A qualitative study of women’s lived experience after deinfibulation in the UK

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Objectives: to explore women’s experiences of deinfibulation and its aftermath.

Design: a qualitative study using semi-structured interviews with data collection via audio-recording and field notes. The audio-recorded interviews were transcribed verbatim and analysed using Interpretive Phenomenological Analysis (IPA) method for qualitative data analysis.

Setting: recruitment for the study was carried out in an African Well Women Clinic in London, United Kingdom.

Participants: there were nine women participants of Somali and Eritrean origin who had Female Genital Mutilation (FGM) type III previously and underwent deinfibulation between January 2008 and September 2009.

Findings: key themes identified were the cultural meaning and social acceptability of deinfibulation; the consequences of deinfibulation within marital relationships; feelings about the appearance of genitalia post deinfibulation and thoughts on reinfibulation.

Conclusions: marital factors and stability of the relationship influence the experience of deinfibulation. Those women who said they had discussed deinfibulation with their husband in advance, and that he had agreed to the procedure, reported less problems afterwards. Single women who had deinfibulation before marriage may face more difficulties in terms of social acceptability within their community.

Implications for practice: sensitivity to social consequences of deinfibulation is important as well as recognition that these consequences vary. When deinfibulation is carried out for medical purposes some women may appreciate the offer of an official letter from a health-care practitioner confirming the medical nature of the procedure. The data suggests that deinfibulated women may dislike the new appearance of their genitalia; therefore, the practicality of performing a concurrent minor cosmetic surgery with deinfibulation procedure may need to be examined. The need for further research conducted in women’s primary language is pressing and should explore issues such as the situation of single women, men’s knowledge of the complications associated with FGM and the benefits of deinfibulation for infibulated women.

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society as a woman. The causes for the continued practice of FGM comprise a mix of cultural, religious and social factors within families and communities, for instance, it is believed that FGM is important in order to maintain tradition and because it improves marriagability (Gibeau, 1998).

FGM’s immediate and long-term health complications differ according to the type and severity of the procedure performed. Bleeding, haemorrhage, shock and sepsis are some of the immediate consequences of FGM (Knight et al., 1999). Long-term complications include chronic genital pain, infertility, urinary tract infections and vaginal stenosis (Brady, 1999; Knight et al., 1999; Obadina, 2008). Deinfibulation (opening the scar) is a minor operation involving a vertical incision to the scar to expose the urethra and vagina. To alleviate or resolve the complications associated with FGM, it is recommended that women with type III FGM who are pregnant or who experience long-term complications undergo deinfibulation (Erian and Goh, 1995; McCaffrey, 1995; Penna et al., 2002). In the UK, deinfibulation is currently offered to all infibulated pregnant women as a necessary component of preparation for labour and vaginal birth (McCaffrey, 1995). Reinfibulation (closing the scar) has not been permitted in the UK since the publication of guidelines by the Royal College of Obstetricians and Gynaecologists in 1994 (Jordan, 1994).

FGM was made illegal in the UK in 1985. The law was further amended in 2004 to prevent children being taken out of the UK for the procedure (Female Genital Mutilation Act, 2003). The need for deinfibulation services still exists in the UK because of the mobility of populations, and immigration of women who have been infibulated elsewhere (Powell et al., 2002).

FGM is a sensitive and difficult to research area (Berggren et al., 2006). Existing studies suggested that infibulated women will benefit from deinfibulation (McCaffrey, 1995; Penna et al., 2002; Nour et al., 2006). However, these studies have been based on a restricted set of analyses on physical benefits of deinfibulation, therefore their findings are of limited use for understanding women’s experience of deinfibulation in communities that continue to value FGM. There are large knowledge gaps concerning women’s perceptions of deinfibulation. A search of the literature (Cochrane library, Medline, Embase, CINAHL, PsycholINFO) identified no UK research conducted specifically to explore women’s attitudes to and experience of deinfibulation.

This article reports on a small exploratory study conducted in London in 2010 which explored women’s experience of deinfibulation and its aftermath.

Methods

A qualitative approach was chosen as the most appropriate research method to investigate the objectives set out for this study. Ethical approval (Ref. no. 10/H0709/5) and Research and Development (R & D) registration from the relevant NHS hospital were obtained before the study commenced.

Recruitment

Participants were recruited via the African Well Women Clinic of a Foundation Trust in London which serves an ethnically diverse population. For the purpose of this study, the sampling was confined to women who had type III FGM and had deinfibulation for any reasons between January 2008 and September 2009. Eligible participants included women who had deinfibulation within the last two years and were aged 18 or older. Due to the sensitivity of the subject and to assure women that privacy and confidentiality within their own communities would be protected, interpreters were not used and only women able to speak and understand English well were included. The questions in the interview guide were discussed and reviewed by a member of a Black Women’s Health and Family Support group familiar with working with women from these communities.

The clinic registers for an 18-month period during 2008–9 were searched by the specialist midwife. One hundred and twenty-three women with type III FGM were identified as previously undergone deinfibulation. Eighty-eight women were accessible and met the inclusion criteria for the study. From an initial approach by the clinician 46 women said that they were interested to know more about the study, 33 requesting the participant information leaflet and 11 asking a telephone explanation. From these after 14 women agreed to participate in the study a date and time for the interview was arranged at the participant’s convenience. Two interviews took place in the interview room in a NHS hospital, 7 at the participant’s home, and 5 did not keep their appointment. Written consent was obtained from all participants prior to interview. Each interview took on average between 40 and 50 mins to complete. Participants were offered the option to attend the interview with their partner or a friend; however none of the participants took up this option.

The age of participants ranged from 19 to 44 years old. The mean age of the women when the circumcision was performed was at 6 years with the range of 7 day to 10 years. All but one participant were originally from Somalia and the length of residence in the UK ranged from 4 to 20 years. Deinfibulation had been carried out a minimum of 8 and maximum of 23 months prior to the interview for a range of reasons. Almost half of the participants had no formal school education, 6 of the women were unemployed, 3 had part-time jobs as shop assistants or carer and one was a student. Two women were single, one was divorced and 6 women were currently married. Four of the husbands were from Somalia, one from Eritrea and one from Algeria. Finally only 9 women agreed to take part in the study. The ability to understand and speak English could be one of the reasons for high refusal rate (Table 1).

Data collection

A semi-structured interview schedule was used to facilitate in-depth exploration of women’s experience of deinfibulation of subsequent events, and combined with field notes. The interviews were audio recorded. Open questions were asked in order to obtain more in depth data. Initial questions requested demographic and health characteristics such as age, ethnicity, marital status, occupation, obstetric history and living circumstances. Further questions were asked to explore the woman or her husband’s decision to perform deinfibulation, the woman’s experience of the procedure and its aftermath, the reactions of friends, family and male partners, any changes in sexual pleasure and confidentiality within their own communities would be protected, interpreters were not used and only women able to speak and understand English well were included. The questions in the interview guide were discussed and reviewed by a member of a Black Women’s Health and Family Support group familiar with working with women from these communities.

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<table>
<thead>
<tr>
<th>Participant</th>
<th>Ethnicity</th>
<th>Age of FGM (year)</th>
<th>How long lived in UK</th>
<th>Currently single/married</th>
<th>Husband’s ethnicity/age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Somalia</td>
<td>10</td>
<td>20 years</td>
<td>Single</td>
<td>N/A</td>
</tr>
<tr>
<td>2</td>
<td>Somalia</td>
<td>12</td>
<td>4 years</td>
<td>Married</td>
<td>Somalia/22</td>
</tr>
<tr>
<td>3</td>
<td>Somalia</td>
<td>5</td>
<td>10 years</td>
<td>Divorced</td>
<td>Algeria/50</td>
</tr>
<tr>
<td>4</td>
<td>Somalia</td>
<td>2–3</td>
<td>4 years</td>
<td>Married</td>
<td>Somalia/27</td>
</tr>
<tr>
<td>5</td>
<td>Somalia</td>
<td>6</td>
<td>7 years</td>
<td>Married</td>
<td>Somalia/31</td>
</tr>
<tr>
<td>6</td>
<td>Eritrea</td>
<td>7 days</td>
<td>19 years</td>
<td>Single</td>
<td>N/A</td>
</tr>
<tr>
<td>7</td>
<td>Somalia</td>
<td>3</td>
<td>13 years</td>
<td>Married</td>
<td>Eritrea/39</td>
</tr>
<tr>
<td>8</td>
<td>Somalia</td>
<td>8</td>
<td>15 years</td>
<td>Married</td>
<td>Algeria/40</td>
</tr>
<tr>
<td>9</td>
<td>Somalia</td>
<td>6</td>
<td>18 years</td>
<td>Married</td>
<td>Somalia/39</td>
</tr>
</tbody>
</table>
Data analysis

The content of transcribed interviews was examined with the focus shifting back and forth from the key statements of the participants to find recurring patterns, thoughts, feelings or ideas. Meaning units (recurring thoughts, feelings and ideas) were tagged with a name and coded (coding). The related codes then were given a name that presents the idea or perception that underpins the theme or category (categorisation). Similar themes were grouped under much broader themes (master coding). The final set of themes were finally summarised into a table (coding list) where extracts from the text were given to back up the themes (Table 3).

An Interpretive Phenomenological Analysis (IPA) approach was employed for this exploratory study to analyse the data. IPA is concerned with the way participants make meaning from their experiences (Smith et al., 2009). In IPA the researcher collects qualitative data from research participants using one of a number of methods such as interview, field notes or focus group (Smith et al., 2009).

Study limitations

The limitations of the study need to be taken into account. The small number of women willing to take part in an interview suggests that there may be something unusual about those who did. The decision to conduct interviews in English will have created a bias, favouring women who are more integrated into UK society and tending to exclude those who are not or who are more recently arrived.

Participation in research studies is not something which this ethnic group have had much prior experience of.

Women's own words have been used as much as possible in this account but research conducted by someone from a different cultural background to that of the participants increases the risk of misinterpretation. My identity as a midwife and the recruitment through the clinic, may have had the advantage of allowing women to speak about such matters without fear of gossip within the community but it may also introduced the possibility that responses get filtered according to the perceived interests of a health system audience.

Findings

Issues of FGM, deinfibulation and sexuality are sensitive and the insights from eight Somali and one Eritrean African women living in the UK in this study are useful in helping health-care providers to consider the design and planning of the care for this group of women. The findings indicate that sensitivity to the social consequences of deinfibulation is important as well as recognition that these consequences vary according to the social circumstances of the woman.

Three key themes emerged from the analysis that are particularly relevant to the work of health-care practitioners: cultural meaning and social acceptability of deinfibulation; the consequences of deinfibulation within marital relationships; and feelings about the appearance of genitalia post deinfibulation and thoughts on reinfibulation.

Cultural meaning and social acceptability of deinfibulation

It was notable that the majority of the women interviewed had not discussed their deinfibulation with even their close family or friends. The reasons they gave for this were a feeling that others ‘would not understand’ and a strong desire for privacy, or secrecy. For some participants it was an issue too personal and intimate to discuss with others:

Nobody, because is part of my religion and I should not tell anyone. I want to keep the secret for me. It’s not like other things… I am too shy to tell anyone (Participant 5, married). …I do not know. I am shy. To say ‘mum I got that’. No seriously I am shy… (Participant 4, married). …Because I thought it was my privacy. I would have told someone like my husband maybe but not everybody else (Participant 1, single).

As well as the sense that issues related to sexuality and the sexual organs are deeply personal, a need for secrecy was expressed that related to worries over shame and disgrace. Particularly the fear of being marked out as a ‘non-virgin’ and promiscuous:

…Yes because they believe that if you are not closed down you are not a virgin. That is what they say (Participant 3, divorced).

Table 3

Cultural meaning and social acceptability of deinfibulation

<table>
<thead>
<tr>
<th>Cultural meaning and social acceptability of deinfibulation</th>
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</thead>
<tbody>
<tr>
<td>Sharing deinfibulation's idea with husband makes deinfibulation acceptable</td>
</tr>
<tr>
<td>Deinfibulation is a secret</td>
</tr>
<tr>
<td>Men may dislike deinfibulation</td>
</tr>
<tr>
<td>Families against deinfibulation</td>
</tr>
<tr>
<td>Deinfibulation before marriage not allowed</td>
</tr>
<tr>
<td>Deinfibulation is untellable subject</td>
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<tr>
<td>Feeling shame</td>
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The consequences of deinfibulation for marital relationship

<table>
<thead>
<tr>
<th>The consequences of deinfibulation for marital relationship</th>
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<tbody>
<tr>
<td>Exploring lived experience</td>
</tr>
<tr>
<td>Deinfibulation before marriage cause problem</td>
</tr>
<tr>
<td>Deinfibulation before marriage affects on relationship</td>
</tr>
</tbody>
</table>

Feeling about the appearance of genitalia post deinfibulation

<table>
<thead>
<tr>
<th>Feeling about the appearance of genitalia post deinfibulation</th>
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</thead>
<tbody>
<tr>
<td>Deinfibulated genitalia look abnormal</td>
</tr>
<tr>
<td>Deinfibulated genitalia is like an empty space</td>
</tr>
<tr>
<td>Open genitalia is more healthy</td>
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</table>

Thoughts on reinfibulation

<table>
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<tr>
<th>Thoughts on reinfibulation</th>
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</thead>
<tbody>
<tr>
<td>Prefers to be closed</td>
</tr>
<tr>
<td>Prefers to stay open</td>
</tr>
<tr>
<td>Reinfibulation makes genitalia tighter</td>
</tr>
<tr>
<td>Reinfibulation improves incontinence in women</td>
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Table 2

Interview guide.

<table>
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<tr>
<th>Interview guide</th>
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<tbody>
<tr>
<td>How far are you? Who lives with you in your household? How long have been married/how many children/how long have you lived in London/UK/where do you live before?</td>
</tr>
<tr>
<td>Can you tell me about your own experience of being opened (deinfibulation)? How you came to attend the clinic at xxx hospital/whose idea was it that you should be opened?/What was the reason for doing it?/How did you feel about the idea?/How did your family react to the suggestion?/Your husband?</td>
</tr>
<tr>
<td>Has being opened changed your relations with your husband in any way?</td>
</tr>
<tr>
<td>How long ago is it that your were opened? And do you want to stay that way or would you have liked to be closed up again? Why is that?</td>
</tr>
<tr>
<td>Did you make a request to be closed up again?</td>
</tr>
</tbody>
</table>
...I am scared to see what happen because they may think that I have had sex or something like that. I would really get in trouble if they found out.... Just scared that my family would find out. Every time I would go toilet I was scared they would realise I walk a funny way or something like that... No just I shared it with the guy I married and he was all right with it. But my family would be not... (Participant 2, married).

For single women this situation was acute because of a fear of not being able to get married, especially in a community in which marriage for women is highly valued. One of the participants was clear about what the traditional views on marriage would have been:

I am married now but if it happened before maybe yes especially if I was back in Somalia. If I would have got married and the man found out I was open he may ask for divorce because he may think you had sex before... (Participant 2, married).

Other women found the same attitudes were prevalent in UK communities. One participant, who was single when her deinfibulation was performed, told a sad and painful story of how her prospective partner left her as soon as he found out:

...One man he wanted to marry me, when he found me like this he said 'no. I don't want. You are not normal' and he left me. I feel bad. [....Long silence] I can't talk now. [Crying]... They think something wrong, they will leave you, they don't talk, just 'Bye'. You are not good. That's it! (Participant 6, single).

She also made it clear that her situation was not far from unique:

So many people are like this. They don't tell anybody, they just crying and they live alone. They never say anything to people and that's all... (Participant 6, single).

The consequences of deinfibulation within marital relationships

This theme describes some of the feelings related to being deinfibulated outside the marriage.

The woman quoted below was 44 years old, single mother at the time of the interview, she felt her second marriage had failed in part to her husband's preference that she be circumcised:

He did not like it. He liked me to be circumcised (Participant 1).

For some women these pressures were too great to go through with deinfibulation even though their own heath might be under threat:

I know my friend she wants to do that (deinfibulation) but her husband doesn't let her... I don't know, I told her, this is good for you go and do. She said ok but her husband said no. She said my husband doesn't want so she left it... she didn't do the operation. Maybe if she did this (deinfibulation), it would have been a big problem in the family. So she said no, I don't want. She has got 4 children all by operation only cesarean section... (Participant 6).

In contrast, another participant said that it had been her husband who decided that she should be deinfibulated. An asylum seeker in her early twenties, she was homeless when she met her 50-year-old husband. He was not from a community in which FGM is practiced, and he decided that she should undergo the procedure in the first two weeks of marriage, when he found out that having sex was impossible. Their marriage still only lasted for a few months and he left her while she was pregnant.

Not all men from communities which traditionally practiced FGM are against deinfibulation, however, some of participants were married women and infibulated before marriage. Each had discussed the deinfibulation with their husband and had his agreement before it was carried out. One participant described her husband's reaction as:

He was so scared for me but I told him that they would give me injection and then I would be all right. But still when I went he told me 'are you sure you want to do that?'... (Participant 7, 30 years old, married).

Married women who had their husbands’ prior agreement to the procedure, seemed to have fewer problems subsequently:

He saw I was closed before so he does not mind (Participant 2, 19 years old, married).

Feelings about the appearance of genitalia post-deinfibulation and thoughts on reinfibulation

As deinfibulation tends to be carried out in order to improve women’s health or to prevent damage and morbidity, it might be easy for health staff to forget that the new appearance of the genitalia can be disconcerting and unsettling to the women. One woman described the deinfibulated genitalia as ‘healthy’:

It is open wide now. It does not matter. I do not mind. As long I feel ok with it and my husband is happy. And I think it is healthier like that (Participant 7).

But she was the exception; most of the women were far less content:

I got used to what it was before and I think it is not normal now.... (Participant 9, 33 years old, married and pregnant).

One participant described her new genitalia as ‘like empty place’:

You feel funny. I don't like it. It’s like empty place (Participant 1).

Another said:

I think it looks funny and it looks better if it is closed and like this does not look nice.... I do not know. It does not look good and I do not feel comfortable with the look of it. Now even the colour has changed. Before it was all black but now is pretty much pink...... but then adding he does not look at it at all so it's ok (Participant 2).

Among this group of participants there was a range of opinions regarding the prospect of reinfibulation. One woman saying that she had never thought of or requested reinfibulation, another admitting that she had made a request to be ‘closed up’ after labour but this was turned down by her midwife. Despite the discontent with the appearance, five participants stated that they did not wish to be closed up again. For two this was linked to a desire to have more children and three women said that did not wish reinfibulation as they did not want to experience pain again. Two women would consider reinfibulation later in their life. One woman believed that reinfibulation can correct the incontinence caused by the aging process:

...I think when a woman becomes old the muscles become loose and the urine she cannot hold it... (Participant 9).
One participant believed that reinfibulation is necessary after multiple pregnancies and birth as it can provide the tighter look for genitalia and vagina:

…not now maybe later on when I have many babies. It becomes bigger and that is not nice (Participant 4).

Recommendations and conclusion

With the above caveats, recommendations for practice need to be made with caution. While it has been proven that circumcised women benefit from deinfibulation (Erian and Goh, 1995; McCaffrey, 1995; Penna et al., 2002), it is important to try to minimise distress consequent to deinfibulation. The findings do suggest that some deinfibulated women will face considerable difficulties with regard to the acceptability of the procedure before marriage within their community. One woman’s suggestion of provision of written confirmation regarding the medical need for deinfibulation may be worthy of further exploration. It also raises the question of whether a policy of offering partial reinfibulation as is the case in some other European countries should be revised.

The data suggests that deinfibulated women may be disconcerted by and dislike the new appearance of their genitalia. Therefore, extra care and attention is needed when giving care to this group of women. The ethics and practicality of performing a concurrent minor cosmetic surgery with deinfibulation procedure may need to be examined.

The study also highlights the need for further research in several areas. Among these, further research into the experience of deinfibulation using an independent interviewer who can speak the primary language of the participants is highly recommended. If this is impossible then research using an out of area interpreter who is not known to the women in the study would be an advantage. This would enable recruitment of women who cannot speak English and could provide greater understanding of the experiences of those women who are more isolated from the host culture. This study has provided some detailed but limited description of single women’s experience of deinfibulation. Further research of the experience of this specific group of deinfibulated women is now required to understand why deinfibulation for single women tends to be problematic and what can be done to assist. Finally findings suggest there may be a need to educate men in affected communities about the difficulties that infibulated women experience as the results of their FGM as well improving their understanding of the benefits of deinfibulation. How best to do this requires further research.

In conclusion, existing studies of the complications associated with infibulation and which recommend deinfibulation to solve the related problems provided some evidence on physical advantages of deinfibulation. However, the question of the psychological and social aftermath of deinfibulation is under-researched. This qualitative study explored the experience of deinfibulation and its aftermath for a small number of African women living in the UK. Understanding women’s experience is important for health-care providers working in midwifery services, African Women clinics and other related areas, if adequate support is to be provided. The need for further research is pressing.

Conflict of interest

There are no conflicts of interest.

References


