



Report from the Sheila Kitzinger seminar

“FGM: where have we got to? And what comes next?”

27 February 2016 - Green Templeton College Oxford

**THE SHEILA KITZINGER
PROGRAMME AT
GREEN TEMPLETON COLLEGE**



**FGM - where have we got to ?
and what comes next ?**

We are extremely grateful to the Sheila Kitzinger Programme for enabling us to develop a half day meeting in Oxford on the subject of female genital mutilation (FGM).

The meeting was entitled “FGM: where have we got to? and what comes next?” and was held on 27.2.2016 at Green Templeton College, Oxford.

Our aim was to gather together experts across disciplines, including advocacy groups and survivors, working in and around FGM. We wished to create an opportunity to meet together and consider recent developments, actions and innovations in the field and to share learning and ideas about what is (or is not) helpful in improving treatment and protection of women and girls. We wanted to create a collaborative event, which gave all members of the meeting an opportunity to reflect on and share their ideas about future opportunities, priorities and the challenges for those working to support women and families who may be affected by FGM, and to develop from this an understanding of the meeting delegates ideas about priorities for future work and research in FGM.

We invited a wide range of participants, including (amongst others) members of community groups, including the Oxford Rose community, BK Luwo, and the Midaye community association. We invited people working in clinical services (including obstetrics and gynaecology, midwifery, health visitors, paediatrics and safeguarding, primary care, psychiatry and sexual health), multi-agency team workers (including police, social services and community outreach workers), legal and ethics experts, members of charitable organisations who are leading the way in developing understanding of FGM and in providing services and support for women, families and communities (including FORWARD, Afruca, Oxford Against Cutting, Shifting Sands, 28 Too Many), academics and researchers working in FGM

(from disciplines including creative writing, public health, anthropology, the Refugee Studies Centre Oxford and three recipients of Mary Seacole awards working on FGM related projects

We were also privileged to be able to invite to perform and then speak with us all the dance and performance group DIASPORAN HANDS; who are “a group of Sierra Leoneans living in the United Kingdom has thought it fit to come together to form an organization geared towards educating and empowering women and girls in Sierra Leone. Diasporan Hands was set up in April 2012 as a way to give voice to the voiceless through awareness raising, advocacy, and direct support to enable the less privileged to access services.”

We gathered together 55 delegates (the meeting was fully booked and fully attended), with representation from across all the groups of invitees, other than legal and police (who had to pull out at the last minute)

We chose not to record the talks or the open floor discussion, to allow a free and uninhibited participatory meeting.

Prior to the meeting we were fortunate to be sent various papers of interest including a personal view from invitees who were unable to attend. This gave us the idea to set up a portal for sharing learning and writing about FGM. To this end, we have established a shared Dropbox folder, in which meeting delegates are invited to share, add and utilise any documents that have been made available here. The agenda for the meeting is detailed below.

“FGM: where have we got to ? and what comes next ?” 27.2.2016

9.30-11 session 1 “ Where have we got to ?” chaired by L Locock and S Dixon

Naana Otoo-Oyortey from FORWARD “ Responding to FGM in the UK : an overview of the journey”

Sarah Malik from Afruca, “The work done as an emotional well being coordinator“

Brenda Kelly a Consultant Obstetrician and lead clinician for the Oxford Rose clinic “Multi-agency working in Oxfordshire – now and the challenges ahead “

Susan Bewley, Professor of Women’s Health, King’s College London spoke on “The importance of confidentiality”

Kate Agha and the Oxford Against Cutting team spoke on “Research projects and community engagement in Oxfordshire”

Emma Plugge from the centre for tropical medicine and global health Oxford talked about the development of a “Participatory action research project in Oxford”

Sharon Dixon (Oxford), Lisa Hinton (Oxford) and Sarah Penny (Brunel University) spoke on collaborating and “Developing a patient and public involvement (PPI) project in FGM”

11.30-12.30 Session 2 “what comes next “ Introduced by Brenda Kelly and chaired by Helen Salisbury

Open floor and group discussions about future directions of travel, including priorities and challenges, opportunities and ideas

12.30-1.00 Dance performance and meeting with DIASPORAN HANDS

1.00-2.20 Lunch and networking

The meeting was characterised by marked energy and passion. The morning talks were all excellent, varied, and passionately delivered.

Naana Otoo-Oyortey from FORWARD shared her experience and reflections upon the progress that has been made in the UK, and also the changes and challenges for on-going work.



Sarah Malik from Afruca spoke about her work in Manchester developing a resource and service to provide emotional and well-being support to women and families affected by FGM, under the auspices of the charity Afruca.



Brenda Kelly, who has founded the Rose Clinic in Oxford,(a dedicated service for women who have experienced FGM, which offers medical support including deinfibulation, assessment and advice, maternity advice, psychosexual advice and psychological support) reflected on the progress that has been made in Oxford to develop holistic services and resources, including a robust multi-agency working model, and considered the challenges of how to reach those women who find it difficult to access services. She encouraged us to reflect on how we can enhance services and reach out to communities and women who find it harder to access services or to speak out.



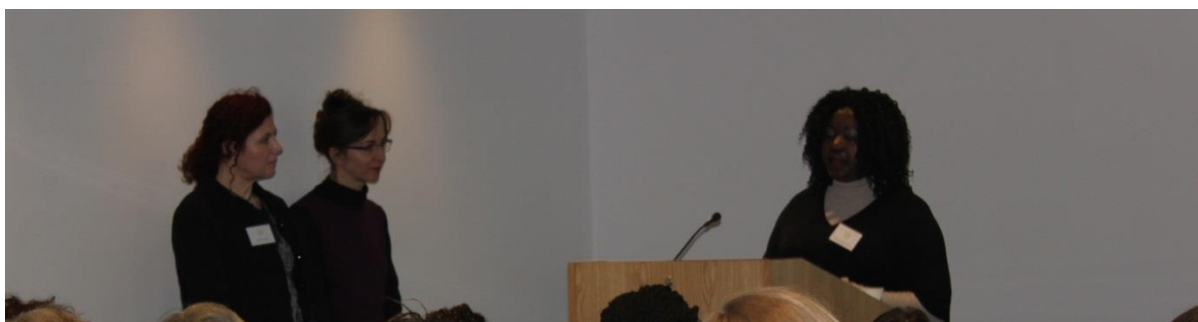
Susan Bewley spoke with great passion about the need for confidentiality and trust as central necessities in any kind of medical work, noting the vital importance of this for enabling professionals to support and care for vulnerable or frightened individuals. The potential impact of new legislation upon this was considered.



The Oxford against Cutting team spoke about three of their projects in Oxford. Firstly, Kate Agha described and showed some of the outputs of their work in local schools which is both raising awareness and also empowering young people to speak out against FGM, to make changes, and seek support.



Secondly, Kate Clayton-Hathaway explained that Oxford Against Cutting have been funded by Healthwatch to explore service provision and the needs of women affected by FGM in Oxfordshire. And finally Kaddy M'Tourabe explained about the establishment of an Oxford community of survivors called the Rose Community who have been able to run a series of social and educational events (including an event for men, an event considering the meaning of Honour). She explained what this community and these events have meant for her as a survivor of FGM.



Emma Plugge introduced a participatory action research project being run in Oxford, using community researchers to work within their communities to explore understandings of FGM and to educate and facilitate change.

Finally, Lisa Hinton and Sharon Dixon spoke about the project they have been involved in (funded by a Green Templeton College small grant), co-designing research into FGM. This is a patient and public involvement project, which has involved holding focus groups with stakeholder groups including survivors, advocates, health professionals and teachers. As part of this project we have collaborated with Sarah Penny, a creative writing researcher from Brunel University, who has worked with diasporan communities using dramatherapy techniques to facilitate storytelling and discussion, which have created podcasts of community stories for the communities to hold (the Seeds for change project). We held a collaborative workshop with a small group of Somali women in London, as an innovative and experimental PPI event with the support of the Midaye community centre. We were asking what peoples priority areas would be for research work into FGM. We shared the following word map capturing what we have heard during our focus group work.

After a well-deserved coffee break, we re-convened for the second session of the morning.

The session was chaired by Dr Brenda Kelly and Dr Helen Salisbury.

People were divided into small groups of approximately 6-10 and asked to spend 15 minutes discussing what future priorities, opportunities or challenges might be in the field of FGM research.



We then came back for a whole group discussion, though with people remaining seated in their small groups. We had three empty posters at the front of the room entitled:

1. Challenges and opportunities
2. Services and needs
3. Questions to ask

As each group shared their priorities, Helen and Brenda facilitated a discussion involving the whole meeting, and Lisa and Sharon placed the post it notes on one of these three posters.



These posters remained available throughout the remainder of the meeting and reflected the key points raised by those at the meeting.

These have been collated and the outputs comprise a summary of the themes and questions that were raised for discussion by the delegates at this meeting. These are detailed below, (drawn from the post it notes, and our notes of the discussion). The questions raised and discussion summary are also available in the meeting Dropbox folder. We aim that the final outputs will be jointly constructed by all those who were at the meeting, and we have circulated these documents to all invitees, asking for comments, additions, clarifications and corrections. These have been now received and incorporated.

DISCUSSION NOTES from the Sheila Kitzinger seminar on 27.2.2016: “FGM: where next?”

1. Questions relating to service design and support needs

Understanding mental health needs & service needs: The importance of ensuring that the mental health, emotional and psychological needs of women affected by FGM are acknowledged and met was discussed. Alongside this there is a need to understand what services women who have experienced FGM should have available to them. This includes consideration of what would be provided within those services (for example emotional and psychological support and also practical support including deinfibulation if needed), and also practical consideration of factors such as where clinics should be based and how they can be accessed. There is a need to work with communities to understand how to develop services that would help enable them to come forwards and seek support. This would require understanding what women and communities would need from a service in order to make it useful and acceptable to them, so that they feel able to access services. Consideration of factors such as confidentiality, privacy, location (for example based in hospital, community health settings, or other community locations), access to interpreters and community health advocates are important and should be considered.

Clitoral reconstruction: Within the discussion about service provision, there was consideration of whether clitoral reconstruction should be offered in the UK. There would need to be an understanding of the role and place for this procedure including consideration of what the evidence is for the effectiveness and also the potential risks of this procedure. The discussion included whether and how such a service should be funded, and who it could be available to. It was raised that there is some uncertainty around the place for this procedure, and some concerns that it might legitimise or lend acceptability to the initial practice of FGM if there is a perception that it could be “reversed”, and the need for understanding that reconstruction is not the same as reversal. That said, it will be important to understand how effective it may be, including understanding which women may derive benefit from it.

The new legislation: In discussing how to make services acceptable and accessible to women and communities, the potential impact of the new legislation in the UK was raised. Questions were asked about whether criminalising FGM will dissuade women from accessing services. It is not known whether the legislation will act effectively as a deterrent, or whether it may drive the practice underground, and make FGM harder to talk about, in both community and professional interactions. It is also possible that the type of FGM practiced may change in response to these laws. It was noted that the laws on FGM also impact on the practice of other procedures not usually considered to be FGM, such as cosmetic surgery and genital piercing. There are difficult ethical and practical considerations about how these practices are (or are not) aligned with FGM in the UK. It is not known how this will be perceived, or what the impact will be. Other countries have experience of legislating around FGM (e.g. Australia) and we could consider what the UK can learn from experiences in these other countries. The example of compulsory examination in France was raised, and a discussion followed. It was stated that there had been a fall in FGM in response to this practice, and that as it was universal it was not discriminatory. In response concerns were raised that it was not compulsory as if you could have private care you could opt out of it, and also that the fall in FGM was not proven to have been attributable to this change, and that considering an association is not proof of a causal link.

How much do we know? A notable challenge in planning services is that it is not known how much FGM is currently being performed in the UK. Neither the type of FGM, nor who, where, and when it may be being carried out in the UK are clearly known. It is speculated that FGM does occur in the UK, and indeed there has been speculation that women travel from other countries (e.g. France) to have FGM performed here, but this has never been proven definitively. The lack of successful prosecutions was noted to be a potential challenge to the effectiveness of the legal deterrents. It was noted that if FGM is being performed in the UK, or indeed if girls are travelling to have FGM abroad and returning to the UK, there have been no proven cases of this, and so it is not definitively known. It is also not clear what type of FGM is now being practiced, and it is possible that there is a shift towards less immediately recognisable or identifiable forms of FGM, such as a move away from type 3. It would be valuable to gain information and a greater understanding of these questions. There are significant barriers to collecting the data (including the criminal legislation against FGM). It is not clear that current data collection methods will enable this understanding.

FGM beyond healthcare settings? There has been a focus on identifying FGM and providing services and support to women who have experienced FGM in health settings. It is clear that FGM can have health consequences, including both physical and psychological health needs, and so in many ways it seems reasonable that medical services can provide appropriate frameworks to respond to these needs, as they are potentially identified within this setting. However, it was noted that many communities do not perceive FGM to be a health issue, and so questioned whether health was the right setting for FGM services. Schools and community groups have a role to play in identifying FGM, including both families and individuals affected by FGM, or who are potentially at risk of FGM. It was asked what these groups need in terms of resources and support, and what roles they can play in service development.

Importance of communities: Central to the consideration of service design was the need for communities to be at the centre of all aspects of service design and provision. This would include ownership of services, service development, solutions and training. The importance of allowing communities to have a voice in how services for them will be shaped, and especially to have a voice in training and educating the professionals who will deliver the services about what is important and what is needed was felt to be of critical importance. It was discussed that in many areas there will be a number of different diasporan communities and this provides both the challenge and opportunity for shared working and for learning from each other. The challenge of providing services that meet the needs of many differing communities is significant, but one that it would be important to embrace, and this can only be done through promoting engagement and involvement and shared learning.

2. The challenges and opportunities for future work in FGM

Trust: In order to discuss FGM, to create services, or develop understanding or research questions, that it would be necessary to establish trust in professionals and institutions. Confidentiality was seen as a vital component needed for the development of this trust. Therefore, when considering what potential barriers there may be for further work in this area, we need to understand what is needed to create trusting relationships between communities and professionals or authorities, and where these might be difficult or challenging. There is a documented pre-existing lack of trust, compounded by cultural taboos around discussing FGM, and apprehension around the rules of consultation and confidentiality in health, including fearfulness of the use of interpreters. Fearfulness of institutions such as social care and health visitors were described.

How will legislation impact on trust? There was discussion about the unknown effect that the UK legislative and policy changes will have upon the relationships between communities and professionals working in FGM, and this was identified as a significant potential barrier to future work that warranted further exploration. Specifically, the concern that criminalising FGM may deter women from accessing services or disclosing their FGM (or indeed may prevent professionals from asking about FGM) was raised. The process of community involvement and representation in the legislation development was discussed. Questions were asked about what the community involvement had comprised and whether there was a possibility of on-going consultation or feedback. It was discussed that community involvement was cited in the Department of Health reports, but that perhaps more understanding was needed about what communities understand about mandatory reporting and how they feel about it. It was described that some communities and community members feel “attacked” and that mandatory reporting is perceived as discriminatory and stigmatising. While the discussion largely focussed on the potential effects of the legislation on communities, there was also reflection on the possible impact on individuals, who may feel that being reported to the police compounds their own sense of trauma and shame.

Similar concerns were explored during the discussion about the FGM enhanced dataset, and also the risk identification system. Concerns were raised about access to data, data sharing, and the potential onward use of data. The database held on the spine of children under 18 perceived to be at risk because of a family history or community involvement with FGM without concern caused significant disquiet during discussion. It was also raised that there has been less information and coverage of these interventions, in comparison with mandatory reporting, but that it was important to develop and share awareness of these. Again the question of whether these will complicate or reduce trust in professionals and the government was raised as a significant potential future barrier to care and service and research development that warrants further exploration. This understanding would also include what data would be feasible, acceptable to collect, and useful.

Understanding FGM in the context of women’s lives: A challenge in future work is balancing these issues whilst still ensuring the effectiveness of on-going work to safeguard women, girl’s and their communities. It was raised that FGM is just one part of a woman’s life story. Often she and her family have other complex difficulties and needs, and her care needs to encompass all of these needs, and that while FGM is important and may act as a focus for her access to care, it is occurring in the much wider context of individuals lives. Care will need to be responsive to all the issues facing women, their families and communities.

What is “community voice”? Throughout these discussions there was reflection upon what a “community voice” means. It was noted that activists are often taken to represent the views of whole communities and are able to be listened to and often influence decisions and policy, but it is uncertain whether their personal views can be assumed to be representative of whole communities. The view was expressed that this is often not the case, and raises the challenge of how we can hear or understand the widest possible range of community views, and gather unheard voices, so that these can be fed into policy development. This includes unheard voices within communities where there are prominent activists and also communities that are less often heard from. This would also enable sharing of experiences and views between communities.

Dangers of medicalising FGM: The focus on the harms of FGM was identified as a potential barrier to future work because by medicalising FGM, the wider social and cultural context and meanings may be lost. This would be too narrow as an approach and was felt to be a concern. The focus on harms in educating professionals also meant that the important concept that FGM is practiced within loving families as an act of love may not be understood, and community members felt that if professionals do not understand this, then it is a potential barrier for them feeling able to discuss FGM and be understood and not judged.

Broader than Africa: A further challenge for developing future work and research in FGM was in shifting the focus away from the narrative focus on Africa and type 3 FGM. This bias towards talking of Africa and type 3 FGM may mean we are not exploring issues such as FGM in non-African cultures and communities and other types of FGM. The need to understand the role of the medical profession in some settings where FGM has been made “safer” by being moved into medical settings and the effective medical sanctioning of FGM in some areas of the world is a significant challenge and another less well explored area which was identified as needing to be understood more, including developing an understanding of FGM practice in the Far East.

3. Questions asked for consideration

The importance of moving towards a greater global understanding of FGM in order to be able to develop global solutions and strategies for FGM requires us to know more about how we can work to gain this understanding. It would be necessary to develop research that tells us what methods can most effectively and acceptably be used to gain knowledge. This is likely to vary between countries and community groups. It was noted that there is a lack of understanding of evolving practices of FGM throughout the world, including that we do not know how much FGM is occurring within the UK. Developing further knowledge about what is occurring nationally will support the effectiveness of interventions developed within the UK but it would also be hoped that by increasing research knowledge that this could inform the development of interventions and services globally. There is a need to seek opportunities to talk to people who may not wish to be outspoken or to talk about FGM and those who may not align their cultural practices with FGM, and there is a need to develop an understanding of how that might be achieved. There is a need for both greater knowledge about attitudes and beliefs worldwide about practices of FGM, and also greater knowledge of what research techniques or strategies can be used to develop this understanding. This includes negotiating the potential barriers that make FGM hard to talk about, including intrinsic cultural taboos, and also perhaps the context of the fearfulness created by new UK legislation. There is a need to hear from as many members of as many communities as possible and to ensure that the voices of many are heard in addition to the voices of the few advocates and campaigners who feel more enabled to tell their stories. The advocates’ and initial campaigners’ contributions have been truly enormous and immeasurably valuable. They have led the way to allow FGM to become a subject that is spoken about and they have enabled change for both individuals and organisations, but it was noted that that is not the same as saying that their voices are representative of all the voices in their communities, or that they speak for other community groups.

FGM is traditionally a women’s subject, and one which men would not normally participate in discussion about. It was acknowledged that men are also affected by FGM, through their families, their wives and their daughters. It was noted that psychosexual difficulties arising as a consequence of FGM affect men also, and that in that sense they are also victims of this harmful cultural practice. It is only recently that men have begun to be involved in discussing and campaigning against FGM, and this is a welcome change. It is important to learn more about how men can be involved in making changes and be part of the process of eradicating FGM. It would also be valuable to understand more about their beliefs and needs in the context of FGM.

FGM is traditionally performed by cutters, who have financial and status dependent upon their role. If change is to occur, it is important to consider and learn about the role and needs of the cutters.

Finally, there was an overarching desire for solutions, resources and change to develop from communities upwards to professionals and authorities. The learning and resources need to be created and constructed in such a way that they can be effectively shared between women, communities, and professionals. This would allow understanding of

what will create effective change, services and training. We need to understand how we can develop and support this process happening, and what techniques, resources and research would be needed to allow this.

We need to learn this from the communities themselves.

Following this discussion section, we were privileged to have a performance by **Diasporan Hands**, who used dance, storytelling, and music to tell an individuals' story of the experience of FGM. Afterwards, they described for us their working campaigning in the UK and in Sierra Leone, including describing some of the resistance to change and anger about anti-FGM campaigning they had experienced. They engaged in a discussion with the audience taking questions from the delegates, and engaging in conversation. If new research questions were raised during this discussion, LH and SD added them to post it notes, to continue the process of capturing issues raised by the meeting. This discussion raised important questions including considering the experience and needs of the cutters themselves, and how that fits into the journey towards eradicating FGM. They spoke about the trauma of hearing other girls being cut. They spoke about the needs of men affected by FGM within their communities and how they can be empowered to take a role in supporting the eradication of this practice. The group described the challenges they faced when returning to their home country to take their message that FGM is harmful and should be eradicated. They spoke about the challenges of changing cultural practices through generations.



We adjourned for a wonderful lunch at GTC and the conversations and network creations continued in full flow. We agreed to generate a list of shared contacts and email addresses from delegates who gave their consent for this, and this is a resource which has been created as part of this meeting.

Outputs of the seminar and ongoing work

The meeting supported the development of new connections and relationships, for example the Midaye community association members were interested in the Oxford Rose Community, and were able to meet with members of Oxford Against Cutting.

The meeting itself generated a wealth of discussion points and questions to support the development of research proposals as a source of patient and public involvement priorities to inform these.

All those who attended the meeting were given the opportunity to join a post seminar email community to facilitate on going contacts, and we have curated this email group. We shared the drop box folder link and we invited all those who were interested to send in documents of interest to be shared with all the seminar delegates. We are pleased that this in itself is a useful collection of documents and research.

We did not formally collect feedback of the meeting, but were very pleased to receive emails from delegates expressing that it had been valuable for them, both as a discussion, and as a way of fostering on going work, as illustrated by the these quotes below.

“We would like to thank you for inviting us to the FGM event. We really enjoyed the discussion. We are glad to meet you all and hear about the fantastic work you deliver at Oxford. We will share with you the progress of our work and the community consultations we are planning to hold in London”

“Many thanks indeed for today, excellent day.”

“Thanks for the detailed feedback of the session. I only just got the chance to read it today. This is fantastic work, so rich and meaningful.”

As an output of the meeting, we circulated the outputs of the meeting (in the format of the documents contained in appendix 1 and appendix 2) to all of the meeting delegates, and invited them to comment and add any amendments, with the aim of creating a shared record of this event for all who attended to reflect on and use as they wish to.

A comment received was that some may consider clitoral reconstruction a form of FGM in its own right. There have been no other corrections or amendments received.

Since the meeting, members of the Health Experiences Research Group (LH and SD) in partnership with Dr Emma Plugge (from the Oxford University’s Centre for Tropical Medicine and Global Health) have submitted a research fund application to the NIHR research for Patient Benefit funding stream. The basis of this research application was the questions raised during this workshop and the preceding patient and public involvement events supported by Green templeton College Oxford. We collaborated with FORWARD, Afruca, Dr Brenda Kelly, The Midaye Organisation, Oxford Against Cutting, and with Arianne Shahvisi (an ethicist from Brighton University, a connection made via the meeting) as co-applicants for this grant application. These were all connections that were established and developed during this workshop event.

In addition, since the meeting SD has been awarded an NIHR In practice fellowship application (supervised by S Ziebland) to continue to develop this work. Specifically this proposed project looks to gain further understanding of the impact of the recently introduced UK legislation, an area identified as a clear priority by this meeting.

LH and SD have supported Sarah Penny in a collaborative paper submitted for publication describing our innovative dramatherapy workshop.

LH and SD have been invited to speak at a meeting being held in Oxford celebrating Nigerian artists and FGM. We will be speaking about the seminar outputs and our work in FGM.

SD has been invited to participate in a FGM workshop at Brighton University.

*Through the Eyes
of Nigerian
Artists
Confronting FGM*

6th – 16th June, Lady Margaret Hall,
Jerwood Room, University of Oxford
Weekdays 12:00 to 6:00 p.m.

Vernissage 6th June 6 p.m. with

Godfrey Williams-Okorodus, artist and curator; Hibo Wardere, author and educator; Holger Postulat and Elisabeth Wilson, the Global Alliance against FGM (Geneva); Maggie O'Kane, award-winning head of the Guardian Global Campaign to End FGM; Naomi Rosen, Humboldt Fellow and Kaddy Touray (Oxford against Cutting)

Finissage 16th June 6 p.m. with

Comfort Momoh MBE, FGM specialist midwife; Hilary Burrage, author; Nolan Victory, Equalities, Diversity & Human Rights Manager, London North West Healthcare NHS; Dr Barbara Harrell-Bond, OBE Rights in Exile Legal Aid; Dr Sharon Dixon, Donnington Medical Partnership in Oxford and Fatou Ceesay

Curator: Dr Tobe Levin von Gleichen.
Historical exhibition curated by Joy Keshi Walker in Lagos and FORWARD-Germany.

Sponsor: Dr Maria Jaschok, Director, International Gender Studies Centre, Lady Margaret Hall, University of Oxford

With support from Oxford without Cutting and 28 Too Many.



For further information email tobe.vongleichen@lmh.ox.ac.uk
Sculpture „Infibulation Stone“ by Alloyisius Osagie

APPENDIX 1:

Discussion notes from the Sheila Kitzinger seminar on 27.2.2016

From section 2 , “FGM: where next?”

Questions relating to service design and support needs

The importance of ensuring that the mental health, emotional and psychological needs of women affected by FGM are acknowledged and met was discussed. Alongside this there is a need to understand what services women who have experienced FGM should have available to them. This includes consideration of what would be provided within those services (for example emotional and psychological support and also practical support including deinfibulation if needed), and also practical consideration of factors such as where clinics should be based and how they can be accessed. There is a need to work with communities to understand how to develop services that would help enable them to come forwards and seek support. This would require understanding what women and communities would need from a service in order to make it useful and acceptable to them, so that they feel able to access services. Consideration of factors such as confidentiality, privacy, location (for example based in hospital, community health settings, or other community locations), access to interpreters and community health advocates are important and should be considered.

Within the discussion about service provision, there was consideration of whether clitoral reconstruction should be offered in the UK. There would need to be an understanding of the role and place for this procedure including consideration of what the evidence is for the effectiveness and also the potential risks of this procedure. The discussion included whether and how such a service should be funded, and who it could be available to. It was raised that there is some uncertainty around the place for this procedure, and some concerns that it might legitimise or lend acceptability to the initial practice of FGM if there is a perception that it could be “reversed”, and the need for understanding that reconstruction is not the same as reversal. That said, it will be important to understand how effective it may be, including understanding which women may derive benefit from it.

In discussing how to make services acceptable and accessible to women and communities, the potential impact of the new legislation in the UK was raised. Questions were asked about whether criminalising FGM will dissuade women from accessing services. It is not known whether the legislation will act effectively as a deterrent, or whether it may drive the practice underground, and make FGM harder to talk about, in both community and professional interactions. It is also possible that the type of FGM practiced may change in response to these laws. It was noted that the laws on FGM also impact on the practice of other procedures not usually considered to be FGM such as cosmetic surgery and genital piercing. There are difficult ethical and practical considerations about how these practices are (or are not) aligned with FGM in the UK. It is not known how this will be perceived, or what the impact will be. Other countries have experience of legislating around FGM (eg Australia) and we could consider what the UK can learn from experiences in these other countries. The example of compulsory examination in France was raised, and a discussion followed. It was stated that there had been a fall in FGM in response to this practice, and that as it was universal it was not discriminatory. In response concerns were raised that it was not compulsory as if you could have private care you could opt out of it, and also that the fall in FGM was not proven to have been attributable to this change, and that considering an association is not proof of a causal link.

A notable challenge in planning services is that it is not known how much FGM is currently being performed in the UK. Neither the type of FGM, nor who, where, and when it may be being carried out in the UK are clearly known. It is speculated that FGM does occur in the UK, and indeed there has been speculation that women travel from other countries EG France to have FGM performed here, but this has never been proven definitively. The lack of successful prosecutions was noted to be a potential challenge to the effectiveness of the legal deterrents. It was noted that if FGM is being performed in the UK, or indeed if girls are travelling to have FGM abroad and returning to the UK, there

have been no proven cases of this, and so it is not definitively known. It is also not clear what type of FGM is now being practiced, and it is possible that there is a shift towards less immediately recognisable or identifiable forms of FGM, such as a move away from type 3. It would be valuable to gain information and a greater understanding of these questions. There are significant barriers to collecting the data (including the criminal legislation against FGM). It is not clear that current data collection methods will enable this understanding.

There has been a focus on identifying FGM and providing services and support to women who have experienced FGM in health settings. It is clear that FGM can have health consequences, including both physical and psychological health needs, and so in many ways it seems reasonable that medical services can provide appropriate frameworks to respond to these needs, as they are potentially identified within this setting. However it was noted that many communities do not perceive FGM to be a health issue, and so questioned whether health was the right setting for FGM services. Schools and community groups have a role to play in identifying FGM, including both families and individuals affected by FGM, or who are potentially at risk of FGM. It was asked what these groups need in terms of resources and support, and what roles they can play in service development.

Central to the consideration of service design was the need for communities to be at the centre of all aspects of service design and provision. This would include ownership of services, service development, solutions and training. The importance of allowing communities to have a voice in how services for them will be shaped, and especially to have a voice in training and educating the professionals who will deliver the services about what is important and what is needed was felt to be of critical importance. It was discussed that in many areas there will be a number of different diasporan communities and this provides both the challenge and opportunity for shared working and for learning from each other. The challenge of providing services that meet the needs of many differing communities is significant, but one that it would be important to embrace, and this can only be done through promoting engagement and involvement and shared learning.

Discussion around the potential challenges and opportunities for future work in FGM

It was discussed that in order to discuss FGM, to create services, or develop understanding or research questions, that it would be necessary to establish trust in professionals and institutions. Confidentiality was seen as a vital component needed for the development of this trust. Therefore when considering what potential barriers there may be for further work in this area, we need to understand what is needed to create trusting relationships between communities and professionals or authorities, and where these might be difficult or challenging. There is a documented pre-existing lack of trust, compounded by cultural taboos around discussing FGM, and apprehension around the rules of consultation and confidentiality in health, including fearfulness of the use of interpreters. Fearfulness of institutions such as social care and health visitors were described.

There was discussion about the unknown effect that the UK legislative and policy changes will have upon the relationships between communities and professionals working in FGM, and this was identified as a significant potential barrier to future work that warranted further exploration. Specifically the concern that criminalising FGM may deter women from accessing services or disclosing their FGM (or indeed may prevent professionals from asking about FGM) was raised. The process of community involvement and representation in the legislation development was discussed. Questions were asked about what the community involvement had comprised and whether there was a possibility of on-going consultation or feedback. It was discussed that community involvement was cited in the department of health reports, but that perhaps more understanding was needed about what communities understand about mandatory reporting and how they feel about it. It was described that some communities and community members feel “attacked” and that mandatory reporting is perceived as discriminatory and stigmatising. While the discussion largely focussed on the potential effects of the legislation on communities, there was also reflection on the possible impact on individuals, who may feel that being reported to the police compounds their own sense of trauma and shame.

Similar concerns were explored during the discussion about the FGM enhanced dataset, and also the risk identification system. Concerns were raised about access to data, data sharing, and the potential onward use of data. The database held on the spine of children under 18 perceived to be at risk because of a family history or community involvement with FGM without concern caused significant disquiet during discussion. It was also raised that there has been less information and coverage of these interventions, in comparison with mandatory reporting, but that it was important to develop and share awareness of these. Again the question of whether these will complicate or reduce trust in professionals and the government was raised as a significant potential future barrier to care and service and research development that warrants further exploration. This understanding would also include what data would be feasible, acceptable to collect, and useful.

A challenge in future work is balancing these issues whilst still ensuring the effectiveness of on-going work to safeguard women, girl's and their communities. It was raised that FGM is just one part of a woman's life story. Often she and her family have other complex difficulties and needs, and her care needs to encompass all of these needs, and that while FGM is important and may act as a focus for her access to care, it is occurring in the much wider context of individuals lives. Care will need to be responsive to all the issues facing women, their families and communities.

Throughout these discussions there was reflection upon what a "community voice" means. It was noted that activists are often taken to represent the views of whole communities and are able to be listened to and often influence decisions and policy, but it is uncertain whether their personal views can be assumed to be representative of whole communities. The view was expressed that this is often not the case, and raises the challenge of how we can hear or understand the widest possible range of community views, and gather unheard voices, so that these can be fed into policy development. This includes unheard voices within communities where there are prominent activists and also communities that are less often heard from. This would also enable sharing of experiences and views between communities.

The focus on the harms of FGM was identified as a potential barrier to future work because by medicalising FGM, the wider social and cultural context and meanings may be lost. This would be too narrow as an approach and was felt to be a concern. The focus on harms in educating professionals also meant that the important concept that FGM is practiced within loving families as an act of love may not be understood, and community members felt that if professionals do not understand this, then it is a potential barrier for them feeling able to discuss FGM and be understood and not judged.

A further challenge for developing future work and research in FGM was in shifting the focus away from the narrative focus on Africa and type 3 FGM. This bias towards talking of Africa and type 3 FGM may mean we are not exploring issues such as FGM in non-African cultures and communities and other types of FGM. The need to understand the role of the medical profession in some settings where FGM has been made "safer" by being moved into medical settings and the effective medical sanctioning of FGM in some areas of the world is a significant challenge and another less well explored area which was identified as needing to be understood more, including developing an understanding of FGM practice in the Far East.

Questions asked for consideration

The importance of moving towards a greater global understanding of FGM in order to be able to develop global solutions and strategies for FGM requires us to know more about how we can work to gain this understanding. It would be necessary to develop research that tells us what methods can most effectively and acceptably be used to gain knowledge. This is likely to vary between countries and community groups. It was noted that there is a lack of understanding of evolving practices of FGM throughout the world, including that we do not know how much FGM is occurring within the UK. Developing further knowledge about what is occurring nationally will support the effectiveness of interventions developed within the UK but it would also be hoped that be increasing research

knowledge that this could inform the development of interventions and services globally. There is a need to gain opportunities to talk to people who may not wish to be outspoken or to talk about FGM and those who may not align their cultural practices with FGM, and there is a need to develop an understanding of how that might be achieved. There is a need for both greater knowledge about attitudes and beliefs worldwide about practices of FGM, and also greater knowledge of what research techniques or strategies can be used to develop this understanding. This includes negotiating the potential barriers that make FGM hard to talk about, including intrinsic cultural taboos, and also perhaps the context of the fearfulness created by new UK legislation. There is a need to hear from as many members of as many communities as possible and to ensure that the voices of many are heard in addition to the voices of the few advocates and campaigners who feel more enabled to tell their stories. The advocates' and initial campaigners' contributions have been truly enormous and immeasurably valuable. They have led the way to allow FGM to become a subject that is spoken about and they have enabled change for both individuals and organisations, but it was noted that that is not the same as saying that their voices are representative of all the voices in their communities, or that they speak for other community groups.

FGM is traditionally a women's subject, and one which men would not normally participate in discussion about. It was acknowledged that men are also affected by FGM, through their families, their wives and their daughters. It was noted that psychosexual difficulties arising as a consequence of FGM affect men also, and that in that sense they are also victims of this harmful cultural practice. It is only recently that men have begun to be involved in discussing and campaigning against FGM, and this is a welcome change. It is important to learn more about how men can be involved in making changes and be part of the process of eradicating FGM. It would also be valuable to understand more about their beliefs and needs in the context of FGM.

FGM is traditionally performed by cutters, who have financial and status dependent upon their role. If change is to occur, it is important to consider and learn about the role and needs of the cutters.

Finally, there was an overarching desire for solutions, resources and change to develop from communities upwards to professionals and authorities. The learning and resources need to be created and constructed in such a way that they can be effectively shared between women, communities, and professionals. This would allow understanding of what will create effective change, services and training. We need to understand how we can develop and support this process happening, and what techniques, resources and research would be needed to allow this.

We need to learn this from the communities themselves.

Appendix 2:

The Sheila Kitzinger Seminar "FGM: where have we got to? And what comes next?"

QUESTIONS RAISED

Questions relating to service design and support needs

1. How do we encourage women who have experienced FGM to come forwards? what do they need from services? what services do they need?
2. How can services be designed to ensure the mental health and psychological needs of women affected by FGM are met? What is the best way to address these needs ?
3. Should clitoral reconstruction be offered as a service (and if so how ?/what would the service need to offer?/be like?)? What is the evidence for this? What might be the advantages or disadvantages? How should a service like this be funded?

4. What will the impact of criminalising FGM be on service use? Will it work as a deterrent? What are the potential risks or adverse consequences be ? What are the impact of the laws about FGM on women wishing to choose cosmetic genital surgery or genital piercing?
5. What can the UK learn from other countries experience of legislating in FGM (Eg France and Australia)
6. What are the needs of schools and community groups with respect to FGM?
7. We don't know what is happening now with the practice of FGM in the UK, including when/how much/what type/where it is being performed- how can we try to understand this? What information could we find? What are the barriers to understanding this?
8. Is FGM a health issue? is Health an appropriate service to tackle FGM through ? It was commented that communities may not perceive FGM to be a health issue – though it has potential consequences that are encountered in health settings.
9. Communities should be central to service provision – with ownership, design, solutions and training coming from communities. Note that this raises the opportunity for shared learning between communities and organisations.

Questions relating to challenges and opportunities for future work in FGM

1. Mandatory reporting – will it affect women accessing services or making disclosures? What was the consultation with communities? How can communities understand more/educate then speak out to the DOH and about consultation ? does criminalising FGM rather than educating and supporting help communities? does the law and need for reporting exacerbate peoples experience of trauma? Is MR proportionate and fair? How do communities perceive MR, noting during discussion descriptions of communities feeling discriminated against and attacked? How will this affect future service design and use? And future understanding and research ?
2. How do we create services built on confidentiality and trust ? Noted that these are vital for effective service provision, development and access. What will the impact be of the new UK laws on this? Concerns raised over access to data, data sharing and impact of this on trust – from both individual and community standpoints ? noted some communities already express mistrust for professionals – what will the impact of the new FGM dataset be on this? Mistrust of interpreters an issue for many women. Could health advocates have a role in mediating and giving voices to community members ?
3. Concerns raised about the database of children under the age of 18 who may be at risk because of community or family history of FGM without consent – the RIS system.
4. How can community members communicate about policies that affect them? Noting that activists may not be representative of all community views. How can all voices be heard?
5. FGM is traditionally not discussed or spoken about, and is taboo to discuss, which makes it harder to hear from all voices.
6. Important for professionals to note that FGM is an act performed because of love and that this needs to be understood when discussing FGM.
7. Is it right to medicalise FGM ? do we lose the social context and wider understanding of FGM as a cultural and social issue ?
8. Too much of the narrative focuses on type 3 FGM and Africa. There is not enough information or discussion about medicalising the practice of FGM or of medically sanctioned practice of FGM.

9. There is a need for greater understanding of FGM in non-African countries, including in the far east where it is often performed and sanctioned in medical settings.

What questions were asked ?

1. How do we gain a clearer global understanding of FGM and where it is happening? and shift the emphasis from Africa? What do we know (and how can we understand more) about FGM in other parts of the world such as the Middle East and Asia? How can we understand where and how this practice occurs, what it means and what the needs of these communities are? do they perceive their practice as FGM? We need to move towards a global solution of what is best for women and girls around the world.
2. There is a need for the development of primary school resources. How can we support teachers of primary age children to talk about FGM? And to enable and reach primary school age children? We need to explore the barriers to this in order to facilitate and reach out to this group of young people.
3. Is it possible that the focus on confidentiality makes it harder for FGM to be spoken about?
4. Is FGM still occurring in the UK?
5. If there has already been a substantial change in behaviour among migrant communities why is there a perceived need for a high profile ongoing campaign?
6. What is the impact of MR on communities attitudes towards professionals – will it cause them to lose trust ?
7. How do we reach groups who do not believe that their cultural practices align with FGM ?
8. How can we ensure the voices of communities are heard above the voices of a few campaigners and advocates?
9. We need to understand the impact of the recent legislation politicising FGM, it places GP's in an impossible situation. Are these laws a barrier for professionals and women to be able to talk about FGM ? will they prevent disclosure ?
10. How can we involve men in the debate and the process for change. FGM is usually considered a women's subject, and would not be discussed by men. FGM does impact on men, through the impact on their wives and families, and the impact on sexual relations. What are men's views and knowledge about FGM?
11. If data is needed, what data should be collected and how?
12. Is MR discriminatory ? is it proportionate? Does it increase stigma?
13. What are the needs and views of the cutters? How can we understand their needs and part in the process of change?
14. We need to facilitate learning from the bottom up and share this between women.

Appendix 3.

Diasporan Hands Flyer

The flyer features a large, stylized title 'DIASPORAN HANDS' in bold, yellow, 3D block letters. Below it, 'Drama group' is written in a smaller, black, sans-serif font. The background is a collage of a green and white flag, a large wooden drum, and a group of people. The group consists of seven individuals: four men and three women. Two men are standing on the far left and right, wearing suits. The three women in the center are wearing white tank tops and long, yellow, fringed skirts. The two men in the back row are wearing patterned shirts. The overall design is vibrant and culturally themed.

DIASPORAN HANDS

Drama group

About Us
Diasporan Hands was formed by a group of Sierra Leoneans living in the UK to educate and empower women and girls in Sierra Leone. We believe that everyone in Society should have equal access to opportunities regardless of gender, age, race, colour, creed, status, etc.

Our Vision
To give voice to the voiceless through awareness raising, advocacy, and direct support to enable the less privileged to access services. This is why we are working closely with women and girls to support and raise awareness on Female Genital Mutilation (FGM), Child marriages and Child abuse in Sierra Leone and West Africa.

Contact: email: info_diasporanhands@mail.com
Tel: 07944205252 / 07758938840

DIASPORAN HANDS Drama group

Mission Statement:
"Giving Voice to Voiceless"

Our Work

Our ultimate goal is to develop strategies and initiatives to eliminate the practice and provide support to women and young girls already affected by FGM. We are saying that education is the key to addressing this matter. Communities need to be made aware and to be educated about the various implications and effects of FGM such as health, psychological and social. We recognise the potential danger that can be caused by insensitive and poorly designed strategies, therefore we choose drama to work in a high standard of ethical conduct which will be defined in our "Do no harm initiative".

Get Involved

In July 2003 the African Union adopted the Maputo protocol promoting women's rights and calling for an end to FGM. The agreement came into Force in November 2005, and by December 2008, 25 member countries had ratified. However in 2014 research shows the practice is still prevalence in 30 African Countries. According to a survey in 2008 91% of women in Sierra Leone between the age of 15-49 have undergone FGM.

In some parts of Sierra Leone young girls are taken out of School to undergo FGM and then marry them off as child brides to men who are old enough to be their Fathers. Therefore these children are not giving the opportunity to complete their education and contribute to Society, resulting into the widespread poverty witnessed in the Country Today.

FGM is seen within a wider context of violence and discrimination against women and girls. We want to build a sustainable network of people, groups and Organisations through partnerships, research and policies.

Please join us to
"SAY NO TO FEMALE GENITAL MUTILATION".

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