

Project Title: Somali women's experiences with obstetrician care providers during childbirth in

Canada

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#### **Abstract**

**Introduction:** In the context of international migration, an increasing number of women from countries that traditionally practice FGC have immigrated to Canada (Perron et al., 2013). Given these demographic shifts, it is necessary to provide appropriate reproductive care to newcomer women who have undergone FGC, and to do this it is important to understand women's perceived childbirth experiences

**Methods:** The purpose of this study was to explore how Somali women who have undergone FGC perceive their experiences with childbirth and their interaction with obstetrician care providers in British Columbia. The study used qualitative method of focus group interviews.

**Results:** Thematic analysis was conducted and 5 main themes were identified, including: preference for a natural birth; health care provider interaction; clinical care for FGC including vaginal examinations, de-infibulation, re-infibulation; desire for greater decision making capacity and differences in biomedical and Somali cultural practices.

**Discussion:** The results show that there still remain largely unmet needs regarding appropriate clinical care for FGC and provider-patient interaction. In particular, there is tension between Somali women's preference for a natural birth and perceived extra interventions by obstetricians. Furthermore, the Somali women reported dissatisfaction with aspects of the clinical management of FGC during delivery, particularly the timing of de-infibulation. Improving patient-provider communication and addressing issues of power-asymmetry could mitigate tensions, improve trust and reduce dissatisfaction experienced by Somali women during the childbirth experience.

## 1. Background

In the context of international migration and an increasingly diverse population in Canada, health professionals have been responsible for providing pregnancy and childbirth care to patients who have previously undergone female genital cutting (FGC). The practice is also referred to as female circumcision (FC), or the term female genital mutilation (FGM) by those who are strongly opposed to the practice; this capstone will predominantly use the more neutral term of FGC. FGC encompasses four main types of procedures that involve partial or total removal of external genitalia: clitoridectomy, excision, infibulation and other types of cutting (WHO, 2001). FGC is predominantly practiced in 29 countries located in western, eastern and northeastern regions in Africa as well as in parts of Asia and the Middle east (WHO, 2014). Currently an estimated 125 million women and girls have undergone FGC, and this practice is typically performed on girls between infancy and age 15 (WHO, 2014). An estimated 95% of women in Somalia have undergone FGC with the majority undergoing Type III FGC, which is known as Pharaonic Circumcision or infibulation and is the most extensive category of female circumcision (WHO, 2001). Infibulation involves narrowing the vaginal opening by cutting parts of the labia majora, labia minora and may involve the removal of the clitoris (Chalmers and Omer-Hashi, 2002). Subsequently, a suture is performed to join the two sides of the vulva and leaves a very narrow opening that allows for the passage of urine and menstrual blood (Chalmers and Omer-Hashi, 2002).

Female genital cutting is associated with adverse health outcomes. Short-term health effects may include: severe pain; shock; hemorrhage; bacterial infection and urine retention; bleeding; septicemia and death (Reisel and Creighton, 2009). The long term health consequences may include: urinary tract infections; cysts, infertility; future surgeries; pain during intercourse and reduced libido (Reisel and Creighton, 2009). Type III FGC, infibulation, also poses increased health risks and obstetric challenges during pregnancy and birth (GSN et al., 2006; Berg and Underland, 2013). Women who are infibulated have a very narrow neointroitus, vaginal opening, with scar tissue covering the vulva, and thus require deinbiulatation either before or at birth to create a greater opening for the fetus (Straus et al., 2009). The scar tissue and narrow opening of the vulva increase the risk of complication during vaginal delivery; these risks are more severe for women who remain infibulated until delivery (Nour, 2004). The specific obstetric complication resulting from infibulation may include: prolonged labor; obstetric tears and lacerations; higher prevalence of C-sections; obstetric hemorrhage and may result in both maternal and perinatal mortality (GSN et al., 2006; Berg and Underland, 2013).

Although there are no statistics available on the prevalence of FGC in Canada, an increasing number of women from countries that traditionally practice FGC have immigrated to Canada (Perron et al., 2013). Given these demographic shifts, it is expected that obstetrician care providers will increasingly encounter patients who have previously undergone FGC. Accordingly, comprehensive policies and guidelines for professionals to increase capacity to provide quality and culturally appropriate care is needed.

An important component of developing these policies and guidelines is understanding the perspectives of women with Type III FGC. There is currently limited literature available detailing the pregnancy and birthing experience in Canada for women who have previously

undergone FGC, and in particular infibulation. The literature that is available indicates that infibulated women have experienced negative interactions with health care providers in settings where FGC is uncommon. Somali women have reported feeling humiliated by care provider's reactions and comments during delivery, which ranged from shock to disgust (Chalmers and Omer-Hashi, 2002; Nour, 2004; Johansen, 2006; Rashid, M and Rashid, MH, 2007; Straus et al., 2009). Somali women also expressed a fear of stigma among health providers when seeking prenatal care during pregnancy, which affects the level of preparedness and care given during childbirth (Omer-Hashi, 2002). Additionally, women reported experiencing the burden of having to educate providers about FGC, concern on whether the care provider was trained to provide the appropriate care needed, and a worry that obstetrician care providers were biased towards performing C-sections on women with infibulation (Omer-Hashi, 2002; Straus et al., 2009).

The Canadian national guidelines for maternal and newborn care were last revised in 2000 and have a very limited focus on clinical guidelines for providing appropriate care for women who have undergone FGC. Additionally, The Society of Obstetricians and Gynaecologists (SOGC) of Canada have updated their clinical practice guideline, which addresses FGC, in 2013. Nevertheless, we don't know enough about women's experiences to understand if these revisions meet the needs for appropriate care among the infibulated population. The SOGC indicated as one of their recommendations that there is a need for further research to assess the experiences accessing sexual and reproductive health care services of women who have undergone FGC's. This study intends to address this gap in the literature

# 2. Purpose

- To explore how Somali women who have undergone FGC perceive their experiences of obstetrician care providers during childbirth in hospitals located within British Columbia; and
- 2) To make recommendations for obstetrician guidelines based on experiences and insight shared from Somali women who have given birth in British Columbia.

## 2.1 Research Question

How do Somali women who have undergone FGC perceive their experiences with childbirth and their interaction with obstetrician care providers in British Columbia?

#### 3. Research Procedures and Ethical Considerations

The stated objectives and purpose of this research guided the selection of an appropriate method. Given that the purpose of this study was to explore Somali women's self-perceived experiences with obstetric care providers in the lower mainland and to make recommendations for guidelines, qualitative methodology was chosen for data collection. Focus group discussions (FGDs) were selected as the most appropriate method to collect data. Group conversations in FGDs allow for multiple perspectives to be shared and for participants to build off each other's ideas, as hearing other participant's feedback can serve as a stimulus to uncover one's own experiences (Davis,

2011). FGD also allow for a greater number of respondents to participate in comparison to individual interviews, which was important for this study as it allowed us to gain a more comprehensive understanding of Somali women's childbirth experiences in B.C and subsequently shape appropriate recommendations. We were also guided by Asanin and Wilson's experience researching health care access with Canadian immigrants, which found individual interviews were insufficient to gain insight into a diversity of experiences and thus recommended FGDs as more appropriate for this goal (2008). FGDs have been successful in eliciting strong discussion among minority groups in Canada (Thierfelder et al., 2005). Chalmers & Omer Hashi (2005) and Vissandjee et al., (2014) have conducted FGDs with over 600 women from different communities, including Somali women. Furthermore, FGDs with Somali women on childbirth experiences have been found to be effective in allowing participants to discuss positive aspects and challenges of current childbirth delivery, as well as to generate recommendations (Chalmers and Omer-Hashi, 2002; Thierfelder et al., 2005). Furthermore, we chose FGD as we hoped that interactions among participants could allow for participants to realize collective issues faced by the community. Hearing other participants being affected by similar issues can help create a supportive environment (Thierfelder et al., 2005) as well as galvanize collective action in the community (Wallerstein). Overall, FGDs were an appropriate method for gathering data on Somali women's childbirth experiences in British Columbia, as Somali culture has a strong oral tradition (Adam, 2005).

Noting the difference between how Somali women may view FGC and how non-Somali Canadians may regard discussions about FGC was important to determining our method. Non-Somali Canadians may consider the topic as sensitive or stigmatizing for participants, and our Office of Research Ethics suggested that individual interviews could provide stronger confidentiality to mitigate potential harm to participants from identification as women who have undergone FGC (Davis, 2011). Among Somali-Canadian women, however, FGC in general was not considered stigmatizing or sensitive. Our inclusion criteria specified circumcised Somali women, and WHO (2013) statistic suggest that Somalia has a 95% prevalence of FGC. The high prevalence of Somali women who have undergone FGC creates a normative attitude towards this practice amongst Somalis, making it unlikely that participating in this study would be stigmatizing for participants (Upvall et al., 2009). In fact, qualitative interviews with Somali women who immigrated to the UK perceived FGC as a necessary procedure to avoid stigmatization among Somalis (Momoh, 2005). To further create a supportive and comfortable environment for discussion, the facilitator was a Somali woman who had undergone FGC and given birth in BC and all FGD staff were Somali women. We should also point out that like in Canada writ large, giving birth is a gendered expectation for married Somali women. Again, this created a normative attitude toward discussing birth experiences amongst Somali women. Finally, to take into account individuals who may feel different than the community at large, women were informed of the topic and the nature of the focus group during recruitment. We emphasized that focus group questions were tailored to focus on childbirth experiences and there were no questions that pertained to the experience of undergoing female genital cutting. At this point, any individual woman who did not want to discuss her birth experiences with her peers was encouraged to decline to participate.

While participants were not concerned about the sensitivity of discussing FGC and childbirth among their peers, a major concern for them was whether or not participation in this study would

involve child protection services if they expressed supportive attitudes towards FGC. Chalmers & Omer-Hashi (2002) found that Somali-Canadian women expressed fear and unhappiness with a written consent procedure, as it was viewed as a possible means of identification (Chalmers & Omer-Hashi,2002). More specifically, women reported fear of identification by immigration authorities and losing refugee status and had a perception that child protection authorities could be alerted regarding the information they revealed in the study (Chalmers & Omer-Hashi, 2002).

We addressed these concerns through numerous adaptations to our protocols. First, we decided that all parts of this study would be conducted in Somali, as it was anticipated that potential participants would have varying levels of ability and comfort with speaking in English, and their understanding and comfort was paramount. Second, we used a verbal consent procedure. A Somali medical translator proficient in both English and Somali was identified through the PI and facilitators' networks and contacted to translate the verbal consent form, recruitment form and focus group questions. At the beginning of each FGD, the facilitator gave each participant a copy of the consent form, went over it with the participants, answered any questions and then sought verbal consent. Third, our verbal consent form specifically addressed the non-Somali legal context in which our FGD were embedded, describing the perceptions of Canadian law regarding FGC and alerting women to what topics were safe to discuss (e.g. their childbirth experiences) and what topics would be cut off by the facilitator to ensure the safety of participants (e.g. opinions regarding circumcising, particularly children) (See Verbal Consent Form Appendix C). Finally, we decided to forgo an audio-recording of the FGD, as voice recordings constitute a positive form of identification, and rather used two note takers to keep track of comments.

#### 3.1 Setting:

We chose to conduct 2 of the focus group discussions with Somali women in Surrey, as a large Somali immigrant population in the lower mainland have settled in Surrey (ISSofBC, 2014). One of the FGDs was conducted in Vancouver.

# 3.2 Recruitment Inclusion Criteria

- Somali women, over the age of 18 who have undergone FGC and given birth in British Columbia, Canada in the last 10 years;
- Somali women who had an obstetrician care provider during childbirth.

#### **Exclusion Criteria:**

- Women who have undergone FGC, but who do not self-identify as Somali;
- Somali women who have not undergone FGC;
- Somali women who have given birth more than 10 years ago;
- Somali women who have given birth in a setting other than a hospital;
- Somali women who have given birth in any location outside of British Columbia.

Purposive sampling was used to select women who have undergone FGC and given child-birth in a hospital in British Columbia, Canada. More specifically, snowball sampling was used for the FGD and two Somali women community leaders were asked to assist with the recruitment process. One of the community leaders has worked with the MOSIAC, a non profit organization

that supports immigrant and refugee populations in BC, for over ten years. The other community leader assists with Somali cultural customs in collecting money from the Somali community to give to families who have a newborn and for families who require support for funeral preparations. A recruitment letter in both English and Somali was given to these two Somali community leaders to show potential participants, and obtain permission from these potential participants on whether their contact information could be given to the researcher. The recruitment letter also had the PIs contact information, to allow participant to directly contact the PI to participate in the FGD. The two community leaders were also provided consent forms to be given to potential participants, as this allowed for potential participants to have a better understanding of the research topic and consent process before they attend the FGD.

A total of 32 potential participants were contacted by the recruiters to participate in the study, and ultimately 15 participated. Recruiters noted that reasons not to participate included fear and/or shyness to discuss FGC-related topics, busy time-schedule, having no caretaker available and transportation barriers (i.e. lack of access to a vehicle).

#### 4. Data Collection

We held three FGD sessions, with five participants per session. We stopped recruiting for subsequent focus groups when saturation and thematic redundancy in the data collected was reached (Krueger & Casey, 2000). The length of each FGDs was between 1 to 2 hours, and participants explored 8 open-ended questions (See FGD Guide Appendix A). The literature guided the development of the focus group questions. The same notetakers were there for each focus group as this increased reliability and consistency of findings. Taking into consideration my identity as a Somali-Canadian woman, it is customary at a Somali gathering that the host provides tea and refreshments; since I had invited the participants for FGDs, tea and refreshments were provided before discussion ensued (Chalmers & Omer-Hashi,2002).

Transcript notes during the FGD was recorded by the PI on a laptop in Somali, and the PI also noted some of the few comments that were made in English. The other note-taker took notes in Somali by hand on paper, these notes were later transferred to the PIs laptop and transcript. Notes were taken on a laptop and before the coding process, the PI translated any notes in Somali to English, with the assistance of a Somali medical translator.

Child care was provided for the first FGD, since one of the recruiters was working in a health promotion program supporting immigrant mothers, and allowed us to use the space for the FGD. The second FGD was conducted at the Somali community centre/mosque, there was a room for older children to play, as two of the participants brought 2 children. The last FGD was conducted in a recruiter's home in Surrey, in a neighbourhood close to where many of the participants lived. The last FGD was conducted in the evening to take into account caretaking role of many of the participants. Nevertheless, as recruiters noted with contacting potential participants, childcare and transit were barriers to participating in the FGDs.

## 5. Data Analysis

The aim of this study was to develop a greater understanding of Somali women's experiences during childbirth with obstetrician care providers. Thus the analysis of the data was focused on identifying themes and allowing for a greater explanation of the data collected to answer the research question. Data analysis occurred once the data collection process started.

The PI was present for all the FGDs, and would take field notes and memos after the discussions regarding observations, re-occurring ideas, potential themes, and questions regarding the data. Furthermore, the PI being present for each focus group allowed for greater understanding of the data. Reflexive analysis by locating the researcher's role in the data collected is important, the PIs Somali-Canadian background assisted with data analysis i.e. understanding cultural cues/terms to interpret responses. The themes were identified in an iterative process during data collection and through initial and focused coding of transcripts. Initial codes were developed by generating a free list of codes, labeling relevant text text passages and coding for numerous categories i.e. respondent perspective, descriptions, actions and initial ideas. Coding was both data driven and theory driven, meaning that codes were based on emerging themes from both the data and the research questions by coding in relation to childbirth experiences. A codebook was created in a separate word document, and then the PI went through the transcripts again for focused coding. Focused coding included eliminating and combining categories, looking for related ideas, connecting codes to discover larger themes or patterns in the data. In a separate word document, the PI collated data relevant to each code under potential themes. Themes were reviewed to see if they were appropriate in relation to the coded extracts. Themes were defined and refined, i.e. if the PI discovered that there was not enough data to support a theme. Coded data within the themes were assessed if there was a coherent pattern.

#### 6. Conflict of Interest

The author declares no conflict of interest. The Institutional University Research Ethics Board (REB) at Simon Fraser University reviewed and approved this study.

#### 7. Results

The participant population was predominantly homogenous, all the women were Muslim, most were previously refugees, with many reporting longer term residence in Canada. The women mostly had larger family sizes, which reflects the high value placed on motherhood role and fertility in Somali culture, and as such childbirth experiences are life events for Somali women (Dybdahl & Hundeide, 1998). Brief demographic information was collected to inform the discussion and add a contextual understanding; information was collected on family size, the number of years residing in British Columbia and the type of female genital cutting the women had undergone, and this information is presented in Table.1. The number of years residing in Canada ranged from newcomers to long term immigrants, and the women had lived in British Columbia from 2 to 23 years. Women also reported having between 2 to 8 children. In order to gain a greater understanding of obstetric challenges and childbirth experiences, women were also asked what type of female genital cutting they had previously undergone. The majority of women (12) had undergone infibulation FGC, 2 women reported undergoing clitoridectomy

FGC, which they referred to as Sunnah circumcision, and 1 women reported undergoing FGC that was in between, which is most likely clitoridectomy or excision (See Table 1).

The main qualitative questions asked included: expectations of childbirth; childbirth experiences in British Columbia; interactions with obstetrician care providers and suggestions on how to improve care. The main themes that arose from the FGDs are reported in Table 2, and they include: a preference for a natural birth; health care provider interaction; clinical care of FGC; desire for greater decision making capacity and differences in biomedical and Somali cultural practices. Below, illustrative quotes are presented to demonstrate the key themes regarding childbirth experiences in British Columbia hospitals for Somali women who have previously undergone female genital cutting.

## **Demographic Characteristics and Themes**

Table 1. Characteristics of Participants			
Time in British Columbia	Range: 2-23; Average = 14.3		
Number of children	Range: 2-8; Average: 5.9		
Type of female genital	10 infibulated		
cutting	4 clitoridectomy		
	1 excision		

# Table 2. Themes of Childbirth Experiences in British Columbia Hospitals (N=15)

Health care provider interaction Preference for a Natural Birth

Clinical care for FGC

- Vaginal Examinations
- De-infibulation
- Re-infibulation

Desire for greater decision making capacity

Differences in Biomedical and Somali cultural practices

#### Health care provider interaction

A significant concern for participants before childbirth and especially regarding patient-provider interaction was stigma against female genital cutting. Women described having an expectation that health care providers would stigmatize FGC, with one women saying that she was "worried that they will ask me questions like "why were you cut, who did this to you?" To manage this, women reported seeking out and receiving advice from friends about the types of questions health care providers would ask them, as well as notes regarding how health care providers treated them at specific hospitals. This initial advice affected expectations of the childbirth experience and participant health-seeking behaviour. Sharing of advice and preference is

facilitated by close-knit Somali communities in the diaspora, and strong oral based culture (Whittaker et al., 2005). Indeed, some participants expressed a preference for a specific hospital based on community and friends' perceptions of how well providers treated pregnant Somali women.

Nonetheless, participants reported feeling stigmatized by their health care providers. Many of the women reported that providers would ask questions about their FGC with an expression of shock upon seeing the perineum. Provider also questioned Somali cultural practices. Stigmatization of FGC and non-Somali Canadian providers' lack of familiarity with the practice created fear among participants that obstetricians would have limited knowledge about adequate treatment protocols for pregnant women who are infibulated. One participant expressed this poignantly when she said "We are afraid, especially I was worried that they would think that my circumcision was a burn. One lady asked me if I got burned. They need to study more about women who are circumcised. They should not be surprised, that will be a scary experience". Women also felt discriminated against for their larger family sizes, with one women commenting "[...] doctors made too many comments, you have too many kids". Another concerning aspect of health care provider interaction with patients was that women felt discriminated based their background religious identity, with a participant reporting "Sometimes if they see the hijab, they get a bad attitude. She even looks you up and down." These experiences indicate women feeling stigmatized due to their cultural background, family size and having undergone FGC.

The terminology and language used by health care providers also formed an important aspect of the childbirth experience for participants. All the women expressed a preference for the term female circumcision, as this term was the most literal translation from the Somali term for this practice *gudniinka dumaarka* (female circumcision). Alternatively, when health care providers used the term 'female genital mutilation' to refer to procedures that participants had undergone, participants took this as an indication of the health care provider's viewpoint towards FGC. More specifically, participants felt that the term FGM reflected a negative judgment and signified that the provider viewed FGC as an abnormality. There was unfamiliarity and a lack of understanding of the term female genital cutting among participants.

Participants also discussed that a positive childbirth experience included having a health care provider that was patient and respectful, and many women indicated the importance of the delivery process not being rushed. Dissatisfaction with health care providers largely stemmed from their lack of patience i.e. rushing the childbirth process, the language used (described above) and interactions that the participants perceived as rude. Women noted a very positive experience and good interaction with obstetricians. However, interactions with other providers, particularly with nurses, varied widely. While some participants recalled polite interaction where they felt respected, others reported that nurses rushed them, were impatient and rude. The quote below highlights the types of friction that were typical of negative participant-nurse interactions.

The nurses are not patient. Some don't like when the ladies scream, they say close your mouth you opened your legs for a man. They have too much stress, it is a stressful job. If you scream they talk to you seriously. Not a lot of compassion.

Another obstacle that participants encountered was a language barrier that made some women not feel welcomed by health care providers and affected their interactions and childbirth experience. A number of participants emphasized a desire for Somali or health care providers that know about FGC, as well as the consistent offer of translators available to accompany them in the health care setting. As illustrated in the quote below, participants felt that having people like themselves present in the health care setting was essential to them feeling welcome. "They should welcome us. The language barrier is hard. They should have a translator. They should have more Somali doctors. I would like a doctor that knows more about FGC."

Care providers are undoubtedly aware of some of the challenges that Somali-Canadian women may experience on the delivery ward, and one women noted attempts by staff to provide culturally appropriate care. In this example, she reports: "They brought an African lady to talk to me. I didn't know why she was there. They told me that she was a lady brought to help me, but I already had a nurse. The second day the African nurse came to me. I think they brought her to relate to me culturally." As this example illustrates the Somali-Canadian participant did not feel a connection to this African nurse. In fact, one participant reported a negative encounter with an African nurse, "My nurse was very bad. She was impatient, and mean. Whenever I asked questions she would say "you know better than me". Like she was judging me. She was an African lady." As demonstrated in these responses, current strategies for providing culturally appropriate care are insufficient.

#### **Preference for Natural Birth**

A central aspect of childbirth experiences was characterized by a strong preference for a vaginal delivery, referred to by participants as 'natural birth'. This preference was largely associated with an aversion to induced labour, fear of C-sections and trust in Allah (God). The first aspect of the natural birth process that was emphasized by participants was that the delivery process should should not be rushed. Participants held a common perception that labour should start when contractions are felt. Unfortunately, Somali-Canadian participants also felt that health care providers frequently tended to disregard the natural rhythm of birth in favor of a timed schedule set in advance. The comments below highlight how common obstetric practices, like calculating due date, can be at odds with Somali-Canadian participants' views of natural birth.

A human being should be allowed to have contraction and allow the child to be delivered according to their time. They keep calculating based on a due date, they don't wait for natural birth and rush induced labour. It leads to more C-section. Allah knows how long a pregnancy will last. You should not force contractions. They should allow you to be ready.

They said I'm at 40 weeks, you have to give birth. I said no, not until I feel contractions. They said we will give you 10 days, and after 10 days I still did not give birth. So I got a C-section. I said no at first because I wanted natural birth.

I wanted a normal delivery. But she already put in my file that I will have C-sections. When I had contractions, I arrived and they said I will have C-section. I fought that. We fought and they brought another doctor. They tried to push me to have a C-section. My husband talked with them.

The quotes above emphasize that women perceive Canadian obstetrical practices as creating more opportunities for intervention, and interventions as being at odds with their cultural and religious views of childbirth. As the participant stated "Allah knows how long a pregnancy will last." Pregnancy and birth were perceived as being under the control of God, and occurring naturally when contractions are felt, and not needing for what was perceived as extra intervention by obstetricians.

These participants also outline an awareness of how prohibiting pregnancies that last longer than 42 weeks as well as inducing labour increases the risk of C-section. The aversion of induced labour was strongly related to a fear of C-sections, which in Somali is translated as *galeen* meaning "slaughter." Participants viewed C-sections as leading to more complications than a natural birth for an infibulated woman, such as causing infection, harming the infant, interfering with daily activities such as the women's caretaker role, and burdening other family members who temporarily assume the women's daily responsibilities/roles. These concerns are reflected in the following quotes:

A C-section can lead to your stomach opening later on or an infection. You cannot carry heavy things for a long time afterward, and it will be hard to take care of your children.

C-section you can't do your work, they will make stiches on your stomach, you can't do anything. But a natural birth you can do all your work afterwards. The C-section can damage you and your baby. You will lie down for two weeks. My friend, when she had a c-seciton the family had to take care of her and the baby.

Furthermore, participants worried that obstetricians might choose to perform C-sections because of limited experiences of providing care for women who have undergone FGC. Women indicated for their first childbirth experiences in B.C, that it was very important to have a natural delivery. One woman's response demonstrates the importance, as she described "If you deliver normally the first baby they probably will not pressure you to have C-sections for the next deliveries. If they start with your first baby with C-section they will keep making you have C-section." This shows that women perceived that factors other than medical necessity, such as women's previous childbirth experiences influenced an obstetricians decision to perform a C-section on a patient. As illustrated by the quote below, the women viewed natural birth as an easy and straightforward experience regardless of FGC.

A natural birth is easier than a C-section for a woman with female circumcision, you just open up the stitches and you can have a natural birth.

Still, a lot of ladies went under a C-section because they do not know about circumcision. A lot had a C-section because the doctors did not have experience delivering a lady who has female circumcision.

More alarming, participants were concerned that obstetricians might choose to perform C-sections due to profit. This further demonstrates the concern women expressed, that

obstetrician's decision to perform a C-section was influenced by other factors other then medical necessity. The following quote illustrates this perspective.

It is easier to allow Allah given natural birth. The doctors rush because it is a business they make more money from C-section.

Although the participants preferred a natural birth, women reported acceptance of a C-section procedure if they were given more time to decide, and if the health care providers communicated the reasons why this procedure is medically necessary for the health of the child.

It is fine if the child is in risk. I had a normal child, they didn't tell me, they need to make sure it is needed.

The first time it was too much of a rush at a check up. After the other ones I had more time to think over the decision, they also made more sense. I had labour, so I understand why they asked me to do C-section, to prevent the child having damage.

I was happy because they explained everything. There was no rush. I was only shocked the first time. The first time they sent counsellors who explained it. They said it is normal, it is for your life and the healthy. They should make sure the person understands.

These quotes illustrate that more effective communication is required between health care providers and Somali women, particularly regarding explaining why C-sections are medically necessary for the patient. Women overall, had a distrust of health care provider's decision to perform C-sections, so providing effective information, particularly from a trusted source is essential.

#### Differences in Biomedical and Somali cultural practices

Many women compared their childbirth experience in Somalia to hospitals in British Columbia (B.C), and participants described both positive and negative observable differences in biomedical and Somali cultural practices for childbirth. Women described a number of improvements that they perceived birthing in hospitals in B.C, such as appreciation for the availability of clinical care, a healthy environment to deliver as well as the attention that they received for their care. A notable positive aspects of childbirth management in BC was the orientation toward pain. Women were very satisfied that staff offered them pain relief, with one women commenting "I liked that they gave me pain relief that reduced the pain for the labor". Overall, participants felt staff supported them through pain and that there was reduced stigma in B.C towards women expressing pain during delivery in comparison to Somalia.

Participants also comment on the different role of men in childbirth in B.C. Women expressed surprise with cultural childbirth customs in British Columbia of a husband being present in the delivery room. Women's reaction to this custom ranged from feelings of embarrassment, bemusement to welcoming this support. One woman explained, that as a newcomer and not having other family present, her husband was a crucial support system during the childbirth process in B.C. "I did not have any family. I was afraid of the non-Somali people to be alone. I

came here when I was young, he was the only one. If you have your family here, then you can decide." The response also demonstrates, that having more family members, would give the women more options between choosing Somali childbirth practices of having women family members present for the delivery versus the biomedical norms in B.C. Furthermore, women expressed a preference for female health care providers, and described a male obstetrician assisting with the childbirth process as embarrassing and not compliant with religious customs. One women explained her preference saying "I want a woman. It is embarrassing for the man to see me. And because of my religion he cannot see me like that".

Women were shocked to hear certain phrases used by health care providers during delivery, in particular the phrase "not too push." "My nurse was bad during my delivery, when the baby was about to come out she said don't push. I was shocked with that comment when I was in so much pain". While in Somalia, a woman's natural urge to push is regarded as the signal to begin, whereas in B.C. a care provider's assessment of cervical dilation is needed to authorize pushing. Many of the women reacted with surprise when told not to push despite the fact that their body was urging them to. This disjuncture resulted in increased dissatisfaction with care provided.

Finally, vaginal examinations and the use of fingers to determine dilation were noted as shocking, unfamiliar and painful. These experiences are described in the upcoming sections.

## Desire for greater decision making capacity

The childbirth experience was characterized by a limited autonomy and desire for greater decision making capacity regarding the delivery process. Almost all women described feeling rushed during delivery. As outlined above, the rushed delivery was viewed as competing with a women's desire for a natural birth, and one participant stated that during the delivery process "the person should have more choice". Nevertheless, participants felt uncomfortable or afraid of expressing their displeasure, with one participant describing how she "wanted to complain, but I did not think I have the power to complain. I have never seen anything like the delivery here, I gave birth previously to children in Africa." This demonstrates the power asymmetry between patient and provider regarding decisions-making during the delivery process.

Navigating the health care system as a newcomer was challenging, due to language barriers, differing customs, and a fear of legal repercussions, all which affected decision-making capacity. Women expressed fear that non compliance with health care provider decisions regarding delivery could result in repercussions including legal liability, involvement from child protection services, and/or influence a health provider's decision to perform a C-section as opposed allowing a natural delivery. Women described the process of being asked to sign liability forms as creating significant fear. This fear was heightened when women were newcomers and unfamiliar with the health care system. In many cases, women felt they had no choice but to have a C-section performed against their will. The following quotes illustrate this point:

People new here are scared, they did not read properly. They sign because you may get reported.

They made me liable, and they made me sign a form if I did not agree with their opinion [about delivery]. Allah knows what can happen. I signed the forms because I was afraid.

They looked at my baby's position and said we have to deliver. I said I'm not in pain, my friend was with me. They told me if I leave they will call the police. I thought they would take away the kids. I accepted whatever they said, I signed the form.

They said to me if I don't undergo a C-section and the baby dies, you and her husband will go to jail.

These comments demonstrate concerning power-asymmetry and lack of patient decision-making regarding obstetrician decision to preform C-sections. Participants felt that increased number of years of residence in Canada resulted with increased knowledge of the system and greater confidence in advocating for one's desires during childbirth.

#### Clinical care for FGC

A major area of discussion for participants regarded how health care providers in Somalia, who are experienced providing care for infibulated women, provided appropriate prenatal care, while physicians in BC lacked experience and therefore, did not always provide the best clinical care. One example that participants provided to illustrate this contention concerned provider support to prevent obstetric complication such as rectal lacerations. For example, one women commented [in] *Somalia they use more protection, they [obstetrician] hold your bottom during delivery, to make sure no cut or hole develops between the rectum and vaginal opening.* Participants also highlighted that other areas where they perceived clinical care as inappropriate for women with female genital cutting. Below we discuss three specific areas highlighted: vaginal examinations, de-infibulation and re-infibulation.

#### Vaginal Examinations

The biomedical childbirth practices experienced in British Columbia, most notably vaginal examinations by obstetricians, were regarded by participants as unfamiliar, uncomfortable and an overall painful process. Vaginal examination refers to a health care provider inserting fingers into the vagina of a woman to check progress of labour. While vaginal examination is routine in many parts of the Western world, the WHO regards evidence supporting a positive effect on outcomes as lacking (Downe et al., 2013). Most of the women were surprised by the procedure, which is not used in Somalia. This surprise and unfamiliarity can be noted in this participants description of the examination "It was a surprise that they used their finger to check me during the visit. I said why did they have to do that, I got mad and it was something new to me, I told all my friends. They told me it was to see how big the head is [dilation], that was my first check up. It was painful, she used a metal and finger. I will never forget that." The general discomfort of participants with regard to this foreign procedure is represented in the previous quote. It is important to note, that the narrow neointroitus and infibulated scar provides a barrier making it difficult to performing vaginal examinations. Given the shock and surprise to this procedure, communicating information to patients is crucial, however proper and timely communication was sometimes absent, for example one women mentioned only being informed for the purpose

of procedure afterwards. Another woman also perceived that the procedure led to negative health outcomes, such as difficulty with bladder. The timing of de-infibulation also significantly affects the level of pain during the vaginal examination.

## De-infibulation

Participants highly valued reducing pain during childbirth, and proper clinical management was seen as key to this. Women with type 1 and 2 FGC, Sunnah circumcision, are not as likely to experience obstetric challenges (Nour, 2004). However, for women who are infibulated, greater care is required because infibulation leaves a very narrow neointroitus (vaginal opening). Furthermore, infibulation increases the risk of perinal tears, infection, separation of epistomy, and postpartum hemorrhage (Nour, 2004). The infibulated scar and narrow opening creates a barrier that can result in brain damage and intrauterine fetal death (Nour, 2004). Therefore, deinfibulation, is a necessary procedure for infibulated women during childbirth, which involves removing the mechanical barriers of the suture at the introitus. Infibulated participants viewed performing de-infibulation at the correct time during pregnancy and birth as essential to reducing pain during delivery and preventing obstetric challenges.

FGD participants perceived that care providers in BC either performed de-infibulation too early or late during the childbirth process due to a lack knowledge on how to provide care to a woman who is infibulated. While a woman can be de-infibulated during pregnancy, participants perceived that the correct timing was at the start of labour. The following quote highlights this perception: It is better to open the stiches when the person is in labour. If it is done before, it will be painful until you give birth. It is better the time the baby is coming. De-infibulating at the correct time helps mitigate unnecessary pain and women described feeling significant pain due to the obstetrician waiting too long to de-infibulate. "They let us go through too much pain. The baby can die because they wait too long to de-infibulate". The experiences women reported shows that appropriate timing of de-infibulation was a significant concern during the childbirth process.

Lack of appropriate timing of de-infibulation led to a fissure between Somali-Canadian women and their non-Somali Canadian care providers. One woman said: *They look at us like we are herd animals because they wait too long to unstich us during delivery.* In this quote, she refers to the fact that animals are treated callously, while people deserve more compassion. By asserting that care providers "look at us like we are herd animals" this participant is drawing attention to the fact that providers do not do enough to mitigate unnecessary pain during birth.

Overall during the childbirth experience, women indicated a need for more support. Women who have undergone FGC, particularly infibulation have severe perineal trauma, and require additional and extra care. Although women described appreciation for the support they currently received, on call staff and other services provided, they also felt that given their increased need for greater care, even more support should be provided. They need to provide more care for women with circumcision, especially if the woman is new here. They need to learn to deinfiublate early during delivery to prevent pain and other problems. Additional care was thus seen as one solution to improving the clinical care Somali-Canadian women received.

#### Re-infibulation

Re-infibulation refers to sewing the external labia back after de-infibulation. Most of the women who had undergone infibulation expressed an expectation that obstetricians would re-infibulate after delivery. The expectation that the vaginal opening would be re-stitched was associated with the perception that a smaller vaginal opening was normal and beautiful. One woman described this preference for re-infibulation "If they open I want them to close it back. I want it to be beautiful there, they already cut it, I don't want it to be left open. It will be too big. I don't want an open door". An opening that is too big is perceived as abnormal and unattractive thus re-infibulation was an expectation that was held.

All of the women who had asked for re-infibulation after delivery indicated that the obstetrician complied with their request. "In Somalia, they cut and restitch it afterwards. They did the same here." and another woman commented that "There was no problems, and they never said anything about restitching here." Indeed, re-infibulation was relatively uncomplicated between patient and care provider.

#### 8. Discussion

The findings show that there is unmet need regarding clinical care of FGC and patient-provider interaction, during childbirth for infibulated Somali women in B.C. Significant findings from the focus group discussions include: tension between Somali women's preference for a natural birth and perceived extra medical interventions by obstetricians; management of FGC during delivery i.e. timing of de-infibulation; a lack of effective provider-patient communication; and patient-provider power asymmetry which affects Somali women's decision-making during the childbirth process. Understanding the experiences of women who have undergone FGC, in particular infibulation can help address the unmet needs regarding appropriate clinical care for FGC during childbirth.

Somalis strong oral-based culture was reflected in women reporting that they received advice and information by word of mouth regarding health care provider interactions, experiences and preferred hospitals. These experiences and care provider interactions can influence health seeking behavior and may provide a barrier to seeking antenatal care (Nour, 2004). Women described a fear of stigma from health providers before health care visits and delivery, which can be associated with previous personal or peer experiences. Factors associated with dissatisfaction of obstetric care among Somali women were the experiences of judgment from providers, stigma, harmful comments, overall feeling rushed during delivery and limited autonomy.

There was a very strong preference among the Somali women for a natural delivery, and a belief that the childbirth process should not be rushed. The preference among Somali women for reduced intervention during child birth and a desire for a natural delivery is well documented in the literature (Chalmers & Hashi, 2002; Deyo, 2012; Missal et al., 2016). Women reported a strong aversion to induced labour and a fear of C-sections. In biomedical standards, induced labour is offered when a pregnancy is considered overdue after 39-40 weeks, and this was in

direct conflict with many of the women's perceptions of Somali cultural birthing practices, which views a typical gestation as 42 weeks (Deyo, 2012). Women felt that childbirth delivery should follow a natural rhythm of birth and start when contractions are felt. Many participants perceived that obstetricians did not give sufficient time to allow for a natural delivery, and that the healthcare providers practices favored interventions such as induced labour and C-sections. However, the perception among Somali women of experiencing increased intervention by obstetricians i.e. C-sections is also supported by the literature, with a systematic review of western countries such as Canada, showing that Somali women had disproportionally higher caesarean rates (Merry et al., 2013).

The aversion to C-sections among the women stemmed from perceptions of of negative social and health outcomes, and religious beliefs. Women perceived C-sections could cause infections, affect mother and child health, and the recovery time interfered with caretaker responsibilities and the women's daily roles. In Somalia new mothers rest indoors with their baby for 40 days' post-partum, which is known as afantanbah, a cultural practice where female relatives take care of household duties, however studies show that practice is often not observed due to resettlement fracturing family structure (Merry et al., 2013). Since afantanbah is often not practiced after resettlement, C-sections create added recovery time post-partum, which caused concern for some of the women. Since 99% of the Somali population is Muslim, Islamic religious beliefs influenced expectations and experiences around childbirth. In particular, women felt that labour would start "when Allah wills" and that it should not be induced. However, despite fear and dislike of C-sections, women were accepting to undergo the procedure if it was medically necessary for mother and child health. Women expressed greater acceptance of the C-sections when they receiving information indicating medical necessity and given sufficient to make the decision with their spouse.

The management of FGC during childbirth, especially to avoid complications such as obstetric fistulas, were considered very important by the women, and most notably the women had expressed dissatisfaction with management of de-infibulation and vaginal examinations. The timing of the de-infibulation procedure is crucial in preventing obstetric complications and to reduce pain during vaginal examinations. The women interviewed indicated a strong preference for de-infibulation after the onset of labour, yet the Royal College of Obstetricians and Gynecologist clinical guidelines recommend antenatal de-infibulation be performed either during early pregnancy (before 20 weeks of gestation) or the second trimester to prevent obstetric challenges during delivery (Rashid, M & Rashid M.H, 2007; RCOG, 2003). Antenatal deinfibulation allows health care providers to diagnose and manage potential complications pregnancy including: urinary tract infections, vaginal infections and heck proteinuria (Rashid, M & Rashid M.H. 2007). Additionally, antenatal de-infibulation removes the mechanical barrier at the introitus, which facilitates for easier vaginal examination and reduces pain. This has obstetric implications, since the narrow neointroitus and scar of infibulated women, poses a significant problem for stage 2 of labour, and can prolong labour and inhibit fetal descent (Nour, 2004). Antenatal de-infibulation facilitates for an easier delivery, and decreases the risk of perineal and vaginal lacerations, and in fact "once defibulated, patients have the same incidence of operative deliveries as the general population" (Nour, 2004). Thus antenatal de-infibulation is a crucial aspect of managing obstetric challenges for infibulated women. Antenatal de-infibulation also increases the ability of the health care provider to monitor fetus descent in labour, and delaying

de-infibulation until the onset of labour results in an increased risk of C-sections (Rashid, M & Rashid M.H, 2007). The difficulty of fetal monitoring, along with a lack of adequately trained obstetricians at the time of childbirth, is associated with higher rates of C-sections performed for infibulated women (Starus et al., 2009). Notably, most participants in this study declined health care provider recommendations for antenatal de-infibulation.

Antenatal de-infibulation also can allow for less painful vaginal examinations for infibulated women. Antenatal vaginal examinations allow health care providers to determine the extent of a physical barrier at the vaginal opening, as women with a narrow introitus are at an increased risk for major perineal damage, such as a tear between the anus and vagina (Rashid,M & Rashid M.H, 2007). Given that women described significant discomfort during vaginal examinations at antenatal visits, greater efforts are required to communicate the purpose and effects of antenatal de-infibulation. Promoting antenatal de-infibulation can reduce discomfort and pain women described during vaginal examinations. Furthermore, promoting antenatal visits will allow health care providers to prepare for clinical care required for women with FGC, and studies have shown that lack of attention before childbirth can lead to a bias towards performing C-sections (Struass et al., 2009). Part of promoting antenatal visits with health care providers, requires improved positive interactions with women who have undergone FGC, including language used, comments, lack of judgment, and respect.

Patient-provider power asymmetry which affects Somali women's decision-making during the childbirth process was also evident. While health care providers ostensibly use written forms enrich the process and documentation of patient consent, our data shows that the effect on Somali women giving birth in BC is actually the opposite. Rather than ensuring consent, obtaining written consent from patients with terms such as legal liability, is actually perceived as a potential threat. The findings show that there is a fear among Somali women that non-compliance with health care provider decisions can lead to legal liability, child protection services involvement, and a bias toward providers performing C-sections. Ultimately, this fear significantly reduces patient participation in decision making, let alone patient autonomy. Limited sense of self-advocacy, informational and power asymmetry between Somali women and provider interaction is also noted in the literature (Gurnah, K., Khoshnood, K., Bradley, E., & Yuan, C., 2011). Communication of procedures for delivery should be in a way that conveys sharing of information to reduce power asymmetry, and communication by health providers should avoid terms that involve legal repercussions i.e. calling the police.

Effective patient-provider communication is essential for could mitigate tensions, build trust and reduce dissatisfaction experienced by Somali women who have undergone FGC, during the childbirth process. Communication issues, such as medical terminology and complicated language have also been noted in this study, as well as the literature regarding Somali women and their interactions with providers (Straus et al., 2009). An important aspect of health care provider interaction is using language terminology that is understood by patients and reduces barriers to care. In particular, women expressed a preference for the term 'female circumcision' as it was a literal translation from Somali.

Differences in biomedical and Somali cultural practices were noted, and women feared that providers would not accurately know how to care for an infibulated woman. This fear among

Somali women of providers lack of knowledge is documented in the literature (Nour, 2004; Johansen, 2006; Straus et al., 2009). As such, and also reported in the literature, women felt that appropriate care tailored for FGC was limited and that providers would not provide extra care required to prevent obstetric fistulas, as midwives in Somalia (Deyo, 2012). It is also important to note Somali women reported experiences of positive aspects of childbirth, for example women reported an appreciation for care received, support from providers, pain relief management, and respectful encounters with providers, however as previously discussed there still remains largely unmet needs regarding appropriate clinical care for FGC and provider-patient interaction.

There is a need for tailored an appropriate care for women who have undergone FGC, in particular infibulation. Currently is a disconnect between SOGC policies and provider actions, an example of the disconnect is that many of the women who were infibulated, had an expectation, to be re-infibulated after procedures, and obstetricians complied. Recommendations are discussed in an upcoming section.

## 9. Strengths and limitations

The strengths of this study included conducting the FGDs in Somali, to ensure that all participants felt comfortable communicating and sharing their experiences. Having a Somali woman who gave birth in B.C, along with an all female Somali staff helped create a supportive environment. One participant had mentioned that she trusted talking about this topic with other Somali women, which shows that having a female Somali staff for the FGDs was conducive to creating a trusting atmosphere, and thus women were able to share more of their experiences, which improved reliability and credibility of the findings. The FGD method was also a strength, as the discussions allowed women to build on each other's comments, with many sharing similar experiences. A supportive environment was demonstrated when women even shared childbirth advice with other women. The use of a verbal consent and de-identifying names was a strength, as women did not want their names kept on records, primarily citing a fear of social services and legal repercussions associated with FGC. The PI was present for all FGDs, and was very familiar with the data, which assisted with being able understand and analyze the data. The PI, being from a Somali background, and having a shared cultural understanding and background with participants, also assisted with the analyses and understanding of the data. Furthermore, the PI had an extensive Somali network, and was able to identify recruiters that were trusted in the community.

However, the findings should be interpreted with certain limitations in mind. Limitations involve not using an audio-recorder, but rather note-taking for the FGDs, which meant not being able to record all comments during the FGD. Steps to mitigate this limitation were taken by having 2 note-takers. Having only the PI coding was a limitation, since 2 or more coders could improve reliability of the findings. Another limitation was not being able to interview other individuals involved in the childbirth experience of women who had undergone FGC, such as spouses and health care providers. Interviewing spouses and health care providers who would contribute to developing a greater understanding of the process and potential support required. There were also barriers to attending the FGDs for women with younger children, such as care-taking, as only one of the FGDS had caretaker. Another barrier to participating also was transportation, especially for women who lacked access to a vehicle. Lastly, not having a separate focus group

for member checking was a limitation as this would increase the trustworthiness of the data analysis and interpretation. The PI attempted to mitigate this limitation by summarizing points during the last FGD and checking with participants.

## 10. Moving Forward, Recommendations for SOGC

The Society of Obstetricians and Gynecologists of Canada provides health providers with a number of guidelines to promote good care for women, like participants in this study, who are infibulated. Among these are an emphasis that providers be careful not stigmatize women, a focus on knowledge and skills in managing FGC, a recommendation to add information on FGC into curricula for health care professions, a focus on cultural competency, as well as discussion regarding how to decline to re-infibulate women you deliver. While SOGC recommendations currently are strong in representing provider perspectives, this research on Somali-Canadian women's perspectives on birth uncovered additional recommendations to that should be include.

- 1. Promoting cultural safety as opposed to cultural competency
  - Given Somali-Canadian women's dissatisfaction with interactions with care providers, feelings of being stigmatized by providers and fear at expressing discontent, cultural safety rather than cultural competency should be promoted among health providers to guide clinical interactions. Cultural competency allows for increased understanding of patient perspectives by focusing education of health providers on a patient's culture (Kirmayer, 2012). Cultural safety, on the other hand, is focused on producing safe interactions between health care providers and patients. (Kirmayer, 2012). Cultural safety achieves this by drawing a provider's attention to the larger social context of interaction and requiring that health providers examining their own positions, roles and attitudes (Crampton et al., 2003). As interactions between Somali women and health care providers demonstrated power asymmetries as well as a feeling of limited autonomy, i.e. participants felt threatened with legal repercussions and police for not consenting to obstetrician procedures. Practicing self-reflexivity could allow providers to become conscious of these realities and positively influence interacactions with participants.
- 2. Knowledge translation concerning positive effects of antenatal de-infibulation
  - As described in the discussion, there were opportunities for knowledge translation to improve infibulated women's childbirth experiences, especially regarding antental de-infibulation. While Somali-Canadian women are currently reluctant consumers of antenatal care and in general refuse antenatal de-infibulation, this study revealed a number of their concerns could be attenuated through such care. Knowledge translation materials that acknowledge and address how antenatal care attends directly to Somali-Canadian women's pregnancy and delivery concerns would be important to encourage better use of antenatal care. For example, women described a fear of C-sections, pain, epistomies and perineal tears. Promoting knowledge translation, could communicate to patients who are infibulated, that antental de-infibulation reduces the risk of C-sections, pain and

epistomies from a trusted source could be an effective strategy towards safer deinfibulation practices.

- 3. Acknowledging and celebrating the important role of community support in women's life and reproductive decision-making
  - Current Canadian guidelines regarding FGC emphasize a women-centered care approach, with a view of western understanding of female autonomy that is focused on the individual's needs. This approach has an implicit focus on the immediate health of the mother during pregnancy and birth, and while this approach is important in providing care that is tailored to patients needs, a central aspect of what women need for a good childbirth experience is not addressed. The autonomy framework does not fully address how Somali women are situated in social relations and connections that influence childbirth and reproductive decision-making. Especially given that Somali culture emphasizes interconnectedness of the community and prominence of oral culture, which was demonstrated through how information is shared by word of mouth (Lightfoot et al., 2016). Sharing of information and social connectedness also extends to sharing health information (Lightfoot et al., 2016). The data from this study showed the importance of Somali community identity in defining women's desires around birth. Responses from participants in this study indicate that Somali women in the community share advice about childbirth experiences, i.e. whether to de-infibulate before or during labour. The focus groups also highlighted the important role Somali husbands play in terms of support and childbirth decisions (Gurnah et al., 2011). As reported by Somali women in this study, immigrating to Canada, often as refugees, meant losing traditional support women had in Somali during the childbirth process (i.e. other women in the family). Women described husbands as a crucial source of support during childbirth and with reproductive decision-making. For example, responses indicated how husbands would communicate with health care providers against performing a C-section. Therefore, a women-centred approach emphasizing female autonomy, does not take into consideration the other members of the community that influence childbirth process and needs. Acknowledging the role of community support, and understanding autonomy from a framework that includes social relationships, as opposed to individualism can improve understanding factors that affect Somali women's reproductive decision-making and childbirth experience (Mumtaz, 2009).

#### 11. Conclusion

The findings gave a greater understanding of obstetric care experiences of women who have undergone FGC, in a context where FGC is uncommon. Greater attention is needed towards promoting respectful patient-provider interaction that reduces stigma and barriers to care. More attention is also needed on how to improve de-infibulation practices and support for women who

are infibulated. To get a greater contextual understanding of the childbirth process for Somali women, and women who have undergone FGC, it is necessary to gather data from all those involved or affecting the childbirth process, including: obstetricians, midwives, spouses, community members.

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## 13. Appendix A – Focus Group Interview Guide

Opening remarks. Verbal consent.

Give tea/refreshments. Ask everyone to introduce each other/ice breaker.

#### **General Questions**

- 1. How long have you lived in British Columbia?
- 2. How many children do you have?

## **Group questions**

- 1. Which term do you prefer be used by health care providers for female circumcision, and why?
- 2. What type of gudniin (female circumcision) do you have?
  - a. Sunniga (Type II), Fircooniga (Type III) or other
- 3. What do you think a good birth looks like? Can you describe this?
  - a. Probe -What expectations did you have about childbirth?
- 4. Can you describe your hospital childbirth experience?
  - a. Can you give examples of how health care providers talked with you?
- 5. Can you describe how your obstetrician care provider interacted with you, during your childbirth experience?

Probes

- a. Did you think having gudniin (female circumcision) influenced your obstetrician care experience in any way?
- b. Were you satisfied/happy with the care you received?
- c. Did the obstetrician perform de-infibulation before or during childbirth?
- d. After childbirth, did you want to undergo re-infibulation? If so, did a care provider re-infibulate you? What happened?
- 6. What are some suggestions on how obstetricians could improve care provided?
  - a. Given your experience in the hospital, what is the best/most important thing the obstetrician can do to make you feel more comfortable?

# 13.1 Appendix B – Focus Group Interview Guide Somali

Focus Group Interview Guide Somali- Wareysi Wadareed

#### **Wareysi Wadareed**

Ogalaansho qiraal afka ah.

Qofwalba hala siyo shaah iyo cunto fudud. Waydii qofwalba inu isbaro qofka kale.

#### Su'aalaha Guud

- 1. Immisa sano ayaad ku noolayd British Columbia?
- 2. Immisa carruur baad haysataa?

#### Su'aalaha wadareed

- 1. Qaabkee u jeceshay inay u isticmaalaan dadka caafmadka daneeya ka hadalka gudniinka dumarka? Iyo sabab?
- 2. Noocee ayaa laguu gudey?
  - a. Sunniga, Fircooniga ama nooc kale
- 3. Maxaad u malaynasaa dhalmada ficaan inay ahaan karto? Fadlan faahfaahin ka bixi?
  - a. Maxaad filaneysay marka ilmuhu dhalanayo?
- 4. Ma faahfaahin kartaa waaya aragnimadii aad ka heshay ku dhaliddii Isbitaalka?
  - a. Tusaale naga sii sida dadka caafmadka ka shaqeeya kuula hadleen?
- 5. Fadlan faahfaahin naga sii sida dhaqtarkii umulisada kuula dhaqmay/ama kuula dhagantay xiliigaad ilmaha dhashay?
  - a. Ma u malaynasaa gudniinka dumaarku inuu saamayn ku samayn karo waayo aragnimada umulisooyinka?
  - b. Ma ku qanacsanayd/ama faraxsanayd sida laguugu xanaaneeyey isbitalka?
  - c. Dhaqtarkii umulisada miyey gudniinkii furfurtey waqtigii dhalmada kahor ama waqtigii dhalmada dhexdeeda?
  - d. Dhalmada kadib, miyaa rabtey in gudniinkagii dib loo xiro? Dhaqtarkii umulsida ma ku xirtay/ ama ma ku xiray? Maxaa dhacay?
- 6. Maxaa talabixin ah oo dhaqaatiirta umulisada la siin karaa si ay u kordhiyaan daryeelka caafmadka ay bixinayaan?

Waayoaragnimada aad ka heshay isbitaalka, maxa uguu wanaagsanaa oo dhaqtarku samayn karo si aad dareentiid

## 14 Appendix C - Verbal Consent Script



## **Verbal Consent - Focus group discussions**

Somali women's experiences with obstetrician care providers during childbirth

#### Introduction

The overall goal of this study is to explore Somali women's experiences with obstetric care providers during childbirth in hospitals located within British Columbia (B.C). This research is being conducted as part of a Masters of Public Health capstone project, by the principal investigator Halima-Sadia Elmi, and under the supervision of Dr. Nicole Berry. You are being invited to participate in a group conversation to talk about your experiences, knowledge and opinions, which are very important to this study. Subsequently, based on the experiences and insights you share, recommendations will be made to improve obstetrician guidelines. We would very much appreciate your participation.

#### What Happens in this Research?

If you agree to participate in this group conversation, you will be asked about your experiences with obstetric care providers during childbirth. This study is about your birth experience. As we are in Canada, there are different cultural norms regarding how they view female circumcision. While it is routine for us in Somalia, here they view circumcising children as abuse. Because of this, we will not talk about whether or not you want to, will or have circumcised your daughters. This is important because Canadians view circumcising daughters as illegal and as researchers we would be obligated to report this to child welfare as evidence of child abuse. I will not ask you any questions about circumcising your daughters and should we veer off topic, I will interrupt and bring us back to talking about your birth experiences here in the hospital. Does anyone have any questions about this?

There will be approximately 6-7 participants in our group discussion, all of whom will be Somali women who have given birth in B.C. Our conversation will last about 1 to 2 hours. A Somali woman who has given birth in B.C will be leading the group conversation. Two note takers, who are also Somali women, will take notes while you talk so we can remember what we learn from you.

Your participation in this group conversation is voluntary. There are no right or wrong answers. We are inviting you because we want to hear your thoughts, though you can also decide at any time not to answer a question. If you decide to participate, you have the right to stop participating or withdraw at any time, and with no penalty.

#### **Risks and Discomforts**

There are no known physical risks for participating in this study. The major risk identified is that someone else might be able to tell that you participated in this study. We will do everything we can to protect your privacy. The only personal identifier we will ask for is your first name. While we want to use the information that we collect to write academic papers and presentations, we will never use your name or tell anyone that you participated in this group conversation. While we may report what you said in our academic papers, we will make up a name and assign it to you, so nobody can tell it was you. Nevertheless, if someone knows you well, there is a small risk that s/he could still identify a story as yours. Since you will be sharing information in a group setting, we cannot guarantee confidentiality of the information you share. You may also feel discomfort from being asked to share your thoughts in front of the other members of the group. Your participation is voluntary; if you are every uncomfortable, you can always stop contributing to the conversation or leave the room without any problem.

#### **Privacy and Withdrawal**

Your interview data will be handled as confidentially as possible. What is said here should not be told to anyone outside of this group. I will make every effort to preserve your privacy. You will never say your last name and we will use a fake name rather than your first name in our own notes. During the group discussion, if the names of any Canadian doctors are mentioned, these names will be kept confidential and not included in the final report. All notes recorded from the group discussion will be stored on a password protected laptop drive, only accessible to the principal investigator and senior supervisor, while I am writing about my results. Once I am done writing, the notes will be saved on a USB and stored in a locked cabinet in the locked office of the principal investigator's supervisor at Simon Fraser University until August 2019. After this time, they will be erased.

If at any point during our discussion you decide that you don't want to continue, you are free to leave. Should you request it then, I will delete any information you shared with the group discussion. However, once our group conversation is over, I will not be able to go back and delete what you said, as I will have removed all personal information from my notes and will be not be able to find or identify only what you personally said.

If you are experiencing health complications due to your birth, below is a list of doctors you can contact:

- 1. Access clinic. Tel: 604-875-3290, Address: 4500 Oak Street, Vancouver
- 2. Crossroads Obstetric & Gynecology. Tel: 604-872-5484, Address: 507 West Broadway Ave. Referral needed.
- 3. South Surrey Medical clinic. Tel: 604-542-7788. Address: 101 15850 26<sup>th</sup> Ave

#### Questions

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you may contact Dr. Jeffrey Toward, Director, Office of Research Ethics <u>itoward@sfu.ca</u> or 778-782-6593. For any questions regarding the study, you can contact the Principal Investigator at: helmi@sfu.ca or 778.712.9301, and the Senior Supervisor Dr. Nicole Berry, at: nsb4@sfu.ca or 778-782-8492.

We will ask you if you agree to participate in this study verbally, giving consent means that you have heard the information about this study and that you agree to participate.

If you agree and say "yes I agree to participate" then we will start the group conversation. Does anyone have any questions?

Do you agree to participate in this study?

14.1 Appendix D – Verbal Consent Script- Somali

Xeshiis Afka Ah- Dood-Wadareed

Waaryo araagnimada dhumarka Somaliyeed ay kala kulman dhakhtarka ummilinaya waqtiga dhalmada

#### Xorudhac

Hadafka darsiddan waxa weeye fahmidda waaryo araagnimada dhumarka Somaliyeed ay kala kulman dhakhtarka ummilinaya waqtiga dhalmada isbitalada ku yaalla British Columbia. Cilmi baaristan waxaa samayneeya Halima-Sadia Elmi, waxaana la taliye ka ah Dr.Nicole Berry, si lo dhammeystiro Master degreega caafmaadka dadweynaha. Waxaa lagugu martigaaday inaad ka gayb gashid dood wadareed ku sabsaan waaryo araagnimada, ciilmigaaga iyo fikradahaaga. Waayoaragnimida iyo xogta aad nala wadagtay waxaan sameynaynaa soo jeddiin la xiriirta horumarina iyu tallaabooy ink aka habboon umulisooyinka waanu kaaga mahad celinaynaa ka gayb galkaaga.

## Maxaa Dhacaya Cilmi baaristan

Haddii aad waafaqdo inaad ka qayb gashid dood-wadareedkan, waxa lagu weydiin doona waaryo araagnimada la xiriirta dhaktarka ummilinaya waqtiga dhalmada. Cilmibaaristan wuxu ku sabsaan yahay waaryo araagnimada waqtigada dhalmada. Wadanka Canada o an joogno, dhaqanka wu ka duwanyahay sida uu fiiriyan guudniinka. Anaga Somalida wa ino caathi, laakin meshaan wuxu ka yahay xadgudubka ilmaha. Taas aawadeed ma ka hadlaan doonaa

6 ila 7 dhumar Somaliyeed oh ku dhalay B.C aya ka qayb gali doona dood-wadareedkan. Doodani waxaay qaadanaysaa 1 ila 2 saac. Naag Somali oo ku dhashay B.C, aya haagaysa doodwadareedan. Labo dhumar Somaliyeed ah aya qoraya doodan, sidaa danted waxbaan ka baranaynaa.

Ka qayb galka doodan waa ikhtiyaari. Ma jirto jawaab sax ah ama khalad ah. Waanu ku martigaadaynaa maxaa yeelay waxaan rabnaa inaan wax ka magalno dhankaaga, waxaad go'aansab jartaa ubaadab ja hawaabub wax su'aal ah. Haddii aad go'aansatid inaad ka gayb gashid, waxaad xag u leedahay inaad jo'ojiso ka gayb galka anaax la'aan.

#### Khataro

Ka qayb galkan cilmiyed ma le dhib soo gaaraya jirkaaga.Khatarta weyni waxay tahay in qof ogaadoinaad ka cilmibaaristan ka gaqyb gashay. Waxaan isku dayaynaa intii awoodayado ah inaan ilaaninno xogtaada. Magaca koowaad oo kaliya umbaan ku weydiinaynaa, xogta aad nala wadagtay waxaan u isticmaalaynaa wargadaha cilmibaarista iyo tusmooyinka, marna ma isticmaalayno magacaaga uma u sheegayno qofna inaad ka gayb gashay dood-wadareeddan. Wargadaha cilmibaarista waxaa laga yaabaa inaad ku darno waxaad tiri, lakin waxaan isticmaalayno magic aan kaaga ahayn, si aan qofna kuu garan. Si kastaba ha ahaatee haddii qof si fiican kuu yaqaan waxaa jiri kara khatar yar inuu ku garan karo. Maadaama aad la wadaaqasd xogtan dad wadar ah ma ballanqaadi karno qarsoodige xoga aad nala wadaagtay. Waxaa laga yaabaa inaad an ku ganacsanayn la wadaagga xogtaada dadka hortisa ka qayb galkaaqa waa ikhtiyaari, haddi aad darrento inaadan ku ganacsanayn doodan waad bixi kartaa waqti kasta.

## Xogta gaarka ee qoofka iyo kabixid

Xogta aad nala wadaagayso waxay nogonaysaa mid qarsoodi oo aan cidna loo bandhigin. Waxa halkan laaga dhex sheego dibadda looma saari karo. Magacaaga dambe loma baahna inaad no sheegtid, waxaan isticmaalaynaa magic been ah intaan isticmaali lahayn magacaaga runta ah qoraaladada. Inta lagu jiro dood-wadareedaan, hadi magaca dhakhtar Canadian sheegtaan, magacaas luguma dhariyo cilmibaaristan. Qoraaladoodu dhan waxaan lagu kaydin labtop driveka oo password lagu geliyo waxaa gali kara cilmibaaraha iyo maamulaha inta wargadda climibaarista la qorayo. Marka aan dhammeeyo qoritaanka xogtoo dhan waxaa lagu kaydin USB, waxaan lagu xirayoosantuukh xiraan oo ku taal xafiiska maamalaha oo dhextaal Jamcaada Simon Fraser ila August 2019. Kaddib waa la tirtirayaa.

Haddi aad go'aansatid inaad isagabaxdo cilmibaaristan, waxaad weydiin kartaa cilmibaaraha in laga isaaro xoogit aad la wadaagtayo dood-wadareeda kaddib xogtii aad nala wadaagtay waala tirtiraya. Suuragalu ma ahan cilmibaaraha inuu tirtiro xogtaada kaddib markii uu maqacagh dhabta ku badelo magic been ah.

Haddi aad la kulanto caafmaad darro ka dhalatay gudniinka waxaad la xiriiri karta dhakhtarkan.

- 1. Access clinic. Tel: 604-875-3290, Address: 4500 Oak Street, Vancouver
- 2. Crossroads Obstetric & Gynecology. Tel: 604-872-5484, Address: 507 West Broadway Ave. Referral needed.
- 3. South Surrey Medical clinic. Tel: 604-542-7788. Address: 101 15850 26<sup>th</sup> Ave

#### Suaalo

Haddi aad qabtid wax su'aal ah oo ku saabsan xuquugdaada cilmibaaristan waxaad la xiriiri kartaa Dr. Jeffrey Toward, xafiiska cilmibaarista Ethics jtoward@sfu.ca ama 778-782-6593. Wixii suaal ah waxaad la xiriiri kartaa cilmibaaraha Halima-Sadia Elmi iyou maamulaha Dr. Nicole Berry, nsb4@sfu.ca ama 778-782-8492.

Waxaan ka weydiin doonnaa haddii aad ka qaybgalisid cilmibaaristan af ahaan, heshiis macnaheedu waxaa weeye inaad magashay xogta cilmibaarista waxaadna waafaqday inaad ka qayb gasho.

Haddi aad tiraahdo waan aqbalay inaan ka qayb galo dood-wadareeda waxaad dhaxdaa "Haa waan ka qaybgalayo", markaas wa la bilawayo dood-wadareeda. Qofna wax su'aal ma gabaa?

Ma aqbashay inaad ka qayb gashid cilmi baaristan?

## 15 Appendix E – Recruitment Letter for Focus Group Discussion



[Date] Simon Fraser University 8888 University Dr, Burnaby, B.C

#### Re: Invitation to participate in a Focus Group Discussion

A graduate Masters of Public Health (MPH) student, Halima-Sadia Elmi at Simon Fraser University is conducting research on Somali women's experiences during childbirth and interaction with obstetrician care providers. There will be four focus group discussions (FGD) with approximately 6-7 Somali women who have given birth in a hospital in British Columbia participating in each session. Your experiences, knowledge and opinion are very important to this study and we would very much appreciate your participation. The duration of the interviews will be 1 to 2 hours. The information shared by members in these facilitated group discussions will help the researcher gain a better understanding of childbirth experience and make appropriate recommendations for obstetrician guidelines. Additionally, the findings will be presented in a capstone research project and may be published in a peer-reviewed academic journal.

Participation is entirely voluntary. If you identify as a Somali woman, are over the age of 18, previously undergone female circumcision and have given birth in a hospital located within British Columbia during the past 10 years, you are invited to participate in a focus group discussion. The discussions will most likely be held in a Somali Community Centre or home of a Somali community leader, and arranged at a time convenient for most people to attend. The FGD will be conducted in a room with only women present and with a Somali women facilitating.

If you wish to be part of this study, please inform the recruiter that you give permission to participate in the FGD. If you give permission, please provide your contact information to to the recruiter. You can also contact the principal investigator (PI) directly, at helmi@sfu.ca or 778.710.9301. The PI will ask you a few questions by telephone or email to confirm your eligibility for this project. If you are eligible to participate, you will be contacted soon afterwards regarding potential dates and times for the group discussion.

We hope that you will be interested in being part of this study. Thank you for your time.

Sincerely, Halima-Sadia Elmi, MPH Candidate

## 15.1 Appendix F – Recruitment Letter - Somali



[Date] Simon Fraser University 8888 University Dr, Burnaby, B.C

Re: Waxaa lagugu martigaaday inaad ka gayb gashid dood wadareed

Ardayadda baranaysa Master degreega caafmaadka dadweynaha, Halima-Sadia Elmi jaamacadda Simon Fraser University oo sameynasa cilmi baaris waaryo araagnimada dhumarka Somaliyeed ay kala kulman dhakhtarka ummilinaya waqtiga dhalmada isbitalada ku yaalla British Columbia. Afar dood-wadareed ayaa dhici doonta tirade 6 ila 7 dhumar Somaliyeed oh ku dhalay B.C aya ka qayb gali doona. Waaryo araagnimada, ciilmigaaga iyo fikradahaaga ada waa lagama maarmaan cilmibaaristan. Doodani waxaay qaadanaysaa 1 ila 2 saac. Xogta aad nala wadaaqtay dood-wadareedan waxay caawinaysa cilmibaaraha inuu fahmo waqtiqa dhalashada ilmaha iyo waxaan sameynaynaa soo jeddiin la xiriirta horumarina iyu tallaabooy ink aka habboon umulisooyinka. Cilmibaaristan waxaa loo isticmaalayaa cilmibaaris iyo academic saxaafadeed.

Ka qayb galka doodan waa ikhtiyaari. Haddi ad tahay haweeney Somaliah, oo ka weyn 18 sano, oo gudan, oo ku dhashay isbitaalaha British Columbia 10 sano ee la soo dhaafay waxaa lagugu martiqaadayaa inaaad ka qayb qasho dood-wadareed an. Dood-wadareedaan wixii ka dhicci doonaa xaruunta Soomaalida, ama guriga hoggacmiyaha jaaliyadda Somalida, waqti ku habboon qof kasta. Dood-wadareedu wuxuu u dhexeeynayaa qol kaliya ay ku jiraan dumar Somaliyeed oo haween ey Somali ah hogaaminayso dood-wadareedan.

Haddii aad rabtid inaad ka qayb gashid cilmibaaristaan u sheeg qofka maamulaya inaad ka qayb galaysid dood-wadareeddan. Haddii aad ka qayb galaysid na sii meelaan kaala soo xiriirno. Waxaad kale oo aad la xiriirikartaa cilmibaaraha, helmi@sfu.ca ama 778.710.9301. Cilmibaaruhu wuxuu ku weydiin doonaa su'alo dhawr ah telephone ama email si uu u hubsado inaad mudan tahay inaad ka qayb gashid iyo in kale. Haddii aad mudan tahay inaad ka qayb gashid waan kula so xiriiri doonaa si aan kuugu helno taariikhdaiyo waqtiga dood-wadareeda.

Waxaan rajeynayaa inaad ka qayb gashid cilmibaaristan. Waana ku mahadsantahay waqtigaaga.

Mahadsanidin, Halima-Sadia Elmi, MPH Candidate

16. Appendix G- Confidentiality Agreement



In recognition of the confidentiality and anonymity assurances you provide to participants of your research, which are informed by the Tri-Council Policy Statement on Research Ethics and the Simon Fraser University Office of Research Ethics, I hereby acknowledge that I will not divulge the names or confidential detail of participants' cases to any other person. I recognize that as the person who translator that you entrust me with highly confidential raw data, and will not compromise this trust in any way. This confidentiality agreement extends to tasks I perform while working with Halima-Sadia Elmi and Dr. Nicole Berry on this study exploring "Somali Women's Experiences with Obstetrician Care Providers During Childbirth."

Name: Sadya flashi Signed: S. Hah.

Date: March 4, 2016

In recognition of the confidentiality and anonymity assurances you provide to participants of your research, which are informed by the Tri-Council Policy Statement on Research Ethics and the Simon Fraser University Office of Research Ethics, I hereby acknowledge that I will not divulge the names or confidential detail of participants' cases to any other person. I recognize that as the person who facilitates the focus group discussion that you entrust me with highly confidential raw data, and will not compromise this trust in any way. This confidentiality agreement extends to tasks I perform while working with Halima-Sadia Elmi and Dr. Nicole Berry on this study exploring "Somali Women's Experiences with Obstetrician Care Providers During Childbirth."

Name: Ubah Mahamed

Signed: WAN MARAGE

Date: March 5 / 2016



In recognition of the confidentiality and anonymity assurances you provide to participants of your research, which are informed by the Tri-Council Policy Statement on Research Ethics and the Simon Fraser University Office of Research Ethics, I hereby acknowledge that I will not divulge the names or confidential detail of participants' cases to any other person. I recognize that as the person who note takes for the focus group discussion that you entrust me with highly confidential raw data, and will not compromise this trust in any way. This confidentiality agreement extends to all the tasks I perform while working with Halima-Sadia Elmi and Dr. Nicole Berry on this study exploring "Somali women's experiences with obstetrician care providers during childbirth".

Signed: Agomand, Amina Osman Date: March 2,2016