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'Don't Judge Me': Narratives of living with FGM

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INTRODUCTION AND BACKGROUND

Female Genital Mutilation (FGM) is a significant yet largely hidden phenomenon affecting the lives of an estimated 125 million girls and women worldwide (United Nations Children's Fund (UNICEF) 2013). The World Health Organisation (WHO) (2016, p13) has defined FGM as "all procedures that involve partial or total removal of the external genitalia, or other injury to the female genital organs for non-medical reasons."

Until relatively recently FGM has been perceived predominantly as an issue for sub-Saharan areas (Mulongo, Andrews and Hollins, 2014) and arguably as such has received comparatively less attention in Western society. However, with changes in migration and globalisation, and the subsequent impact on population demographics, FGM has become increasingly visible as an issue for the United Kingdom (UK) and elsewhere (Abdulcadir, Rodriguez and Say, 2015). For example, it has been estimated that there are over 137,000 women and girls living in the UK who have experienced FGM (MacFarlane and Dorkenroo 2015).

It is now well documented that FGM can result in a range of significant physical and psychological health issues. Physical health problems are both immediate and longer term which includes septicaemia, haemorrhage, pain, urinary infections, antenatal and child birth and sexual health issues (Moxey and Jones 2016). Several studies have identified depression, anxiety and post-traumatic stress disorder as major psychological effects of FGM (Whitehorn, Ayonrinde and Maingay, 2002, Norman, Hemmings and Hussain 2009, Behrendt and Moritz 2005, Reisel and Creighton 2015). The experience of emotional suffering has been attributed to pain, in particular through sexual intercourse and child birth (Norman et al. 2009, El-Defrawl, Lotfy and Dandash, et al. 2016). The extent of psychological symptoms also appears to be context specific, for example Mulongo et al (2013) found that in FGM practicing countries there were many positive attitudes towards FGM including pride and social acceptance. However according to Vloeberghs, Van der Kwaak, Knipscheer, et al. (2012) migration to western countries is likely to impact on women's perceptions of FGM. The realisation of living with FGM appears heighted when women become familiar with Western culture where FGM is not seen as a social norm. Vloeberghs et al.

(2014) found that migrant women who had undergone FGM began to view the consequences of FGM through a different lens. Living in a western culture where FGM is not accepted appears to cause women to question the practice with anger described as a common emotion, often directed at the perpetrators (Norman et al. 2009, Whitehorn et al. 2002). Women also describe feeling shame at being 'different'. It has also been suggested that the impact of these emotions is also exacerbated by the women's' experiences of health care services. Vloebergs et al (2014) for example, reported how women experience looks of disgust and horror from healthcare professionals which added to their feeling of low self-worth.

While the last decade has seen a rise in the awareness of FGM within healthcare provision contexts, this has been largely associated with particular fields of practice for example, midwifery and gynaecology. However, there has been very little exploration of the impact of FGM on the psychological health and wellbeing of women living with FGM (Mulongo, et al. 2014). Correspondingly, while there are a number of available education and training resources for professionals, these again tend to focus on particular interventions or are concerned with raising awareness or information sharing (Johansen, Dop and Laverack, et al. 2013).

As such, to date there remains a paucity of dedicated resources which explore women's experience of living with FGM and the wider impact on health and wellbeing. In addition very few education providers have developed the requisite resources or have systematically implemented teaching and learning among professional students or continuing professional development groups on the particular issues that may arise for women who have undergone FGM. This represents a significant gap in current knowledge and understanding and one which this study sought to address.

AIM

The overall aim of the study was to develop and facilitate a participant led arts based workshop with women who were survivors of FGM in order to explore their experiences and the impact of FGM on their health and wellbeing. In so doing the personal narratives, artefacts and materials created during the workshop would be utilised to develop an open access e-learning resource for use by a range of health care professionals. It was anticipated that the

resources could be used to inform and support health and social care professionals and other agencies in terms of effectively meeting the needs of women who are living with FGM. An e-learning resource was the preferred outcome because of the opportunities that this medium offers to present the women's' experiences directly through audio-recording, direct verbatim quotes and art. Minimal influence from the researcher around the data collection and analysis process serves to present the women's' story free from the potential bias of the researcher. Hearing and listening to stories 'first hand' also facilitates engagement and interactivity (Blake, 2010). E-learning resources have practical advantages in that they are flexible and accessible to a wide range of audiences on an international platform (Wharrad and Windle, 2010).

STUDY DESIGN

The study utilised an arts based research approach which included the sharing of personal stories, the creation of pottery models (artefacts) and the sharing of artefacts for example traditional jewellery. This approach was chosen as the overarching method as arts based research methods, in this case narratives and the production of artefacts, are now well established within the wider qualitative research arena as a meaningful way in which the voices of participants take precedence over those of the researcher. Moreover, it is suggested that arts based research methods are grounded in 'aesthetic knowing' which in turn is linked to the potential to promote reflexivity and empathy and a deeper understanding of the particular situation of others (Leavy, 2015, author, in press). Importantly, within the current context and from the perspective of those involved "stories can be useful devices for individuals to come to terms with their vulnerability, make sense of their lives and construct their versions of reality and identity through social discourse" (Holloway and Freshwater, 2007, p704).

PARTICIPANTS

Women who were living with FGM were invited to take part in the workshop through a local FGM specialist support organisation in one region of the United Kingdom (UK). We established contact with the specialist agency early in the project and due to the sensitive nature of the topic, invitation to take part in the workshop and recruitment was undertaken by the specialists within the

organisation. In total six women agreed to take part in the project and this in part reflects the hidden nature and reluctance to speak about FGM. The age range of the women was 25 – 51 years and their countries of origin were Kenya, Nigeria and Ethiopia.

ETHICAL CONSIDERATIONS

Prior to undertaking the study the requisite ethical and organisational approvals were sought and granted (Ref: L15092015SoHS). Due to the sensitive nature of the topic participants were recruited through a local FGM specialist support organisation and during and after the workshop specialist organisation members were available to provide ongoing support and advice if needed. The project team were also cognisant of the possible impact of the topic and so the team also ensured that there was adequate time assigned at the end of the workshop for dedicated debriefing for team members. The recruitment of the women participants through the specialist organisation and their support before, during and after the workshop was also a priority in terms of ensuring ongoing support for the wellbeing of the women participants.

METHODS

Theoretical framework

The project adopted a feminist theoretical framework and the lens through which we as researchers approached the topic and the consequent data collection and presentation of findings. In so doing we attempt, through utilising a participant led arts based approach where the voices of the women, arguably in contrast to many traditional research findings, are privileged over those of the researcher, to "account for how our research participants are discursively constituted subjects while also giving voice to their perspectives and experiences" (Leavy, 2015, p62).

Data collection and findings from the workshop

The composition of the workshop essentially encompassed two main strands i) the creation of a persona and ii) sharing artefacts. These are described in detail below with supplementary images included as appropriate. With the participants

permission we audio-recorded the 'sharing artefacts' discussion and captured anonymous photographs of some of the artefacts used/created in this part of the workshop. With the participants' permission the discussion and presentation of the artefacts were audio-recorded and subsequently transcribed verbatim. Still photographs (without disclosing facial identify) were taken of the artefacts and these have been presented in the paper alongside the appropriate narratives.

Findings

As previously described we have not attempted to present the findings of the workshop from the perspectives of the researchers but have rather enabled the findings to speak for themselves (author, in press). The rationale for this approach has been echoed elsewhere by Mauthner and Dorset (1998) who state "[…] data analysis stage can be viewed as a deeply disempowering one […] far removed from our respondents we make choices and decisions […] how to interpret their words […]" (p138).

The creation of a persona

At the beginning of the workshop, and following introductions, the project team used a persona approach as an introductory group exercise. This approach has been used previously and is described in detail elsewhere (author, under review). In the present study this approach entailed a member of the project team (author) lying down on a large sheet of paper with an invitation for a member of the group to draw around the body. When the project member stood up we were left with the outline shape. We explained that this was the outline of a survivor of FGM. We asked the women in the group to name the women in order to disassociate themselves from her. They named her Janet. We then discussed Janet's experiences of health care services, her support needs and what health care professionals need to know in order to support Janet effectively. The women then noted their thoughts in pen marker on the shape. Table 1 below lists the comments from the group. Following this exercise we reflected on the comments and we discussed in detail the psychological impact of FGM for the women in the group. We also discussed how the reactions of health care professionals, which had often been negative, had impacted on their decisions to seek further support and care.

INSERT TABLE 1

Sharing artefacts

Women were invited to bring along personal artefacts to the workshop and/or to use some of the arts materials that we had taken to the workshop in order to create an artefact that they could use to talk a little about themselves and their experiences of FGM.

Pestle and mortar

All the women in the workshop described how FGM impacted on their sexuality and how they felt a loss in that they were denied the opportunity to experience positive sexual relations with their partner. For the women in the group sexual relationships were associated with fear and pain. During the workshop one woman made a clay mortar and pestle to symbolise a man and a woman having sexual intercourse. The shape of the pestle represented the man's penis which 'pounded' into the woman. The 'pounding' action signified the pain and trauma associated with sexual intercourse:

So I kind of related it (clay model) to say this is like a man in a woman who feels something terrible has happened to her and then you are pounding the same channel that has being damaged or harmed and oh my god that's so much pain in there so and that's the story that came to mind and that's horrible, imagine if you are pounding and especially if you add circumcision and older age were you can remember the memory so you can always feel that when though you are having sex with your partner, those memories just come and yeah… (Participant 1)

Sometimes I don't even like to have relationship with other man and sometimes I think wow, will he even accept me anymore because of the feeling, the sense, they don't realise they are taking your feeling [after FGM]…it is like losing part of your body (Participant 2)

INSERT IMAGE OF PESTLE AND MORTAR

Cooking pots

The women in the workshop described how FGM was perceived as a time of celebration within the family and wider community. The event [FGM] was celebrated with traditional cooking, music and presents for the girl who has undergone FGM. Many of the pottery artefacts that the women created were examples of cooking utensils used to prepare and present food to mark the occasion:

*[I remember] they dressed up the lady in a certain way then they paint her the colour of fruits and she wasn't circumcised until she was pregnant so she was circumcised while she was pregnant so this pot, they had to do a party for her, cooking, the pestle for pounding the yam, so this was made [looks at the clay artefact] like a pot for cooking the soup…(*Participant 1)

This is a coffee pot and this is a frying pan where you can fry plantain, bean cake, so it is more for celebration even for the FGM that we are talking about as well is negative, some people are celebrating it and then it is having an effect on you… (Participant 6)

INSERT IMAGE OF COOKING POTS

The knife, the mat and the bracelet

The women in the group described that how, as children, they were unaware of the reality of FGM (in comparison to how) they are now and as children were encouraged to be excited about the event. They described rushing home from school as this was their day that they would become a woman. One woman told her story through producing a pottery model of a knife, mat and a bracelet. The images of the knife and blade contrast sharply with the delicate beads which make up the structure of the bracelet. She tells her story in the third person:

She was so happy and so excited and this is the day and this is the knife, this shows a story of what happened to her about FGM, this is the knife and this is the blade and the little girl is like 'what is happening' to the parents and they said don't worry the women had the blade and the knife they said you are going

to become a woman today and the parents said don't cry, congratulations. This is her lying down when the procedure was about to be carried out and after the procedure the parents said don't worry we are proud of you, this is your gift a bracelet and a dress, we are very, very proud of you. This is the mat where they carry out the FGM and they take the blade and this is the knife and this is the little girl, this is the present (bracelet) they give it to her after FGM (Participant 2)

INSERT IMAGE OF KNIFE

Don't judge me

The women in the workshop described experiences of undergoing FGM as a 'brutal' procedure resulting in short and longer term physical and psychological 'loss'. The physicality and imposition of cutting contrasted with women acknowledging their inner strength and the importance of their voice as an important vehicle for change in the way that FGM is viewed. The women discussed how they wanted to be acknowledged as individuals and not as victims. They wanted to be treated with respect. One of the women in the group had written a poem about this during the workshop which she read aloud to the group:

I was a happy little girl, one morning mama said, time to become a woman.

That chilly dark morning, I will never forget it. I closed my eyes and Cut, Cut, Cut.

Then I stood in a pool of my own blood. I was gone, a part of me was gone, my voice was gone.

No, no, no, my voice has not gone. It's here with me.

I have it, just listen to me, listen to my voice don't judge me, stand with me, respect me.

My voice is the voice of others (Participant 5)

The same woman had also brought a traditional necklace to the workshop and she explained why:

The necklace is beautiful and complete. It is made from one continuous thread. If you cut the thread then the necklace will fall to pieces. This is FGM.

INSERT PICTURE OF NECKLACE

DISCUSSION

The present study sought to explore the experiences of six women who were living with FGM. This was set within the particular context of the impact that FGM had exerted on their lives, their health and wellbeing as these facets are inextricably interlinked. It was anticipated that the findings from the study could be utilised to develop e-learning resources for use by a range of health and allied professions and organisations. This was in recognition that many of the available resources to date focus on 'procedural descriptions' (Mulongo, et al. 2014) and while useful, do not fully explore or situate the impact of FGM within the wider context of women's lives. Moreover, many of the studies and resources that are available to date have focused on physical health issues and as such the enduring psychological impact and the wider cultural contexts remains largely hidden. For example as highlighted by women in the present study the sense of 'loss' and 'incompleteness' which while significant, may be difficult to articulate to professionals in health care encounters. This was clearly evident in *pestle and mortar* where one participant describes how she has 'lost part of herself' as a result of undergoing FGM. In *Pestle and mortar* the impact of FGM on longer term sexual intimacy and relationships was also in evidence. Important though this is, in a recent analysis of research gaps in FGM, the authors highlight that, to their knowledge, while studies have highlighted the psychological impact for women (Norman, et al. 2009), there are a paucity of studies to date which have considered issues of body image or partner relationships. In *Persona* it was also clear that FGM can exert a lasting effect on women's ability to seek medical interventions, for example participant's feelings that they were being 'judged'. Similarly, women in the study also spoke of the reactions that they had

experienced from health care professionals when they sought medical attention whereby staff were visibly shocked when they had examined a woman who had undergone FGM. As such, the women in the study discussed how they were reluctant to access important routine medical examinations including cervical screening services. The potential for 'marginalisation' of women through the lack of awareness has been raised elsewhere and further highlights the need for professionals to receive the requisite support to meet the needs of women who present in a variety of health care settings (Moxey and Jones, 2016). Finally, in the present study in *Cooking pots* and *The knife, the mat and the bracelet* it was clear that FGM was bound within the wider societal and cultural contexts of personal identity. As identified elsewhere, the inclusion of these wider facets when considering the particular situation of women is crucial for health care professionals as 'FGM is a subject that requires specific cultural expertise to facilitate communication, counselling, care and prevention' (Balfour, et al. 2016, p5). Jacoby and Smith (2013), in a study concerned with testing an educational intervention, and which included a cultural broker (a women from a similar culture who had experienced FGM) further echo the centrality of cultural understanding in fostering care that is delivered in a 'compassionate and non-judgemental manner' (p455).

STRENGTHS AND LIMITATIONS

The aim of the study was to facilitate a participant led arts based workshop with women who were survivors of FGM in order to explore their experiences and the impact of FGM on their health and wellbeing. In so doing it was anticipated that the personal artefacts and narratives that were captured during the workshop could be used to develop an open access e-learning resource that could be accessible to a range of professionals and agencies. As previously identified we have not attempted to interpret the narratives that were shared during the workshops but have rather let the women and their stories speak for themselves. This approach, in terms of first person narrative arguably offers a different perspective in terms of ownership of narrative and is a strength of our study. We acknowledge that this was a small scale study and as such there are limitations in terms of transferability of the findings.

However, this does not detract from the powerful narratives and insights that the women have brought in terms the impact of living with FGM.

RECOMMENDATIONS AND CONCLUSIONS

The workshop itself was a powerful mechanism through which we as women shared our stories of everyday life as well as exploring the women participant's experiences of and living with FGM. Reflecting on our role in the study, it is evident that as health care professionals we need to listen to the narratives of those who are living with FGM and to focus on a more holistic approach to care and support beyond simply addressing the immediate, often physical, presentation. While there is much work taking place to eradicate FGM, there is also a clear need to support those who are living with FGM. This is set within the context of the longer term health consequences and the enduring impact of FGM on the lives and wellbeing of women. There is a real need for further research to examine how professional education and training can be developed effectively and implemented within curricula and training in order to ensure that women can be effectively supported by those who responsible for care provision.

The artefacts that were created during the present study have formed the basis for the development of an e-learning resource for health care professionals. The resource utilises a reflective model to learning and includes narratives of survivors and FGM specialists alongside the presentation of factual information. Those who utilise the resources will also be able to undertake short interactive exercises in order to test current knowledge and draw attention to any stereotypical assumptions that they may hold with regard to FGM. The resources are a co-production between researchers and survivors of FGM. The overall focus and content reflects identified deficits in current knowledge and service provision as experienced by women survivors of FGM. It is anticipated that the e-learning resources that arise from this study will provide one such way in which this deficit can begin to be addressed.

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Table 1

"Please do not judge me"
"I need privacy and dignity"
"Effective support and prenatal care"
"The culture of silence makes it hard for us to speak about what has happened"
"Be aware of the physical pain, infections, sexual relationship problems"
"I need a knowledgeable, empathic and approachable professional"
"I need to be able to make informed choices about my health"
"Please encourage me to ask questions and use language that I can understand"
"Understand the emotional pain"

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