

Perceived reproductive health needs among Muslim women in the southern US

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Publication Date

November 21, 2020

MJM 2020 (18) 25



www.mjmmmed.com



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ABSTRACT

Despite growing rates of Muslims in the United States, we know little about the health of Muslim women in this country. Due to the stigma surrounding sex, sexuality, and the cultural beliefs of this population, there may be unique and unknown challenges regarding access to reproductive health care for Muslims in the US. **Purpose:** This study aims to examine variables that promote and impede access to reproductive health care for Muslim women in the southern US. **Methods:** This multi-method study included in-person semi-structured interviews (n=15) and an anonymous online survey (n=76). **Findings:** Participants generally had low rates of gynecological care and cervical cancer screening. The cultural (e.g. waiting for marriage to receive gynecological care) and contextual aspects (e.g. gender) that increased or restricted access to care in terms of screening, providers and education are discussed. We also identified some misconceptions related to screening and contraception. **Conclusions:** Influences on reproductive health care experienced by participants in this study have similarities yet are distinct from Muslim populations in other countries as well as other groups of women in the US. This study points to a need for more population-focused education of providers, as well as awareness about reproductive health and health care recommendations and access for Muslim women.

KEYWORDS

Muslim, reproductive and sexual health, cervical cancer, breast cancer

1 | BACKGROUND

In spite of growing rates of Muslim women in the United States (US) (1), their health remains under-researched; this is partly due to a lack of inclusion of religious affiliation in research (2-4). Although Muslims in the US have similar rates of education as the general population, they are more likely to report lower household annual incomes (1). Pew Research Center estimates that the number of Muslims living in the US grew from 2.75 million in 2011 to 3.45 million in 2017, with a predicted growth to 8.1 million in 2040 (5). With this growing Muslim population that may be uninsured, there is an increased need for addressing religious-based discrimination, especially in health care settings.

While the Muslim American population is racially and ethnically diverse, it is still a minority group that is bound by a set of practices that influence their behaviors and experiences (2). Factors affecting potential barriers to health care access include gender preference of provider, family involvement in care, fatalism and predestination, maintaining religious practices during illness, low health literacy and language proficiency, preference for traditional remedies, fear of stereotype and discrimination, and limited health care access (6). Budhwani et al. (4) acknowledge the intersectional aspects of identities among Muslim women in the US, including religion, ethnicity, race, and potentially immigrant status, that influence their health and may be different from other women. Clinical practices in the West are often individual-centered, while Muslim societies tend to be collectivistic and value extended family (3).

Patients' culture influences health care access as well. Health care visits, notably preventive care (e.g. breast cancer screening or cervical cancer screening), are infrequent among immigrant Muslim women (7). American Muslims have lower rates of mammography utilization, likely due to religious engagement (e.g. reading Quran to deal with life stressors instead of seeking professional treatment) and perceived discrimination in health care (8). Additionally, some providers might be reticent about sharing information or asking questions to their Muslim women patients because of the lack of knowledge about

their cultural and religious values (9).

Stigma and discrimination against Muslim individuals in the US may result in negative health outcomes through several social-ecological levels: individual (stress reactivity and stereotype threat), interpersonal (social relationships and socialization processes), and structural (institutional policies, media coverage, general islamophobia) (10, 11). Reporting of hate crimes vary widely by state and therefore data by region is unavailable (12). However, 40% of American anti-Muslim organizations are based in the southern region of the US (13). Based on this, there may be different levels of stigma and discrimination in the south compared to elsewhere in the US.

Given the lack of targeted interventions or initiatives to understand Muslim women's gynecological experiences in the urban South, this study aims to examine variables that promote or impede access to reproductive health care for Muslim women in Charlotte, NC. An examination of Muslim women's reproductive health experiences may inform trainings for providers, educational programs for Muslim individuals, and identify gaps in access to services.

2 | THEORETICAL FRAMEWORK

This study draws upon Aday and Anderson's (14) framework for health care access (as described by 15). This framework includes the following domains: (1) health policy, (2) characteristics of the health delivery system, (3) characteristics of populations at risk, (4) utilization of health services, and (5) consumer satisfaction. We focus specifically on characteristics of populations at risk (perceived needs), utilization of health services, and consumer satisfaction.

3 | METHODS

This study used multiple methods, with an online survey and in-person interview conducted simultaneously. Semi-structured interviews were used to explore the sensitive and personal experiences of Muslim women in

reproductive health care. The interviewer was a hijab-wearing person who spoke Arabic and English fluently, in order to increase the comfort of participants. Surveys provided larger context and commonalities across a larger number of participants. The study was approved by University of North Carolina at Charlotte's Institutional Review Board.

3.1 | Participants

Survey eligibility criteria included: participants between the ages of 18 and 55 years, who identified as Muslim (either religious or ethnic¹ identity), and who were assigned as female at birth. Interview eligibility was the same with the added criteria of living in Charlotte (and/or surrounding areas) for a least one year, and fluency in English. Participants were recruited from a local free health clinic focused on Muslim populations, local Muslim groups, as well as word of mouth. Recruitment for the survey and the interview were done simultaneously.

3.2 | Data Collection

In-person semi-structured interviews (n=15) were conducted by a trained Muslim woman in English. Informed consent was obtained from all participants. Participants did not receive compensation. Interview participants selected pseudonyms that were used in this paper. Interviews were audio-recorded, then transcribed for data analysis. An anonymous open- and closed-ended online survey (n=76) was conducted using Qualtrics.

3.3 | Measures

Interviews asked about experiences accessing maternal and reproductive health care services and provider preferences (see Appendix A for questions). Interviews lasted approximately 45-60 minutes. Survey questions focused on different reproductive care screenings,

symptoms of reproductive health issues, and level of comfort with provider (see Appendix B).

3.4 | Analysis

Dedoose software (16) was used for thematic "theory-enabled" analyses (17, 18). A codebook was created based on the interview guide using components of Aday and Anderson's framework (14), then refined during initial coding of two interviews. Each interview was coded twice by two coders trained in qualitative coding (JB, SE). We sought to identify subcomponents of the framework and also generate and compare emerging health components (18). Reliability was confirmed using Dedoose's test function, with any codes of a kappa less than 0.80 discussed and edited until consensus was reached. Survey results were analyzed using descriptive statistics on SPSS and the open-ended response item was thematically analyzed using inductive methods.

4 | RESULTS

The age of survey respondents ranged from 18 to 54 years, with most participants (n=58, 82.86%)² having health insurance. Interview participant ages ranged from 18 to 55 years (see Table 1 for demographic information). We identified three main themes in the interviews: screening, provider, and education (see Table 2 for quotations).

In terms of gynecological care, participants reported limited access. Many survey respondents (39.13%, n=27) had never been to a gynecologist, and 14.49% (n=10) of all survey respondents had been diagnosed with a reproductive health issue in the past. Only 31.88% visit a gynecologist once a year (n=22), and 8.7% (n=6) visit every six months or more often. Jessica, an interview participant, described the lack of service utilization not as an issue of access but of norms (Table 2, 2a). Katie relates this norm to larger cultural community policing and gossip (Table 2, 1b). In this example, Katie

¹One can identify as Muslim because it is your religion, or because it was passed down through family but may not necessarily be practicing

²Due to variances in participation by question, we report the percentages based on the total number of responses per question

advocates for resisting this policing by “having a backbone” and putting the onus on families in raising their children. Similarly, Sarah felt the silence around Muslim women’s sexuality was dangerous and pushed Muslim women to advocate for themselves (Table 2, 2e).

Among survey respondents, the most common reason for gynecological visits were for pregnancy (38.46%, $n=20/52$), birth control (21.15%, $n=11/52$), pelvic exam (11.54%, $n=6/52$), irregular menstruation (9.62%, $n=5/52$), and breast exam (5.77%, $n=3/52$). Interview participants described accessing gynecological care for major concerns or recommendations from doctors or family members. It is worth noting that many interview participants’ family doctors were Muslim (Table 2, 2j).

4.1 | Screening

Most survey participants (73.42%, $n=58$) were screened for breast cancer. Of all participants, 31.65% ($n=25$) were examined by a doctor, 26.58% ($n=21$) had a mammogram or an MRI, and 15.19% ($n=12$) conducted a self-examination. Participants generally were aware of testing recommendations. Factors that contributed positively to breast cancer screening included knowing someone with breast cancer. For example, Fatima waited for her provider’s recommendation to do a breast cancer screening, as she believed that she might be diagnosed with it due to her family’s history.

Nearly half (47.83%, $n=33$) of survey participants had never been screened for cervical cancer. Twenty-nine percent ($n=20$) percent of participants have one every 2-3 years, and 17.39% ($n=12$) have one every once a year or more often. Jessica describes the reason that the screening rates are low as a lack of perceived risk. (Table 2, 2b) Roughly half (51.72%, $n=35$) of survey participants had never had a pelvic exam, with 33.33% ($n=23$) of all participants getting a pelvic exam every 1-2 years, and 5.8% ($n=4$) every 5 years or less. Participants connected low rates of pelvic screenings to the cultural expectation of Muslim women not being sexually active before marriage, and therefore only starting gynecological visits after marriage (Table 2, 2c, 2d). Family pressure and lack of education may be potential barriers to young

Muslim women accessing sexual health services (Table 2, 2e, 2h). Fatima described both the lack of information given to patients about cervical cancer exams and how her family has encouraged self-exams to gain more control over the process (Table 2, 2i).

Almost half (46.38%, $n=32$) of survey participants had been tested for sexually transmitted diseases (STDs). Given the aforementioned cultural norm of Muslim women’s lack of sexual activity before marriage, Selena’s experience of buying condoms and asking to be tested may be perceived as difficult to do for some (Table 2, 2k). The majority of participants who were sexually active had used contraception at some point ($n=25$, 64.10%), with 28.21% ($n=11$) using condoms, 15.38% ($n=6$) using intrauterine devices (IUDs), and 15% ($n=6$) using pull out/withdrawal method as the most common methods. Survey respondents reported low uptake of hormonal methods (8%, $n=3$). In contraception, some participants who were married prioritized their partner’s opinions. Some participants did not want hormonal contraceptives due to perceived side effects (Table 2, 3l).

4.2 | Provider

Providers’ expertise was generally trusted (Table 2, 3a). Health care providers play a crucial role in the level of comfort Muslim women experience in their office. Generally, the gender of the provider was prioritized over their religion (Table 2, 3c, 3d). Though most participants reported increased comfort with a female provider, some interview participants reported the provider’s gender did not impact their care, unless it was an invasive procedure (Table 2, 3e). Adding to that, some participants expressed concern about the way women’s pain can be perceived by male physicians (Table 2, 3f). Muslim providers increased comfort of provider for Rachel and Cassandra (Table 2, 3g, 3h). Ralph insinuated that if one’s only options were a male Muslim provider or a female Muslim woman without training or expertise, she would be more comfortable talking to the male Muslim provider, due to training and expertise (Table 2, 3i). Then, when asked about the religious or ethnic background of a provider, Ralph acknowledged the possibil-

ity of stigma or ignorance from non-Muslim providers (Table 2, 3k). Beyond gender discrimination, participants agreed that religious/ethnic discrimination makes them less likely to seek care (Table 2, 3n).

The close-knit and relatively small Muslim community influenced some participants' care. Two interview participants reported they did not have "proper" physical exams because their doctor was Muslim and a family acquaintance and hence they would receive less thorough exams. One survey participant describes purposefully avoiding Muslim providers for their sexual health needs (Table 2, 3j). Another strategy in the face of judgment was to ask for provider recommendations from trusted individuals (Table 2, 3b). The Charlotte community was also perceived as supportive of refugees and immigrants (Table 2, 1a).

When asked about access, almost all participants acknowledged cost as a barrier and said transportation was not (Table 2, 1d, 1e, 1f). It was agreed also that language can act as an impediment, especially when discussing a health problem of a sensitive nature. Patients may already feel uncomfortable talking about their reproductive health concerns in addition to not having words in another language to describe these concerns (Table 2, 3o).

4.3 | Information Seeking

Interview participants emphasized the need for better education—both in terms of religion and reproduction (Table 2, 2g). Participants reported an unmet need for awareness within the community, highlighting the role of parents and community leaders to open this conversation (Table 2, 2h). Participants reported that sexual health knowledge received from secondary school was insufficient, and that their sources of information were directly from family members, their college education, online resources, and providers (Table 2, 4a). Participants described tiered strategies in identifying informational support in reproductive health concerns. Cassandra describes prioritizing seeking support from first her mother, then her doctor (Table 2, 4b). Selena included religious texts as part of her sources of support (Table

2, 4c). Fatima discusses the legacies of health information being transmitted within families between women (Table 2, 4d).

On the other hand, some interviewees did not open up to their parents about their sexual health concerns (Table 2, 2f, 4e). Jennifer felt more aware of sexual health issues than her mother, through learning about it on the internet or from biology-major friends in college, yet she deferred to her mother in birth control decision-making (Table 2, 3m). Multiple interview participants mentioned their desire to go on birth control pills to treat period cramps, but not being able to because of a mother's disapproval and their lack of knowledge about side effects. Religious education was described as significant, as it allows women to distinguish between religious guidelines and cultural traditions that may act as obstacles in care. Maria advocated for the masjid (Islamic centers) and sheikhs (religious leaders) to provide classes with health professionals. Katie agreed to this statement as well (Table 2, 4f). Conversely, Mona felt that health care professionals must be more aware of Muslim-specific concerns that their patients might face (Table 2, 4g). This was not a common opinion among our interviewees. Another issue raised is that religious leaders (Imams), especially men, are in no place to educate Muslim women about reproductive health (Table 2, 4h). When asked about effective solutions, almost all participants (60%, n=9) pointed towards health education, but Fatima also questioned the efficacy of outreach (Table 2, 1c). Cassandra added that masjids are often not confidential spaces and people's trust can be compromised. Another way to build trust among participants is a tailored approach for a specific population, such as the youth in the community (Table 2, 4i). It is important to note that 'community' is tantamount to the mosque. Therefore, it is important to consider the health impact of participants' perception of reproductive health being too taboo to be talked about at the masjid. As suggested by some interview participants, an online teaching module would be effective because it ensures people's confidentiality when seeking information.

5 | DISCUSSION

This study identified widespread challenges for accessing reproductive health care among Muslim women in the south. Matin and Lebaron (7) point out that Muslim women may have reservations about clinical exams involving their genitals, regardless of marital status. This study reported supporting evidence with lower uptake of cervical cancer screening. Participants in this study had lower rates of 47.83% (n=33) for cervical cancer screening in contrast to the 84% national average (3). As compared to the 67% of the general U.S. population (8), participants had high screening rates (73.42%, n=58) for breast cancer. Further interview results demonstrate agreement with previous research findings, that knowing someone with breast cancer increases screening (8). Participants also learn about screening from family norms. Many families taught breast cancer self-check and passed down the tradition from mother to daughter.

Participants in our study generally had low rates of contraceptive use, with only 64% of sexually active participants ever using it. According to a 2012 research study (19), 62% of American women in the reproductive age regularly use contraceptives. Of women using a contraceptive method, the most common were the pill (28%) and female sterilization (27%). This may be an opportunity for tailored approaches with the Muslim community. These include acknowledging shared decision-making between spouses and acknowledging the low contraception awareness in this community. In a previous ethnographic research study in India and Bangladesh, minority Muslim countries, participants used prescribed family planning methods, such as sterilization, without the knowledge of their significant others, which could lead to “unfavorable circumstances” if their significant other found out (20). As Muslim individuals in the US are in a minority context, we might expect Muslim women to navigate systems and relationships somewhat similarly as this example, in which Muslim women are learning to navigate decisions and family expectations related to their reproductive health. Fatima describes a provider discounting

her menstrual pain and eventually being diagnosed with dysmenorrhea. Though there are cultural differences in conceptualizations of pain among Muslims (21), the experiences of Muslim women's pain not being recognized by providers connects to larger patterns in the US, since women often experience dismissal of pain from providers (22). Furthermore, race and ethnicity have been linked to differences in pain treatment by providers (23, 24). These issues may be compounded by language barriers, as previously discussed in literature regarding Hispanic patients (23).

5.1 | Strengths & Limitations

One strength of this study is that the interviewer was an Arabic and English-speaking Muslim woman, which may have increased participants' comfort. Recruitment was done through existing networks and word of mouth, which may exclude individuals who are less tied to communities (e.g. recent immigrants). Our sample was predominantly younger, in part due to our connections with existing groups. Given generational differences and how life course changes affect health behaviors, this may reduce the generalizability of our findings. The lack of incentive may have deterred potential participants, attempts were made to make the interview as accessible for them as possible (including offering multiple locations). Another limitation was the use of online surveys only, and the small sample size (n=72) in the survey. Additionally, the use of a mixed-method approach was a strength of this study. We did not ask about the amount of time participants had spent in the US, but longer amounts of time in the US for Muslim women reduce delays in seeking care (25). We also did not ask about income of participants, and though none of the participants mentioned cost as a barrier, they did acknowledge it as a potential issue for others.

6 | NEW CONTRIBUTIONS

Given that participants placed trust and respect in providers, there may be important opportunities to train

providers in culturally-sensitive care. We report numerous misconceptions from patients regarding reproductive health and screenings, such as self-exams for cervical cancer. This issue, and the low rates for screenings, call for awareness to the community through educational programs. Access must be increased to both physical resources (community-focused lecture series or confidential peer programs) and online resources (training modules, private portal, question submission portal). Education for providers on Muslim women's reproductive health needs, such as privacy during pelvic exams and basic knowledge of Islamic values (i.e. fasting during Ramadan), is also needed. As not all Muslim women may be visually discernible from others, providers may need to ask questions to determine patients' religious and cultural identity. In one study, Muslim women in the US delayed seeking health care due to a perceived lack of female physicians (25). This may point to a need to not only promote service awareness, but also provider availability. Overall, education and promotion messaging must be tailored to Muslim communities to maximize efficacy (7). Muslim women's needs are not wholly different from non-Muslim women (7), but comfort and privacy with a provider is important. For younger individuals whose families are less supportive of reproductive health care, providing resources outside of the family environment may be especially impactful.

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7 | APPENDIX A: INTERVIEW GUIDE

1. Have you heard about breast cancer screening? Have you ever been screened? [If not] What do you think it would take for you to be screened?
 - Do you believe breast cancer screening is necessary? Why or why not?
2. Have you heard about cervical cancer screening? Have you ever been screened? [If not] What do you think it would take for you to be screened?
3. What do you normally do if you have any sexual health concerns?
4. Are there places in Charlotte that you feel more comfortable going for sexual health concerns? What about less comfortable?
5. Are there places in Charlotte where you've gone for sexual health services?
 - Have you ever or would you ever use contraception? If you needed to get contraception like birth control pills or an IUD, what would be your concerns in getting those?
 - i. Prompts: Asking a doctor, going to the pharmacy, paying for them or using insurance, understanding how to use them, etc
 - Do you think Muslim women (especially the youth) would have a difficult time accessing sexual health services as opposed to people with perhaps another background?
6. How often do you see a gynecologist?
 - If you do not see a gynecologist, then why?
 - What was the reason why you visited a gynecologist for the first time?
- Do you know of any other sexual health providers other than your general doctor?
7. How does it feel to talk about reproductive health with healthcare providers?
 - If your provider is a woman, how does that change the experience for you?
 - If your provider is Muslim or from a similar cultural background, but maybe not a woman, how does that change the experience in discussing sexual health concerns?
8. Have you, or someone you know, ever experienced discrimination in a healthcare setting?
9. What have you learned about sexually transmitted diseases? Tell me what you know about them?
10. Where have you gained most of your sexual health knowledge?
 - Have you learned or heard about menopause? Where from?
 - What have you learned or heard about sexually transmitted infections such as chlamydia, gonorrhea, syphilis, or HIV? Where from?
11. Can you tell me a time when you talked to others about women's health? That might relate to pregnancy, menstruation or periods, menopause, women's bodies, etc.
 - Growing up, how did you discuss your menstrual cycle with your parents or family members?
 - Thinking about intercourse in the context of marriage, do you think that Muslim women view sex as a form of pleasure or for the purpose of reproduction?
 - [If they have a partner] Do you ever have conversations about reproductive health with your husband/partner?
12. In thinking about other Muslim women that you know, how do you think their religion or culture influences their sexuality?
13. What, would you say, is a source of support for you when it comes to your sexual health?
14. How do you think we can reach this audience of

Muslim women living in Charlotte?

- What programs do you think would be effective in promoting women's sexual health?
- Thinking of this issue on a populational scale, how do you think we can empower Muslim women to learn about their reproductive health?

- Living with parents
- Living with partner
- Living with roommates/shared house
- Living alone

9. Do you have health insurance? Yes No

10. Do you smoke cigarettes? Yes No

11. Are you sexually active? Yes No

12. How many children do you have (including deceased and stillbirths, if any)? ____

13. Have you ever had a UTI (Urinary Tract Infection)?

- Yes, about once a year or more often
- Yes, sometimes (I've had it one or more times)
- No, I've never had it
- I don't know
- Prefer not to answer

14. Have you been diagnosed with any reproductive health issues such as endometriosis, polycystic ovarian syndrome, gynecologic cancer, uterine fibroids, or others?

- Yes
- No
- I don't know
- Prefer not to answer

15. Have you ever been checked for breast cancer?

- Yes, I've had a Mammogram
- Yes, I've had an MRI (Breast Magnetic Resonance Imaging)
- Yes, I've checked myself
- Yes, I've been checked by my doctor
- No, because I don't know about it/how to
- No, because I can't afford it
- No, because I don't need it/want it
- No, but I would like to
- Prefer not to answer

16. Have you ever been checked for cervical cancer (Pap smear test)?

- Yes, I have one once a year or more
- Yes, I have one every 2-3 years
- Yes, I have one every 4 years or less
- No, because I didn't know about it
- No, because I can't afford it
- No, because I don't need it/want it

8 | APPENDIX B: SURVEY QUESTIONS

1. How old are you? ____

2. For how long have you been living in the Charlotte area? ____

3. Do you identify yourself as Muslim? Yes · No · Don't know

4. What is your country of birth? ____

5. What is your relationship status?

- Single
- In a Relationship
- Engaged
- Married

6. What is your sexual identity?

- Heterosexual
- Lesbian/gay
- bisexual/bi-curious
- unlabeled/prefer not to be labeled
- Other
- Prefer not to answer

7. What is the highest level of education you've completed?

- Didn't complete high school, GED, or equivalent
- High school diploma/GED or equivalent
- Some college (no degree)
- Associates degree or equivalent
- Bachelor's degree or equivalent
- Some graduate (no degree)
- Masters/ Graduate Certificate
- Doctorate (or equivalent)

8. What is your living accommodation?

- No, but I would like to
 - Prefer not to answer
17. Have you ever been screened for sexually transmitted infections (such as chlamydia, gonorrhea, syphilis, HIV)?
- No, I've never been tested
 - Yes, but I never tested positive
 - Yes, and I did test positive
 - Yes, and I don't know the results
 - Prefer not to answer
18. In the past 30 days, have you experienced any breast pain, breast or nipple swelling?
- Yes
 - No
 - Prefer not to answer
19. In the past 30 days, have you experienced any of these symptoms?
- Frequent genital itching
 - Unusual vaginal discharge
 - Bad odor from the vagina
 - Rash around the vaginal area
 - Vaginal blisters or sores
 - None of the above
 - Prefer not to answer
20. [If sexually active] Do you experience any pain during intercourse?
- Yes, and I've consulted my doctor about it
 - Yes, but I haven't consulted my doctor about it
 - Sometimes
 - No
 - I'm not sexually active
 - Prefer not to answer
21. [If sexually active] Which birth control method do you use?
- I don't use birth control
 - Hormonal contraceptives (pills, patches, injections, etc.)
 - Condoms
 - Intrauterine device (IUD)
 - Pull-out/withdrawal method
 - Other (sterilization, gel, diaphragm, ring, sponge, etc.)
- Prefer not to answer
22. Is your menstrual cycle regular?
- Yes
 - No
 - Sometimes
 - Don't know
23. How would you rate your knowledge on menopause?
- I know a lot
 - I know some
 - I know nothing
24. How often do you see a gynecologist?
- Once every 6 months or more often
 - Once a year
 - Once every 2-3 years or less often
 - Never
25. How comfortable are you discussing reproductive health with healthcare providers?
- Very comfortable
 - Comfortable
 - Somewhat comfortable
 - Somewhat uncomfortable
 - Uncomfortable
 - Very uncomfortable
26. [If not single] How comfortable are you discussing your reproductive health with your spouse/partner?
- Very comfortable
 - Comfortable
 - Somewhat comfortable
 - Somewhat uncomfortable
 - Uncomfortable
 - Very uncomfortable
27. What do you normally do if you have any sexual health concerns? (Select all that apply)
- Schedule an appointment with my gynecologist
 - Schedule an appointment with my General Doctor
 - Tell a parent or a family member
 - Tell my partner/spouse
 - Tell a friend
 - Try to find information online
 - Other _____

28. Have you visited Shifa Free Health Clinic? If yes, how satisfied were you with the service?

- I have never been to the clinic
- Yes, I've been to the clinic and I'm satisfied
- Yes, I've been to the clinic and I'm not satisfied
- Comments _____

TABLES

Pseudonym	Age*	Place of birth	Relationship status	Educational level*	Living accommodations*
Jessica	18	Yemen	Single	High school	One or both parents
Ralph	18	New York, USA	Single	High school	One or both parents
Maria	18	North Carolina; USA	Single	Some college	One or both parents
Penelope	18	North Carolina; USA	Complicated	Some college	With roommates/ shared housing
Fatima	19	North Carolina; USA	Single	Some college	One or both parents
Cassandra	19	North Carolina; USA	Single	Some college	One or both parents
Sarah	19	North Carolina; USA	Single	Some college	One or both parents
Katie	22	Egypt	Single	Bachelors	One or both parents
Jennifer	23	Pennsylvania, USA	Single	Associates	With roommates/ shared housing
Rachel	26	Louisiana	Married	Graduate	Spouse & child(ren)
Anna	27	Ohio, USA	Married	Bachelors	Spouse & child(ren)
Jamie	28	New York, USA	Single	Graduate	One or both parents
Selena	36	North Carolina; USA	Married	High School	Spouse & child(ren)
Sonia	36	Pakistan	Married	Bachelors	Spouse & child(ren)
Mona	51	Jerusalem	Married	Graduate	Spouse & child(ren)
Mona	51	Jerusalem	Married	Graduate	Spouse & child(ren)

* at time of the interview

TABLE 1 Muslim Women Interview Participants Self-Identified Descriptions (N=15)

Type	Category	Example Quotation	
1. Local context	Muslim supports/barriers	<p>A) "From my recent experience in Charlotte with Muslim females has been that the refugees who are coming here from Afghanistan and all those places- the community here is pretty open in helping them. I'm on a few [WhatsApp] groups that are always asking for help to take the Muslim sisters to the doctor's office or you know just generally helping them. People are very open to help them and taking them to their appointments or just kind of being their translator and all, so if you want help, you can get help." (Sonia, 36 years)</p> <p>B) "Some people are really concerned about the way people think about them, right? ... Especially women, if you go to a gynecologist, for example, there are so many different reasons. It's not only pregnancy... sometimes men go in there with their wives too... So, if they're afraid of someone seeing them from the community, or maybe that's weird for them, possibly. But I think this comes to the fact of Muslim women not having a backbone because of the way they're raised not being strong enough. And this is a conversation I've had of different aspects- not just women's health. Like, women having to care too much about their appearance, and what people could say about them." (Katie, 22 years old)</p> <p>C) "I would say, of course education is the best route, but I also fear that women who need that education are women who are in areas where they cannot access this information. So, if you host a seminar regarding sexual health within the Muslim community, will Muslim women show up... or will they think 'Oh, what does that say about me?' Because I also consider, would posting flyers in the mosque be too much? But I also think that is also because of our general bias of thinking that the mosque -of course it's a public space of unity and it's a place to help one another- but we also think, 'Well, sexual health? No, that can't be in the mosque,'" (Fatima, 19 years)</p>	
	General community supports/barriers	<p>D) "Charlotte has a good ... network over here, so there are a lot of doctor's offices everywhere within a few miles of your home that you can go to... I know Charlotte doesn't have a huge bus system here or transportation, but you can still go... the people who rely on buses and all of those- they already live along those bus routes anyway, so I don't think there should be any problem." (Sonia, 36 years)</p> <p>E) "I feel like transportation is everywhere in Charlotte because if you look at it, if taxis and cabs are expensive, you can take the public buses. So, the buses are not expensive at all, so I feel that with transportation it's fine but probably the cost of the treatment will be higher." (Maria, 18 years)</p> <p>F) "I can see [cost] definitely being a barrier if you don't have insurance. Because I know that it's not cheap. Because we didn't have insurance for a little while- my husband was between jobs and everything was just so expensive that I just didn't go. Something came up and it was waited until it was serious- [praise to God] it wasn't anything too serious, but had I had insurance, I would've gone probably a month earlier." (Anna, 27 years)</p>	
	2. Screening	General low uptake	<p>A) "When I did my health internship, I did a gynecology round with med school students, and I never saw a Muslim woman walk into the gynecology office. Even for my mom- my mom didn't go to the gynecologist very often. I think we have access to them; I just don't think that we are using them." (Jessica, 18 years old)</p>
		Perceived risk	<p>B) "People [don't] think it applies to them. People automatically think [it]—in this situation, breast cancer or cervical cancer—would not ever happen to them" (Jessica, 18 years).</p>
		Family pressures	<p>C) "Because you're supposed to wait until marriage [to have sex], it's like, 'We're just not going to talk about it until you're married.' Even though your reproductive system is a lot more than sex" (Anna, 27 years).</p> <p>D) "In our culture, if you're not married, you don't see an OB/GYN, so you don't get the chance to discuss these topics with a healthcare provider... So, what if a girl gets married at 28 and she's never been to an OB/GYN, who's never explained to her the importance of screening." (Mona, 51 years)</p> <p>E) "So, they already assume 'I haven't done anything, so why would I need anything checked out?' But there are the risks—you could have cervical cancer; you could have ovarian cancer. You can get infections, cysts from not even getting in sexual contact. But you would never know until the last minute and that's really bad. So, I feel like people should embrace their bodies and know what all the functions and details are. Don't be afraid to ask, because it's not just like a married thing—all women go through this." (Sarah, 19 years)</p>

Lack of (sufficient) information	<p>F) "If you tell [your family] that I am having vaginal pain, the first response is going to be, 'What have you been doing?' 'Oh, have you been sexually active?' that's the first response you're going to get..." (Jennifer, 23 years)</p> <p>G) "I can see Muslim women not having access to knowledge about those kinds of things, or discussion. Because they are afraid of how the reaction will be. Even in our local community, there isn't a lot of discussion amongst women in a positive setting." (Sarah, 19 years)</p> <p>H) "...Second, is because of the lack of education that, not just Muslim women, but women in general, are receiving, and the school system. The last time I remember that I was educated on my period was in the 5th grade. After that I have yet to learn anything about my system, or kind of what I need to know and thus forth. So definitely, yeah, it's the response of the family and the lack of education." (Jennifer, 23 years)</p> <p>I) "I've heard of cervical cancer exams, but I don't know much about them to that extent. It certainly feels invasive because often they're not very up front about the procedure. To the extent where my family discuss more self-examination because of that- like a private matter and whatnot, to us. As opposed to the doctor walks in and recommends the procedure" (Fatima, 19 years)</p> <p>J) "The first time I ever went [to the gynecologist] was when I turned 18... I got married in 2014, so four years [ago]. Part of that also is that I was not Muslim until 2014, I still probably would have gone. So, I also went yearly for birth control pills and for STD screening and that sort of thing before I got married. It was recommended by my family doctor that they recommended starting at 18 and so I followed the rules." (Anna, 27 years)</p> <p>K) "I went in to get myself examined and make sure I didn't have STDs, and [the health department] actually accommodated me with free condoms. So, anytime you need free condoms they give them to you." (Selena, 36 years)</p>
3. Provider	<p>A) "If you bring in professionals and tell [the community], 'These are doctors or medical students,' they're going to want to listen. People will listen to people who know their ish [shit]" (Katie, 22 years).</p> <p>B) "If I had to go to a doctor for a specific thing, I would probably ask my primary physician if they could refer me to someone that they know, that they've worked with in the past, that they trust... Just because there's always that risk of discrimination or that underwriting of my pain- I don't like being written off." (Penelope, 18 years)</p> <p>C) "I'd be a little more comfortable talking [to a woman], as opposed to a man. I feel he wouldn't understand what I'm talking about." (Ralph, 18 years).</p> <p>D) "I feel more comfortable with the woman especially if it's a little bit- like if they're going to see my body or they're going to touch anything really like my breast area, then I feel more comfortable it being a woman." (Jaime, 28 years)</p> <p>E) "I don't really care if it's a man or a woman... I hope that either way they have that objectivity; they've been trained the same way. I don't really see a difference as long as they're asking the questions that need to be asked. And if it's an actual invasive procedure, where I'm getting a pap smear or a cervical cancer check, then I'd probably request a woman, just because of comfort sake." (Penelope, 18 years)</p> <p>F) "I feel like women's pain is easy to underrecognize or intentionally misconclude. For instance, I was diagnosed with Dysmenorrhea last year. So, I have very painful periods. But this wasn't recognized by male general practitioner because he said, 'Being in pain when you're on your period is something normal,' and he didn't understand my pain. I feel that a woman practitioner would have said, 'If you're experiencing that much pain, you might have had that early warning or early signal,' or some sort of understanding of it." (Fatima, 19 years)</p> <p>G) "[My previous Muslim doctor] was awesome. Even when it came to women's health, he went straight to the point. He would not spend too much time on it—he wanted to give us our own privacy as females, and because he was the only... pediatrician at the time, he was the only one available to do all the checking and examination. He made us feel so much comfortable even when we needed medicine, he would make sure that the medicine had no gelatin, no pork." (Cassandra, 19 years)</p>
Gender of provider	
Religious background of provider	

		<p>H) "It's nice having a Muslim doctor especially when it's Ramadan—you want to know if you can fast ... while being pregnant or nursing that type of thing I don't think [non-Muslim] American doctors would understand my concerns" (Rachel, 26 years)</p> <p>I) "I feel [if it's] a man and you're talking about sexual stuff, it's a little uncomfortable even if he's Muslim. But I'm not opposed to it, I'm open- he's a doctor, he's certified, he knows what he's talking about, so, he's going to be the best person to talk to, as opposed to just a random female Muslim" (Ralph, 18 years)</p> <p>J) "As a Muslim woman who has been sexually active, I would not seek medical care from a practitioner who is Muslim or associated with the Muslim community due to a fear of judgement, lack of trust, and having to deal with gossip and harmful behavior from Muslims in the past once they discovered I have been sexually active [before marriage]." (Anonymous Survey Participant)</p> <p>K) "I think I'd be a little bit more open [with a Muslim provider], just because they would understand a little more... They wouldn't be so judgmental. If I bring up something like, I don't want to use birth control, they would understand it. They wouldn't be so judgmental like, 'Oh you're a Muslim so, you know, it's weird' and- they'll give you those judgy comments or whatever." (Ralph, 18 years)</p>
	Family involvement in care	<p>L) "I have never used any type of contraception... We chose to just use the natural way. So, I've never used any pills because my husband hates medication and he reads a lot about side effects and he decided that this is not something that we want to go through, and if there are other safer options, we take the safer options before going to any type of injections or pills or whatever." (Mona, 51 years)</p> <p>M) "My doctor tried to put me on birth control, but my mom told me not to because it messes up like your system, is what her understanding of it is...she had prescribed me birth control but my mom, wouldn't let me take it because she thought it would mess up my cycle ... until I got married." (Jennifer, 23 years)</p>
	Perceived discrimination	<p>N) "I think [that discrimination makes patients less likely to seek care], because they would probably feel that most doctors would be the same and they would treat them with the same way... they just wouldn't want to go anymore.. Because a lot of people especially in Muslim communities they're not so accepted in the Western world, so if they feel they're uncomfortable in a certain situation, they try to avoid it most of the times." (Maria, 18 years)</p>
	Language barriers	<p>O) "Language can be a barrier generally speaking, but especially when it comes to sensitive topics, that a lot of people don't feel comfortable talking about... Along with a welcoming environment, we need to have multiple-language speakers... That way people in different walks of life can come into this welcoming environment and feel comfortable speaking about what they're dealing with. Because a lot of people can't express what they're feeling in English. Sometimes, you only know it in Arabic or Farsi or Urdu or other languages." (Cassandra, 19 years)</p>
4.	Education Sources of support	<p>A) "For everything, whether it's health-related issue, pregnancy, stuff with the kids, when I was doing my master's degree, [my husband] was my only support. If you have any problems, you don't seek out other people if you have a husband, if you have a supportive husband, supportive wife, then you try to get the things together." (Mona, 51 years)</p> <p>B) "My mom [would be my first source of information] and then... my doctor [through] the [online] portal." (Cassandra, 19 years).</p> <p>C) "The Bible, the Quran, and just talking to other Muslim women." (Selena, 36 years)</p> <p>D) "My grandmother was diagnosed with breast cancer because she didn't know that was a possibility. And even in my extended family, women didn't even know to check for lumps in their breasts. If it doesn't happen to somebody in the family, then it doesn't become known for everybody else. And so, you lose this line of teaching—your grandmother teaches your mother who teaches you—you lose that. If it doesn't happen to somebody else, then we're not taught to seek that knowledge." (Fatima, 19 years)</p> <p>E) "The more I stepped away from my parents as well, especially my time away for college, I did my own research ... I'm going to do whatever the gynecologist recommends." (Katie, 22 years)</p>

- Recommendations
- F) *"We need to train our own community- I think we need to put less emphasis on health professionals [for intervention] because I really think they know what they're doing and they already have classes on different behaviors from different community members... What we need to educate is our own community- our own sheikhs to talk about this stuff- and they don't even need to talk about it- we need a Muslim leader to bring in people who know how to talk about this stuff." (Katie, 22 years)*
- G) *"Because I worked as a nurse [in the United States], and I worked as an interpreter in the medical setting ... I don't feel that the healthcare sector is being proactive and reaching out to [the Muslim] community. Because they feel that there are so many taboos around these communities, so many issues. So, I think it is very important to diversity training for the healthcare provider about the Muslim community and their healthcare needs, about the way things work, the dynamics of families, the dynamics between husband and wife. But the person who's doing the training has to be somebody who's well-educated in religion and health, preferably. So that they don't give inaccurate information either way" (Mona, 51 years)*
- H) *"Don't make it a religious thing. Don't be like, 'Oh, the Imam is going to talk to you about reproductive health'. I know that there are programs that [have] the Imam talking about menstruation and what that means in terms of: when should I start praying again, how many days should I make up for fasting, etc., I get that, but, that's not the focus of this particular type of education. And the Imam should be respected and trusted person, but this just isn't his area of expertise and he shouldn't be there. And so, it should be women's only events, but with people who are educated in this stuff like medical professionals, probably Muslim medical professionals." (Penelope, 18 years)*
- I) *"I think what would be cool is a peer program. If you set up an organization here with the Muslim girls and gave training modules like, what basic reproductive stuff is, and gave them resources... so they would know where to reach out to if they had any questions. Or if you did like a pairing off program like a mentor-mentee kind of thing. So, if any girl wants to learn about the stuff, whether she wants to know about it for herself or if she wants to be a doctor when she grows up, they can sign up for programs and be assigned someone to talk to. I think this is something better run peer-to-peer. Big sister, younger sister kinda thing? I feel a big flaw in the youth programs that we have is that they're run by adults." (Penelope, 18 years)*

TABLE 2 Themes with example participant quotations