

FGM has no known health benefits [1]. The removal or damage to healthy, normal genital tissue interferes with the natural functioning of the body, with immediate and long-term health consequences. The procedure is painful and traumatic and may cause severe bleeding and infections such as hepatitis. The woman may also develop complications such as dysmenorrhea or stagnation of menstrual blood, recurrent urinary tract infection, dyspareunia, infertility, vulva keloids and dermal cysts that causes pain, especially during menstruation and

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sexual intercourse [2]. Other complications occur during pregnancy and childbirth. Children born to women who have undergone FGM suffer a higher rate of neonatal death than children born to un-circumcised women [2]. There is the added risk of damage to the vagina after birth, leading to formation of fistulas in the bladder and/or the bowels, causing incontinence, a condition that may lead to rejection of women by their families, thus exacerbating psychological stress and traumas [3-4].

Global actions to eradicate female genital mutilation

Eradicating FGM has been in policy discourse globally for many years. Despite the international, national and local actions in policy and research, FGM persists. Data from demographic and health surveys in African countries [5] show that in several countries, the prevalence is around 90% among women of reproductive age. A survey from Somaliland conducted by NAFIS in 2014 found that the prevalence of FGM was 99,8% among women of reproductive age. Of these, 82% had undergone infibulation or what is referred to as the pharaonic type [6]. In 2017 a study by Population Council found there has been a change towards increase in the lighter sunna cut [7]. There is evidence that the law against FGM has had limited impact. Mire describes how the legal instruments in different countries are avoided through having underground clinics such as the one in a slum area in Nairobi, which receives girls from all over the world to undergo FGM. Mire states:

> *The parents travel thousands of miles, paying large sums of money, to ensure that their daughters undergo a procedure….It mostly receives Somali clients from Europe particularly the United Kingdom, Sweden and Norway - and the United States.[8]*

Understanding the reasons for the persistence of FGM has been in focus in studies from different settings. A study in Northern Ghana showed that, in spite of criminalization of FGM, it continues because of social pressure on women and girls to conform to social norms, peer acceptance, fear of stigma and religious reasons [9]. In a study among Somali immigrants in Sweden, FGM was described as just 'a tradition' that has little to do with Islam. At the same time great fear of bringing up an uncircumcised daughter in the liberal sexual morality in Sweden, was expressed [10]. Many other studies [5, 11-14] have created awareness not only of the harm the practice incurs in women's health, but also the reasons why FGM persists. Such reasoning includes cultural norms of ensuring virginity before marriage and fidelity within marriage [9].

The question however is why a practice that inflicts such damage to women's health and rights persists in spite of many studies and interventions to end it. WHO [1] notes that decades of prevention work by local communities, governments, and national and international organizations have contributed to the reduction in prevalence of FGM only in some areas. WHO suggests that this may be due to the preventive approaches used, because where communities have employed a process of collective decision-making, they have been able to abandon the practice, as is clear from the Tostan Project in Senegal [15, 16].

Most studies have so far mostly been based on individual interviews or focus group discussions, with little engagement or feedback to the researched communities or policy makers. The methods used are what Shotter and Gustavsen [17] label as research conducted by outside experts. We aimed in this study to use collaborative or participatory action research (PAR) to generate knowledge while simultaneously empowering affected communities and other stakeholders to critically reflect on the issue. This approach to contribute to the eradication of FGM is well described in an EU supported project known as REPLACE2 [18]. The assumption is that community engagement or encouraging communities to reflect on their reasoning around FGM will empower them to act, in this case starting to question the social norms or conventions supporting FGM.

Conceptual frameworks

This study is based on two conceptual frameworks. The first is social convention theory [15] which focuses on the individual as a member of a community, where fear of breaking norms can be strong, as in the case of FGM. This means that there would be little chance for one family alone to openly abandon FGM. Such a family would be ostracized, stigmatized or even physically harmed by their own community members. The second framework is the theoretical perspective of communicative action and the related opening of communicative spaces, as articulated by action researchers [19, 20, 21]. Communicative action allows participants to consciously and deliberately reach inter-subjective agreement as the basis for mutual understanding about what to do in their particular practical situation, in this case ending FGM. Community engagement, as part of collaborative research, with inbuilt dialogue opportunities, was therefore regarded crucial for changing the social norms supporting FGM.

Research Design

The participatory action research process

We embarked on a PAR process, whose principle is to generate knowledge while simultaneously attempting to change the system or in this case the attitudes and reasoning or norms supporting FGM. This process is an application of what Bradbury and Reason [22] call researching "with" not "on" or "about" the people. The major attribute is the possibility to make people co-researchers and empower them to critically reflect on their insider knowledge, reasoning, experiences and attitudes. In the case of FGM there is also a need for considering the invisibility of the role of men and the patriarchal power that is critical for change. As a bottom-up approach, the focus was on building relationships and relational processes, opening communicative spaces

through which those involved learn and together contribute to social practice [19, 20]. It is a strategy of change, by "doing from within". This brings the researched, and the researchers, into a situation where they must reflect on the complexities of a phenomenon [23].

This collaborative process draws from a growing range of interactive approaches. In this study we used dialogue workshops to help capture the multidimensional and complex life situations. Dialogue workshops are built on the idea that the participants construct meanings out of the dialogue and in telling their stories in workshop meetings [23, 24]. The entire process is organised around a number of activity areas including pre-dialogue activities, which entailed intensive contacts with the women who have had FGM complications, mapping and discussing with the women and other stakeholders.

Pre-dialogue activities are usually followed by at least three dialogue workshops. The first dialogue workshop is organized around four topics including: the vision for the future; the challenges to be met; ideas on how to deal with the challenges identified and finally how to organize for action. At the end of the workshop, task groups are constituted and their activities delineated, as well as how to steer them forward. Thereafter, regular reflection meetings among task groups are organized. Researchers join the task group meetings and reflections. The second workshop is estimated to have more participants, and entails reflecting and exchanging views and experiences of the activities undertaken by different task groups. Task groups then continue with their activities and regular reflection meetings, where researchers participate. The third workshop reflects and evaluates what has been achieved, and how to continue. Post-workshop activities focus on evaluating the process. However, given the problem with COVID-19, this paper presents only the pre-dialogue activities and the first dialogue workshop, as the other activities could not continue.

The research was conducted with the support of the NAFIS network and can be read as an outgrowth of their program activities in Hargeisa, Somaliland [25]. All interviews, as well as the group discussions were conducted after the purpose of the research had been explained to those invited and verbal consent had been obtained as part of the ethical guidelines for research.

Initiating the process: pre-dialogue activities

In the study setting FGM is a practice that is ingrained in the cultural and sometimes religious base, and not everybody is convinced of its harm, especially because the complications are not publicly discussed. Moreover, there is the argument that it is women who do the cutting on other women thus foreshadowing the patriarchal power and the unequal gender relations within which the practice is shaped.

Given these perspectives, we considered it central to start the process by approaching women survivors, who had undergone medical surgery as a result of being exposed to FGM during childhood. They constitute a group that can talk about their suffering as a result of FGM and also about their life after medical surgery. They were thus seen as having the potential to develop into ambassadors of change.

Informing the women and other stakeholders about the dialogue workshop

Fifteen women who had been supported by NAFIS in counselling and medical surgery, were visited at their homes to be informed and invited to the first dialogue workshop. During the visit, they were asked if they were interested to be part of the workshop and whether they knew other women who had the same FGM experiences as themselves, that they in turn could inform and invite to the workshop. They were also asked if they could inform and ask their husbands or other men around them whether they would be willing to participate in a workshop to discuss FGM. Visits were also made to inform and invite representatives of health institutions and other stakeholders about the workshops.

The dialogue workshop

The dialogue workshop took place on 24th March 2019. In total 34 women participated. The participants included twenty survivors who had undergone medical surgery and counselling as part of the activities of NAFIS, their relatives and friends, two reformed circumcisers, two government representatives (Ministry of Education and Science and Ministry of Employment, Social Affairs and Family) and one representative from Somaliland Female Medical Association.

The main objective of the dialogue workshop was to engage the women, using their own experiences of FGM complications, related suffering and to reflect on how to eradicate FGM in the area. The idea was also to open spaces for reaching and engaging other members of the community. This is what may be described as a bottom up approach to facilitate community members to speak out on complications of FGM.

Findings

Given that the dialogue workshop was organized to allow women survivors to tell about the complications and suffering they had endured, it was considered important to engage the Somaliland Female Medical Association, to elaborate on the general health effects of FGM on women and girls. Women survivors were then encouraged to tell about their own experiences and complications. Finally, the two women government representatives were asked to address the group. After the plenary session, four smaller groups were organized to further discuss the vision of ending FGM and to identify expected challenges and thoughts on how to confront the challenges.

The representative of the Somaliland Female Medical Association elaborated on the general health effects of FGM, from the day of the operation throughout the life cycle of girls and women. After this presentation, two

women survivors volunteered to describe their experiences.

The first woman survivor described her suffering after FGM:

"I have undergone FGM resulting in the keloid cyst I have developed".

She continued to explain that she had no idea regarding her problem or what had caused it, but during pregnancy it used to become larger and more painful and had infections.

"During delivery the nurses had suspected it was cancer".

She described how after several visits to hospital she eventually met a midwife who counseled and told her to seek assistance from NAFIS to get an operation for cyst removal. She then added:

I call on all Somali women who are planning to have FGM done on their daughters to think of the survivors' experiences for the future of their girls.

The second woman FGM survivor started her conversation by reflecting back in time saying that:

"FGM is practiced only for culture. During our mothers' time, FGM used to play a crucial role for the girls' marriage. If the girl had undergone FGM, the husband used to pay a hundred camels. But we now understand that it's only for culture not a religious rite.

She then described her own experience of how FGM had affected her health but also how she was helped and how she has helped other survivors to access help:

After undergoing FGM, I developed a keloid cyst. I had no idea why I had it, I was suffering in silence, and after my marriage, it grew larger and I had pain. Financially I couldn't afford to visit a doctor but one day I shared my experience with one of my neighbors. She told me that she had a similar problem but she got assistance from NAFIS and had the cyst removal operation. She referred me to NAFIS, and after counseling there, I was referred to a hospital where I underwent a minor operation. After my successful surgery, I began to advocate for ending FGM starting from my family and neighbors. I have referred a number of survivors who had cysts and have been assisted. FGM has no place in the religion, its only for culture. Let's STOP IT!

After the accounts by the women survivors, government representatives told of their experiences and challenges in their work. The representative from the Ministry of Education and Science described how FGM affects girl's education:

"FGM not only affects the health, it also affects girl's education and their future".

She explained that usually children are sent to school at the age of six when girls have already undergone FGM. By the time a girl reaches class 6 to 8 she usually gets menstruation and experiences pain. She starts to miss classes one week in every month. This means the girl gets low attendance record and consequently low marks. Accordingly, due to her absence, she cannot compete with the boys in her class.

The representative from the Ministry of Employment, Social Affairs and Family, shared the experiences of a friend who had undergone FGM during her childhood in the following way:

The young girl experienced health complications from severe infections. In addition, her mother refused to de-infibulate her when she was a teenager. After years of pain, she got married and had a family for a while, but she could not get pregnant. She visited many hospitals in the country where it was finally noticed that her tubes had gotten closed due to chronic infections. It was suggested that she should travel outside the country, and she travelled to India for an operation. However, even after the operation, she still could not get pregnant normally and some doctors told her the only way she could get pregnant was through a medical procedure.

In her conclusion, the representative said:

FGM can affect girls' life physically, mentally and psychologically. Let's STOP FGM and save our innocent girls.

Reflections in small groups on challenges and possibilities for ending FGM

In the final session of the workshop, the discussion focused on the challenges of ending FGM, and also reflected on what should be done to change. All groups mentioned culture as challenging where grandmothers play an important role in maintaining the practice. Mothers especially from rural areas still believe that FGM protects girls. Many men are still only willing to marry circumcised girls, and they see uncircumcised (often called 'open') girls as women who are prone to have sex with many men.

Stigmatization of uncircumcised girls by circumcised girls and other community members was elaborated. Additionally, the participants meant that survivors might not talk about their experiences of health complications arising from FGM because of uncertainty about their origin. The silence, according to the women, is also dependent on men's lack of awareness and knowledge about the effects of FGM. The absence of FGM law and policy was mentioned as a big challenge. FGM practitioners or circumcisers may also be part of the resistance to change, since the practice is part of their source of income.

In order to facilitate change, the women reflected on the need to involve more women FGM survivors as ambassadors of change at the community level. These women also stressed the need for support to make it possible for them to earn their living and give their time to informing community members of their experiences of FGM. NAFIS was mentioned as an invaluable agent for offering FGM counselling and be referring women for medical treatment. Ignorance among both women and men that much of the complications and pain women endure was connected to FGM, was seen as a great barrier to change. Again, the ambassadors of change supported

by informed husbands, were seen as an important vehicle for change.

Discussion

Reflecting on the process including the dialogue workshop, it can be said that the women participants were immensely active discussing their experiences. They felt the practice should be stopped through continued involvement of more survivors, men, religious leaders, communities and the government. This can be understood as a type of transformative learning which as described by Mezirow [26] involves critical reflection of assumptions that may occur either in group interaction or independently.

In this case we used a dialogue workshop with the special group of women that we refer to as survivors of FGM, to promote open communication on FGM and critical reflection on how to eradicate it. This we see as a start of community based participatory action research (PAR) which according to Hacker [27] is collaborative research approach designed to ensure and establish structures for participation by communities affected by the issue being studied. PAR has the dual commitment to study a system and concurrently collaborate with members of the system for changing the social norms upholding the system. The research process is complex and can take long, as is evident from the REPLACE project that is reported to have taken seven years [18]. However, even with the short engagement we had in this project, it is clear it gave the participating women a chance to critically reflect on their experiences, what is needed to be done to end FGM as well as the challenges involved.

In their reflections the women argued that FGM has to do with a culture where a woman is highly valued in marriage because of FGM. The lack of knowledge that the complications and pain women endure is connected to FGM was underlined in the dialogue while the important role of NAFIS in mobilizing the community through raising awareness of FGM complications was also stressed. At the same time the important role of NAFIS in mobilizing the community through raising awareness of FGM complications was also stressed [24]. They discussed how they were referred to NAFIS or how they too referred others for support in obtaining medical surgery. Their call for expanding the involvement of more survivors in future workshops is in line with the process of community based participatory action research (CBPAR) [27]. Indeed, mobilizing other women and encouraging them to participate in a second workshop was one of the tasks they would have been assigned for, if it was not for the COVID-19 pandemic. This idea of reaching out to a wider network of women survivors is supported by Shell-Duncan and colleagues [15] underscoring that interventions to eliminate FGM should target women's social networks, but also involve men. Since CBPAR is an emergent design, continued dialogue workshops and task group activities would in due course provide ideas of how to reach and engage the men and religious leaders in the research process.

Conclusion

In conclusion, engaging a group of FGM survivors, that have been supported with counselling and surgery can offer a unique opportunity to mobilize community members and policy makers to reflect on ways to end FGM. These are women, who have suffered from FGM and deeply understand its harm for themselves and their families. Moreover, although our process was cut short by the COVID-19 pandemic, the limited engagement of women in only one dialogue workshop seem to indicate the potential for community mobilization through participatory action research.

Summary in Somali

CINWAAN

Haweenka ka badbaaday gudniika hablaha (Female Genital Mutilation/Cutting): Diyaarinta hab iskaashi oo iyaga lagu hawlgelinayo iney-yihiin danjirayaal isbeddel-keen-ah oo laga hirgeliyey Hargeisa, Somaliland

DULMAR KOOBAN

Su'aasha guud ee hagaysay cilmi-baadhistan waxay ahayd: Waa maxay sababta keentay in Gudniinka Habluhu uu wali sii jiro, iyadoo sannado badan laga sameeyay cilmi-baadhis iyo waxqabadyo kale si loo cidhibtiro gudniinka Hablaha (Female Genital Mutilation/Cutting). Maqaalkani Wuxu ku saabsan yahay koox haween ah oo Dalladda la Dagaalanka Gudniinka Hablaha ee NAFIS ay ka caawisay inay helaan daaweyn qalliin ah, kaas oo wax lagaga qabanayo dhibaatadii kasoo gaadhay gudniinka wakhtigii carruurnimadooda, kuwaas oo ka soo qabygalay aqoon isweydaarsi lagaga hadlayay gudniinka hablaha.

Ujeeddada maqaalkan ayaa ah in la qeexo habka loo maray sida loogu abuuray kooxdan haweenka ah kulammo u suurtogeliyey inay dib u milicsadaan wax-yaabihi ay la kulmeen ka hor iyo kaddib markii loo sameeyey qalliinka caafimaad, iyo sida ay uga qayb-qaadan- lahaayeen sidii loo joojin lahaa gudniinka hablaha.

Ujeeddadayada ugu horreysay waxay ahayd in la isticmaalo Habka "cilmi-baadhista ka-qaybqaadashada ficilka ah", kaas oo mabda' ahaan looga golleeyahay in la abuuro aqoon, iyadoo isla markaas laysku dayayo in la beddelo nidaamka, ama, xaaladan oo kale, hab -dhaqanka lagu fuliyo iyo sababaynta la xiriirta gudniinka hablaha.

Si kastaba ha ahaatee, geedi-socokii loogu talo-galay in ugu yaraan laba sannadood lagu fuliyo ma suurtoobin, xanuunka Korona aawadii. Sidaa darteed, cilmi-baadhistani waxay kaliya sharraxaysaa hannaankii ugu horeeyay ee lagu gaadhay haweenka ay dhibaatada gudniinka habluhu saameysey, kuwaas oo aan ugu yeedhno Danjirayaasha Isbeddelka, soona abaabulay aqoon iswedydaarsigi iyo wada-hadalkii ugu horeeyay.

Habkani wuxuu ku bilaabmay waxa loogu yeedhay Khariidaynta Wada-hadal-kahor, kaas oo ku lug lahaa soo booqashada haweenka daryeelka caafimaad ka

helay Dallada NAFIS, sii looga waraysto si shakhsi ah ama koox ahaan, dhibaatooyinka ka dhasha gudniinka Hablaha iyo sida ay noloshoodu noqotay qalliinka caafimaad ka dib.

Sidoo kale waxaa la waydiiyay inay diyaar u yihiin inay ka qabygalaan aqoon isweydaarsi ama wada-hadal lala yeelanayo haweenka iyo daneeyayaasha kale, sidii ay ugala-hadli-lahayeen dhibaatooyinka uu leeyahay gudniinka Habluhu iyo sidii loo joojiin laha. Daneeyayaasha kale waxay u badnaayeen hay'adaha dawladda iyo Ururada bulshada rayidka ah. 34 haween ah ayaa ka qayb galay aqoon isweydaarsiga.

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Author contributions

BMA, SAE, AMW participated actively in the research process from the start and all authors have contributed in the writing of the manuscript.

Disclosure statement

No potential conflict of interest was reported by the authors.

Ethics and consent

This research is part of NAFIS activities which are authorized and can be understood as an outgrowth from NAFIS program of work. All interviews individually or in groups were held after the purpose of the research had been explained and verbal consent was obtained as part of following ethical guidelines for research.

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Paper context

The research was organised around the question of why after so many years of research and other interventions to eradicate FGM, with rates as high as 98-99%, it still exists in the region. Our question then was, can a move from studies that only focus on measuring prevalence, attitudes and intended behavior with little involvement or feedback to communities be made? Can research based on community engagement and participatory methodologies make a difference?

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