Avoiding Obstetrical Interventions among Somali Refugee Women in the United States: A Qualitative Study

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Abstract

Objective: Somali refugee women are known to have poor health seeking behavior with a higher proportion of adverse pregnancy outcomes compared to U.S. born women. Yet unknown is how they avoid obstetrical interventions. This study sought to identify perceived protective mechanisms used to avoid obstetric interventions as well as the underpinning factors that influence aversion to obstetrical interventions by Somali refugee women.

Design: A descriptive, exploratory qualitative study purposively sampled Somali refugee women recruited via snowball technique in Franklin County, Ohio, United States. Data was collected through audio-recordings of individual interviews and focus groups conducted in English and Somali languages. The collected data were transcribed and analyzed using thematic analyses.

Results: Forty Somali refugee women aged 18 to 42 years were recruited. Participants reported engaging in four perceived protective mechanisms to avoid obstetrical interventions during pregnancy and childbirth: 1) intentionally not seeking or misleading prenatal care, 2) changing hospitals and/or providers, 3) delayed hospital arrival during labor, and 4) refusal of care. Underpinning all four avoidance mechanisms were their significant fear of obstetrical interventions, and perceived lack of choice in their care processes as influenced by: cultural and/or religious beliefs, feeling judged or undervalued by service providers, and a lack of privacy provided to them while receiving care.

Conclusion: Like every woman, Somali women also have a right to choose or refuse care. If the intention is to improve access to and experiences with care for this population, building trust, addressing their fears and concerns, and respecting their culture is a critical first step. This should be well established prior to the need for critical decisions surrounding pregnancy and childbirth wherein Somali women may feel compelled to refuse necessary obstetrical care. Bridging gaps between Somali women and their providers is key to advancing health equity for this vulnerable population.

KEY WORDS

Immigrant; migrant; refugee; Somali women; maternal health; obstetric care; avoidance; Community-Based Participatory Research

Introduction

Ongoing forced displacement from decades of war and conflict has resulted in Somalis being among the largest African refugee populations to have been resettled in the United States (U.S.). Significant disparities in health services utilization has been observed and persist among Somali populations (Morrison *et al.* 2012). This occurs against a backdrop of limited English proficiency, low health literacy, distrust of providers, refusal of care, fear of pain and anxiety, stigmatization towards the traditional cultural practice of Female Genital Cutting (FGC) and concerns around patient-provider gender concordance (Essen *et al.* 2000, Carroll *et al.* 2007, Morris *et al.* 2009, Morrison *et al.* 2012, Aubrey *et al.* 2017). In addition, Somali women raise concerns around understanding the value and purpose of Westernized prenatal care and feeling a lack of control and unfamiliarity with labor and delivery care in the U.S., which they often believe God is in control of anyway. These factors contribute to their lack of engagement in recommended health practices (Hill *et al.* 2012).

As a consequence of this limited utilization of health services, adverse obstetrical outcomes have been extensively documented in the literature among Somali women in the context of migration along with robust qualitative evidence of their profound fear of obstetrical interventions and negative birth experiences (Brown *et al.* 2010, Hamid *et al.* 2018). Western medical providers with exposure to FGC-affected women sometimes report being suspicious of them and indicate that they frequently receive requests from these women for intrapartum re-infibulation (re-approximation of the original vulvar scar) (Tamaddon *et al.* 2006). However, regardless of FGC status, migrant women of African descent have been shown to experience increased maternal and neonatal morbidity which has been attributed to suboptimal care including inadequate prenatal care and delay and/or refusal of obstetric care (Gould *et al.* 2003, Cacciani *et al.* 2011, Merry *et al.* 2013, Bakken *et al.* 2015).

In an exploration of perspectives on cesarean birth among Somali women and their obstetric providers, they held discordant views as Somali women expressed fear and anxiety regarding surgical interventions they deemed unwarranted, and took measures upon themselves to avoid cesarean delivery; while their providers voiced frustration and stress regarding their patients' cesarean avoidance and refusal of care (Essén *et al.* 2011). Further exploration of the mechanisms by which Somali women are driven to avoid obstetrical interventions is warranted. The objective of this paper is to report on findings from a qualitative study of Somali refugee women in the U.S. exploring mechanisms they took to avoid obstetric interventions.

Materials and methods

Study design

This was the qualitative arm of a mixed methods study that employed a community-based participatory research (CBPR) approach in its design and implementation. CBPR is a bidirectional experience that requires that the researcher and community work as a team to identify study processes through which data will be collected, analyzed and disseminated. CBPR emphasizes equitable and collaborative community involvement throughout all stages of the research and ensures community empowerment (Johnson, Ali, and Shipp 2009). In this study, community dialogue was first established through the Midwest Network on Female Genital Cutting (MWNFGC), which comprised health professionals, representatives from refugee resettlement agencies, community-based organizations, and immigration law experts from across the Midwest (Minneapolis, MN, Columbus, OH, and Chicago, IL); who shared common goals of working together to foster greater support services as well as culturally competent care for women and girls affected by or at risk for FGC. Through the MWNFGC, local dialogue began with The Columbus Immigration Resource Center (CIRC), a local Somali community organization based in Franklin County, OH that seeks to promote health and well-being for immigrants and refugees. Through CIRC, the Refugee and Immigrant Women's Health Initiative (RIWHI) was formed with its own Community Advisory Board (CAB), which mobilized the local Somali community along with key community stakeholders representing the state public

health department, local academic institutions, and healthcare providers, which coalesced around a shared goal of addressing the health care needs of Somali refugee and immigrant women. The detailed CBPR process of: collaborative partnership development, nurturing and sustaining trust, community mobilization and implementation, dissemination, sustainability, and community empowerment were instrumental throughout the research process and are further delineated at length by Johnson, Ali and Shipp, 2009.

Setting and sample

Eligible participants for this study were women over 18 years of age, who were refugees from Somalia, residing in Franklin County, Ohio, a Midwestern state in the U.S. Somalis are the largest group of African-born refugees in this County. Participants were recruited by trained community mobilizers primarily via word-of-mouth communication, although follow-up telephone contact was incorporated during snowball sampling and also once initial contact had already been made. Participants were identified and recruited from within several Somali communities within the County through face-to-face and word-of-mouth contact in neighborhoods, mosques, community centers, and malls; as well as by referrals from individuals, local community organizations, and community centers.

Data collection

Data was collected through individual interviews and focus groups with recruited eligible participants who consented to partaking in the study, depending on the participant's preference. Given the strong oral tradition of communication in Somali culture, as well as the anticipated high rate of illiteracy among Somali refugees, qualitative interviews were a culturally appropriate way of gathering information (Agbemenu *et al.* 2018). Focus groups were conducted with younger Somali women (18-25 years) in English; while sessions with older women (above 25 years) were conducted in Somali with the aid of an interpreter.

Individual interviews, conducted in either English or Somali (with an interpreter), were used for women who preferred to have their privacy to participate in the study.

Both individual interviews and focus groups were conducted in the homes of Somali women, as preferred by the women themselves. The principal investigator of the study, CJA, conducted all individual interviews and focus groups between January and April 2008. Each focus group session lasted approximately 90 minutes, while individual interviews lasted between 60 and 90 minutes. As an Obstetrician and Gynecologist, who has significant experience providing obstetric care to the target population, she was adept in how to relate to this population. Prior to beginning this study, CJA spent over a year and a half working to establish community partnerships, as well as building trust, networks, and relationships with the second largest Somali refugee community in the U.S. All individual interviews and focus groups were audio-recorded and subsequently transcribed. Field notes collected as part of this study captured rich contextual information from the sessions. CJA, interpreters and transcriptionists all received training to ensure competency in qualitative interviewing and moderating techniques as well as insurance of strict participant confidentiality (Johnson, Ali, and Shipp 2009).

Data analysis

To analyze the data, we followed Braun and Clarke's (2006) six-step approach: becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun and Clarke 2006). Debriefing sessions took place immediately after each individual interview and focus group during which salient themes were discussed. The English audio recordings of the interviews were then transcribed by a transcriptionist and reconciled with field notes, while members of the team of Somali interpreters transcribed and translated the Somali audio recordings to English before reconciling them with the field notes.

Transcripts were then systematically reviewed by a seven-member research team, comprised of the research team and two Somali community members. The two Somali women were integral members of this team as they provided crucial cultural context/relevance to the interpretation of the transcripts consistent with principles of CBPR. Serial group meetings were held to identify overarching themes and emergent codes in an iterative fashion, incorporating consensus-building to resolve any discrepancies and contradictions. NVivo qualitative data analysis software version 10 (QSR International Inc., Burlington, MA, USA), was used to facilitate coding, organization of themes and linkages.

The transcripts were reviewed by at least two other members and examined to assign codes and find themes relevant to an aversion to obstetrical interventions, and actions taken to avoid such interventions. A multidisciplinary team used thematic analysis to identify key emerging themes regarding the reasons for the aversion to aforementioned obstetrical interventions, and the mechanisms used to avoid these interventions. We reported on our study following the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong *et al.* 2007).

Ethical statement

Ethics approval for this study was obtained from the ethics committee of the University of Michigan Institutional Review Board (IRB) (HUM00009502). Participants' written and verbal (for those participants who could not read or write) informed consent was obtained using an informed consent form, which had been reviewed and approved by the IRB. All participation was voluntary, and participants were allowed to exit the interview/focus group if they desired.

Results

Distribution of participants

A total of 40 Somali refugee women were recruited for the interviews, 15 participants in the individual interviews, and 25 participants in the focus groups. Focus groups among the younger women were conducted in English and comprised two groups of five women each. For the older women, two focus groups, comprising six and nine women respectively, were conducted in Somali through an interpreter.

The age of the participants ranged from 18 to 42 years, with a mean age of 33 years. Most of participants (38 of 40) were married and had primary and secondary education as their highest attained education. All participants were Muslim [Table 1]. Women had spent between one and 23 years, with an average of eight years, in the U.S.

Key emerging themes

There were four key themes that emerged from our discussions, with each theme detailing a perceived protective obstetrical avoidance mechanism: 1) intentionally not seeking or misleading prenatal care, 2) changing hospitals and/or providers when care has commenced, 3) delayed hospital arrival during labor, and 4) outright refusal of care.

Theme 1: Intentionally not seeking or misleading prenatal care

Women described intentionally not seeking prenatal care as a means of avoiding any obstetrical interventions. Respondents said that they purposely avoided prenatal care because of the sense of helplessness they experienced as a result of violations of their right to privacy. They described privacy being breached by healthcare providers (HCPs) who photographed them and brought in students and colleagues against the women's will or without their knowledge. The women spoke of feeling disrespected,

viewed with curiosity and being put on display. While a few women spoke of the trust and positive experiences they have had with HCPs, many reflected upon experiences of feeling as if they were treated differently than other patients due to their race/ethnicity, practice of Islam and status as refugees.

> *"I didn't go to the doctor… really, why should I go? For what? Because I am scared of what they can do to me. I will get there, and the doctor will bring some students into the room without even asking me. I have heard from my friends and sisters that this is what they do". Mother 1, Focus Group 4 (M1F4)*

Concerning experiences of discrimination, an English-speaking participant, mother of five, three of whom were born in the U.S. stated:

> *"Before the country was ok, but after 9/11, the situation changed. Women are treated badly. Sometimes I fear going to the doctor because I fear they will do something to me". Individual Interviewee 12 (II 12)*

A 26-year-old English-speaking participant, mother of three, all born in the U.S. (M5F4), said that:

> *"Going for prenatal care, we are afraid, we just feel mistreated and disrespected by the exposure because we have seen it before, we know it [other people will be in the consulting room] will happen again". (M5F4)*

For some of those who attended prenatal care, providing misleading details of their last menstrual period (LMP), while and not trusting the 'technology' of ultrasounds, was a way to avoid obstetrical intervention. There was a general opinion that if the health providers did not have the accurate LMP dates, they would not be able to estimate when the women needed to present in the hospital to prepare for cesarean delivery. An English-speaking 22-year-old Somali women mother of five children, three of whom were born in the U.S stated:

> *"Some of my friends have advised me to tell them a different date so they would not be able to calculate when I am due…. The machine [Ultrasound] cannot tell them [the doctors] what only I can know". (II 5)*

Theme 2: Changing hospitals and/or providers

Some women reported changing providers and/or hospitals because they were particularly fearful of cesarean section. As such they went to providers such as midwives who were not licensed to conduct cesarean sections and believed the birth process and outcomes would be different with midwives. A 31-year old Somali mother of four who was pregnant with her fourth child, stated:

> *"I went to one hospital and they said there was something wrong with my baby and I had to have a C-section, and I decided to leave that hospital and go to a different hospital, and the other hospital told me the baby is fine, then I just had the baby vaginal". (M4F3)*

In this respondent's case, her first two deliveries were by cesarean section and in the third pregnancy she decided to turn to a different provider to avoid getting another surgery. She stated:

"I went to midwives because they cannot perform C-sections… I went to them because I was running away from C-section". (M4F3)

Some Somali refugee women shared that they sometimes changed hospitals as frequently as required until they can find a provider that did not propose or raise potential for a cesarean section or any other obstetrical intervention. There was also a sense of helplessness in the decision to have a cesarean section or not, as some of the respondents reported that from both their experiences and those shared by others, they for the most part did not understand why their babies had to be delivered via cesarean section. A 26-year-old English speaking Somali woman who has lived in the U.S. for 16 years described what one of her friends, who she had accompanied to her prenatal visits to act as an interpreter, did to avoid cesarean section. She stated that,

"Like my friend, a week ago, they told her she will have a C-section, without even asking her if she wanted it... She thought it will be better to stay home. She went through three doctors because she was scared of C-section". (II 10)

Theme 3: Delayed hospital arrival during labor

Somali refugee women delayed coming to the hospital during labor until the last minute. Many participants stated that the providers are not patient with them and do not like to wait for labor to progress and take its natural course, so they will rather stay home and bear the pain until the baby is almost out. A 32-year-old Somali woman who has given birth to thirteen children stated:

"It is part of culture. Our women don't like C-sections, they stay at home. The Somali women are scared to have the procedure. They stay at home longer and go through pain after pain after pain until she has no choice but to go to the hospital". (M3F3)

Some Somali women appear to still delay arrival at the hospital despite understanding the potential consequences of such action including complications of pregnancy for themselves and their newborns. A middle-aged English-speaking mother of six children, who had lived in the U.S. for nearly 5 years was asked her thoughts on women delaying seeking care. She responded:

"They don't even go. Their fear is so great their child during labor is almost injured or they even give birth in the car. Or even the baby tears the woman to anus because they delay going to doctor. Some of them put themselves and the baby in danger to die, while they delay their time to go to the doctor". (II 14)

There was also reported action from family members who counseled expectant mothers not to present themselves early to hospitals. An older Somali woman who has had twelve children, all prior to emigrating to the U.S. and all by natural birth, had advised her daughter to delay going to the hospital while in labor. When she was asked why she did this, she replied saying that:

"Yes, I give her advice. But she is used to American culture. In my culture we wait two days in labor. But she says C-section is easy. I told her to stay, stay, wait for God's will. She says no, she goes with the doctor. I don't take her to the hospital now until she is well in labor. She had four

children normally other than twins and last child. Now in labor I tell her to hold on until child literally comes out and then she goes to the hospital to give a natural birth". (II 13)

There was a general perception that if one waited long enough at home, delivery by natural birth will happen and the women put themselves at risk of a cesarean delivery if they presented to the hospital "too early" in labor. A 29-year-old Somali woman who had lived in the U.S. since 2000 and is a mother of two children both by natural vaginal delivery said:

"I have only had normal births. No problem! I did not ever go to the doctor too early. I waited until I was very close to giving birth; until I have been in labor for a while, because I feared getting a C-section". (M4F1)

Theme 4: Refusal of care

Somali women reported completely refusing care even when told it might be detrimental to the baby. Some participants spoke generally about surgery and other obstetric procedures which they considered invasive. Regardless of the outcome, many women restated their trust in God as having predetermined the course of the birth. Furthermore, many women expressed their mistrust of providers and technology 'proving' the need for obstetrical interventions, declaring that ultimately it was God, and not providers who determines the course of the birth, regardless of the outcome. An English-speaking Somali woman was asked what providers can do to improve Somali women's experiences with care. She answered:

"What can they do? They are tools in the hands of God. Only God knows, the predestination. Sometimes, they [health workers] do their own will…I cannot trust such

people [health workers]. When one doctor told me she will cut me, I refused the care. Even if I did not, my husband would have. We will trust in God, even if the baby dies in my womb". (M1F2)

Some Somali women reported that they refused induction of labor when it was offered to them while in the hospital. "*Labor should start when God says"* was a statement made by many of the women in the study.

"…if a woman has a long labor, it's God's will. But in America, they [Doctors} are always in a rush. They have to slow down, two, three, five, ten hours labor. Wait for them in labor. They try to rush me [induce me], I said 'No!'". (II 8)

Discussion

Main findings

Our study identified the perceived protective mechanisms used by Somali refugee women to avoid obstetric interventions such as induction of labor, and cesarean sections. We found four main mechanisms that Somali women used to avoid obstetrical interventions: 1) intentionally not seeking or misleading prenatal care, 2) changing hospitals and/or providers when care has commenced elsewhere, 3) delaying arrival to hospital while in labor, and 4) outright refusal of care. Factors that led to these actions included: cultural and/or religious attitudes and beliefs, prior health context in non-Western countries, fear of cesarean section, advice from other women in the community on avoidance behaviors, and experiences with a Western-style healthcare system.

Interpretation

The first mechanism we reported on was intentionally not seeking prenatal care. Evidence in the literature demonstrates that Somali migrant women have lower prenatal care use compared to native born women (Råssjö *et al.* 2013). Factors associated with this including untoward experiences with healthcare, prior health care context, distrust, and barriers to care have been previously established in the literature (Essén *et al.* 2000, 2011, Hill *et al.* 2012, Farage *et al.* 2015, Abdulcadir *et al.* 2016, Banke-Thomas *et al.* 2018). Our study suggests that there may be a mix of Somali women – those who simply do not want to go to medical facilities because of their beliefs, and those who are not willing to go for prenatal services in order to avoid obstetric interventions such as induction of labor and cesarean sections. Following the U.S. terrorist attacks of September 11, 2001, Muslim Americans have faced higher rates of prejudice, discrimination, disrespect and violence which have resulted in greater psychological distress and risk for adverse health outcomes (Padela and Heisler 2010). In our study, these experiences have also been shared by the Somali community who expressed that they intentionally do not seek prenatal care because of fear of being treated with disrespect, feeling unwanted and that actions might be taken against them. In fact, cultural challenges, acculturative stress, ethical dilemmas and perceived societal discrimination influence health inequities among Muslim Americans and have been shown to impact delayed health-seeking behavior and resultant adverse health exposures (Vu *et al.* 2016, Padela and Zaidi 2018). In our study, when they sought prenatal care, some withheld information, such as the date of their last menstrual period. Their lack of belief in the health system may underpin why they believe that ultrasonography is not as robust to accurately predicting their expected delivery. Clearly, the normal patient-doctor relationship that is typically founded on trust and mutual respect has given way to fear and distrust (Hernandez 2007).

Changing providers mid-care was another mechanism used to avoid obstetrical interventions. In trying to understand this mechanism, it is clear that these are aversions to care when faced with a situation deemed undesirable. Somali women appear to use this mechanism when they feel like they do not have a choice in the care process. Reasons given for using these avoidance mechanisms ranged from the desire to deliver

naturally, fear of a surgical incision, previous negative outcomes to the mother or child after clinical intervention, or lack of trust of healthcare providers motives. These factors have similarly been reported in previous studies (Brown *et al.* 2010, Essén *et al.* 2011). The literature is replete with evidence of Somali women's desires to avoid obstetrical intervention, and as in our study, evidence indicates a preference for female midwives over other birth attendants (Essén *et al.* 2011, Moxey and Jones 2016). However, in our study, women were able to specifically highlight that their preference for midwives was also a strategy to avoid cesarean birth and other obstetrical interventions. Though other studies have highlighted that this avoidance of obstetric interventions may be a result of a lack of knowledge of healthcare processes in the Western medical system (Pavlish *et al.* 2010, Lazar *et al.* 2013). The argument has always been that Somali women living in the U.S. are navigating a healthcare system that is vastly different from other healthcare systems they may have had previous experience with, which is an important factor that inhibits trust (Hill *et al.* 2012).

Delaying hospital arrival was another mechanism used by Somali women to avoid obstetrical interventions. A previous U.S. study conducted amongst a large cohort of Somali migrants in Washington State found that they are more likely to undergo cesarean section, often associated with fetal distress (Johnson *et al.* 2005). While several obstetric complications may lead to fetal distress, many instances are preventable. However, delay in receiving interventional obstetric care increases the risk for fetal distress. As with intentionally not seeking prenatal care, while this has not been reported in the literature previously, the delay in arrival at the hospital which itself may be due to structural barriers that increase risk for fetal distress, may also be an intentional action of Somali women to avoid any obstetric intervention and let *"God's will be done"*, even at the expense of untoward pregnancy outcomes. The fatalistic attitude alluded to in the preceding quote, seemed to be quite pervasive in our study, and emerges when women feel otherwise powerless to control circumstances seemingly outside of their control, hence chose not to act in the face of impeding negative health consequences (Vu *et al.* 2016). It probably explains why Somali

women are more often delivered by emergency cesarean section compared with native-born women (Råssjö *et al.* 2013).

If and when women arrived at points of care, they also avoided obstetrical intervention by outright refusal of the care that they were offered. This behavior may be predicated on their previous experience of pregnancy and childbirth in the U.S. and on practices that are fear-inducing for them (Upvall *et al.* 2009, Brown *et al.* 2010). Much of this fear can be traced to the incredible importance placed upon women's fertility in Somali culture and the concern that cesarean sections place a limit on the number of children a woman can safely bear (Carroll *et al.* 2007, Brown *et al.* 2010). However, from our study, it was not clear if their refusal of care was an independent decision, as in some cases, the husband or matriarchal forces who are also in the room and hold sway over the disempowered laboring mother's decision-making were the first to refuse intervention. In other instances, the converse was true as well, wherein the women are empowered to make their decision themselves. It is important to highlight the notion of western autonomy and self-determination, as not being normative in the cultural context of the population studies wherein the husband and/or matriarchal family members influence the decisions women make about their care and relevant obstetrical interventions. Underpinning this mechanism of action is the genuine conviction that nothing can go wrong with their pregnancy and if something does, it is God's will. These fatalistic attitudes may impact women's decision-making and outcomes when they otherwise feel powerless in circumstances outside of their control. In prior research, participants believed that cesarean sections were performed as an easy, quick way for providers to avoid dealing with defibulation (procedure through which an infibulation is opened) (Brown *et al.* 2010). However, Somali women's fear of over medicalization of pregnancy and birthing may not be unfounded. It is noteworthy that the rates of cesarean section in the general U.S. population continue to increase, far exceeding the recommended rates (Betrán *et al.* 2016). As of 2016, the U.S. cesarean section rate was 32% (CDC, 2018); and in a recent study, the authors ascertained that FGC was associated with cesarean delivery in women with unclear medical conditions (Rodriguez *et al.* 2017).

Somalia has among the highest FGC prevalence rates globally, with the most extreme form, infibulation (which refers to surgical removal of the external genitalia, with suturing of the vulva together, to leave a small opening for urination and menstruation) (WHO 2018), estimated to be present in 98% of Somali women (Abdulcadir *et al.* 2011). As such it may be difficult to distinguish whether the high cesarean section rate is due to FGC or to the high rate of cesarean delivery in general. A crucial consideration moving forward has to be the need for care providers to critically examine their usage of the medical model of providing care to Somali pregnant women while respecting their choices and agency (Happel-Parkins and Azim 2016).

In addition to the cultural differences between providers and women, many of the women in our study indicated that they felt they would be forced to have an obstetric intervention even if they did not consent to it. This perceived lack of choice appears to underpin why they feel they need to avoid obstetrical interventions by all means. The current study findings highlight the need for health providers to understand that Somali refugees may not have the same expectations from doctors as the general population in the U.S. For example, a study of U.S. nationals indicates that patients relegate all responsibilities to the doctor and do not wish to engage in shared decision-making (Joseph-Williams *et al.* 2014). Studies such as these cannot be generalized to all groups, particularly refugee women who do not have the same level of trust in the health care system. In our study, women experienced an 'othering' of their bodies, whereby they felt they were placed on display and were helpless to combat what they perceived as a violation of their right to privacy. The presence of FGC set Somali women apart, creating an embodiment of the 'Hottentot Venus', which denotes the negative representation of African women's bodies which were placed on display and objectified during the colonial period of early nineteenth century Europe (Magubane 2001). In our study, women expressed angst with the fact that photographing their genitals and bringing in students and colleagues against their will and without their knowledge contributed to their delay in seeking needed health care. Further research is needed to examine the potential impact of avoidance behaviors on maternal and

child health, or whether women who have undergone FGC are more likely to display avoidance behaviors. While this current study provides an examination of the rationale for the use of avoidance behaviors among women who have undergone FGC, it remains unclear to what extent their experience of FGC is a risk factor for avoidance behaviors.

While our study examined and provided the context in which Somali women use avoidance behaviors in terms of health, little is known about whether such tactics leading to delayed obstetrical intervention have negative ramifications on maternal and child health. Women in the study alluded to preferring care of midwives. In terms of care delivery, it is critical that women are informed of the option to have a certified nurse midwife as the provider of choice, as soon as they establish prenatal care. Evidence from a 2016 systematic review showed that globally women who received midwife-led care had fewer episiotomies or instrumental births and increased chances of a spontaneous vaginal birth without any difference in care outcomes compared to other models of care (Sandall et al. 2016). Specifically, in the U.S., a national vital statistics report which reviewed births from 1970 to 2009, showed that births led by certified nurse-midwives had lower average primary cesarean rate for compared to the national rate (9.9% compared to 32%) (Martin et al. 2011), These findings show that midwives can be a good-fit for care delivery for Somali women, as they are not just desired by the women but they are also effective in care delivery. While midwives may offer an approach that appeals to women in our population, the choice to follow midwife-led care needs to be balanced with the specific needs of the woman, especially as avoidance behaviors such as those we identified amongst women in our study can predispose them to a high-risk delivery.

Going forward, possible interventions include a community-based program aimed at optimizing culturally competent care and education of health care professionals to the needs of the Somali community. Such programs could be led by Cultural Health Navigators (CHNs), otherwise known as Community Health

Workers (CHWs), who are lay-practitioners, yet certified medical interpreters and cultural brokers drawn from their own communities of origin (Banke-Thomas *et al.* 2017). These patient navigators provide information to patients in their native language in a culturally-informed and relatable way to increase comfort and understanding in relation to medical care, and they have been demonstrated to be effective to reducing barriers to accessing health care in other at-risk populations (Feltner *et al.* 2012). The use of trusted CHNs who are drawn from the community can potentially address concerns about judgment and fear that lead these women to avoid obstetric care. An additional benefit to specified intervention approaches would be higher rates of informed participation by the Somali community in their health care and such programs could serve as models for national programs that could have far-reaching public health and policy implications.

Thereafter, quality improvement interventions should be designed to improve institutional processes of care, HCP knowledge of FGC and cultural competency, and incorporate community dialogue of ongoing health service needs and persistent barriers to care. Better infusion of existing tools and better dissemination of information to HCP about FGC and cultural preferences of Somali women could increase cultural competence, and therefore build trust and increase patient confidence in provider recommendations and intervention approaches. Since tools and protocols have already been developed, interventions need to be developed to bridge the gap between existing tools/knowledge and the HCPs. The use of CHNs to deliver information to providers could enhance provider knowledge and cultural competence, which may reduce barriers for fearful patients, and improve patient satisfaction and health care utilization. Such measures could have far-reaching implications within the broader context of improving Somali refugee women's health (Feltner *et al.* 2012, Banke-Thomas *et al.* 2017).

Strengths and limitations

This study had several strengths and some limitations. A major strength was the ability to gather information, in their own words, from a marginalized community of women whose voice is not often heard in research. Hearing directly from the community allows us to identify problems and provide culturally congruent interventions. Somali interpretation was used to ensure the study was inclusive and sought different points of view. Use of individual interviews and focus groups was an appropriate technique to collect information from low literacy participants. In addition, focus group settings allow for development of camaraderie, access to more information, and the opportunity to seek clarifications.

CBPR processes remained rooted as foundational elements undergirding all aspects of our team's engagement with the Somali community from the initial design, mobilization and implementation efforts, to the interpretation and dissemination of the data whereby the preliminary findings and key points of discussion were co-produced in conjunction with the community's input and shared with the Somali community. Consequently, clear community empowerment was achieved as RIWHI through CIRC, continued to remain active facilitating referrals to health services for women and girls, advocating for improved access to care, distributing health educational information, and enhancing closer partnerships with local health care providers. Moreover, RIWHI organized statewide efforts to engage the broader ethnic community organizations as well as state and local health agencies through health fairs. These efforts empowered the Somali community to support sustained advocacy for their ongoing health care needs (Johnson, Ali, Shipp, 2009).

Limitations of the study include potential bias in reporting given that the women needed to detail obstetrical avoidance to an obstetrician. The implementation of CBPR would have helped reduce the potential impact of such bias. Participants were recruited via a snowball sampling technique, which means, some participants

probably know each other and potentially share similar opinions on avoiding obstetrical care. While we have tried to recruit as many women as possible into our study, our findings may not generalize to other groups of resettled Somali women.

Conclusion

Every woman, including all Somali women have a right to choose or refuse care. They have a right to make an informed choice regarding their care. If we are to provide the best possible care to Somali women who have resettled in the U.S., we must first understand their experiences accessing care, so we can design interventions to address them. This study increases our understanding of the actions that Somali may women take in avoiding obstetrical interventions. Clearly there are underlying perceptions and beliefs that influence these avoidance mechanisms. These can be addressed by building trust of Somali women in the health system, addressing their fears and concerns, and respecting their culture. In addition, the avoidance mechanisms can be addressed by having trusted human bridges that can support Somali women through their decision making proposes in pregnancy and labor and translating the concerns of the women to providers. Such two-pronged approach that tackles the root and nurtures the relationship is critical to increasing access to health and advancing health equity for this vulnerable population.

Declaration of interest statement

No potential conflict of interest was reported by the authors.

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Table

Table 1: Summary demographics of Somali women recruited for study

Characteristic	**Number (n=40)**
Age category	
18-25 ears	13
>25 years	27
Marital status	
Married	38
Single	2
Education level	
Primary	30
Secondary	8
Tertiary	2
Employment status	
Unemployed	24
Self-employed	11
Employed	5
Religion	
Muslim	40
Parity	
Primiparous (1)	11
Multiparous (1 – 4)	26
Grand multiparous (≥5)	3