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Hesitancy toward Cervical Cancer Prevention Methods among Conservative Muslim American Women in Virginia: An Exploratory Qualitative Study.

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Abstract

Cervical cancer screening (CC-S) and HPV vaccination (HPV-V) are crucial in reducing cancer-related morbidity and mortality. The Muslim population is a growing and understudied minority group presenting with a higher rate of late-stage cervical cancer (CC) diagnosis and a lower rate of HPV-V than non-Muslims. Our study aimed to explore religious, behavioral, and socio-cultural factors affecting Muslim women's decisions regarding CC-S and HPV-V in Virginia, USA. The study included in-depth interviews of 10 Virginian Muslim women to collect qualitative data as part of a mixed-method cross-sectional study in August and September of 2021. The results showed that most of the participants had limited knowledge about CC, CC-S, and HPV-V, with some themes including cultural aspects, misconceptions, and barriers caused by language issues and the complexity of the US healthcare system. Future studies investigating these barriers are needed to reduce the effect of CC on the Muslim population.

Keywords: Muslim cancer, Muslim women, Cervical Cancer Disparities

Introduction

Cervical cancer (CC) is one of the most common cancers among females, with over 600,000 diagnoses and 342,000 deaths in 2020 globally [1]. The projected number of new cervical cancer cases in 2021 is 14,480 in the U.S. and 310 in Virginia [1]. Most cervical cancer cases are preventable. According to the World Health Organization, almost all cervical cancer cases are caused by the Human Papillomavirus (HPV), a sexually transmitted virus [2]. Cervical cancer has been described as the 'silent killer' as pre-invasive and early invasive cervical cancer cases are most likely asymptomatic and detected only during screening tests [3].

Cervical cancer screening is a crucial form of prevention as the treatment of early-detected pre-cancerous lesions reduces its incidence and mortality rates [4]. Earlier studies showed that the five-year survival rate of patients with localized lesions was 90.9%, while for patients with advanced-stage cervical cancer, it was only 17.6% [5]. The National Cancer Institute's Cancer Trends Progress Report has shown that about 81% of women aged 21 to 65 had been screened for cervical cancer in 2018 in the United States [6].

The Muslim population in the United States is considered a minority group with distinguished religious and cultural characteristics that greatly influence their healthcare practices, behaviors, and attitudes [7]. According to the Pew Research Center, 2.7% of Virginia's population is Muslim [8]. Muslim Americans are a population that is challenging to identify in surveillance databases, therefore information about Muslim American Women's participation in cervical cancer screening and HPV vaccination is lacking [9]. Various targeted studies have been conducted to address the healthcare-related behaviors of Muslim American Women. In a study by Islam et al. investigating the factors that impacted Muslim women's beliefs and practices regarding cervical and breast cancer screening, the researchers identified some barriers and challenges that these women encountered at clinics and hospitals, such as lack of translated information and access to native-speaking healthcare providers, insurance and cost, immigration status, limited social network, fatalism, and gender norms. These barriers created a gap between Muslim American Women and healthcare providers [10].

The significant difference in the cancer stage at the time of diagnosis between Muslim and Non-Muslim women in Virginia may

be attributed to these barriers, especially for preventable cancers such as cervical cancer [11]. Hearld and Budhwani examined the HPV vaccination rates among Muslim American women. They found that the participation rates were low because of multiple reasons, including the cultural stigma of taking vaccines related to a sexually transmitted disease, considering it non-mandatory, and the perception that it contains pork products. Myths, fake news, and lack of education and awareness about cervical cancer symptoms, complications, and mortality rates also affected the HPV vaccination rates [12]. A common argument is that if a woman is not sexually active outside of her marriage, she is fully protected from cervical cancer, which ignores the fact that it is much more acceptable for men to engage in extramarital sexual intercourse, potentially making them carriers of the HPV virus [13].

Additionally, the religious perception that an individual's health outcome is inevitable and predetermined by God sometimes forces Muslim American women to delay care-seeking [14]. The theoretical framework "Cultural Construction of Clinical Reality" hypothesizes that religion might influence health and healthcare-seeking behaviors, and a review by Padela and Curlin using this framework concluded that the illness experience was influenced by cultural factors and affected how Muslim American women perceive, evaluate, and seek medical help [15]. Pratt et al. showed that delivering faith-based messages through Imams was essential to support efforts to engage Somali American Muslim women in breast and cervical cancer screening [16].

Our study explored multi-contextual factors, such as religious, behavioral, and socio-cultural elements that could influence Muslim women's decisions regarding cervical cancer screening and HPV vaccination. The research questions addressed in the project are I) How do cultural and religious beliefs affect the participation of Muslim women in Virginia in cervical cancer screening? II) What are the barriers and facilitators of HPV vaccine uptake, including the potential role of vaccine hesitancy among Muslim women in Virginia?

Methods

Setting and Participants

This publication reports on the results of the qualitative pilot part of a larger mixed-method, cross-sectional study. There were 110 participants in our pilot study, which included 10 participants for the qualitative part and 100 for the quantitative part of the study. The sample size was based on a statistical power analysis, which suggested an optimum sample size of 110 for a pilot and 360 for the main study. The qualitative study used in-depth interviews in August and September 2021. Participants were recruited at the Masjid Yusuf Islamic Center of Richmond, where the study team set up an informational station with educational material about cervical cancer and a team member to answer questions. Eligibility criteria included being a Muslim woman older than 18 years old, a Virginian resident, able to speak, read and write in English, and able to give consent. The study team approached 15 women in the Mosque before and after Friday prayers, and 10 of them agreed to participate in the study. Most women completed the interview in person at the Mosque, and others via phone. Personal information was not recorded or associated with research data; participants' names were only registered upon consenting. All study procedures were approved by the Institutional Review Board (IRB) at Virginia Commonwealth University (2021). For this study, the Massey Cancer Center (MCC) at Virginia Commonwealth University collaborated with Islamic Centers in Richmond, VA, engaging Mosque leaders as Community Advisory Board members. Researchers' capability to access and use Mosque facilities is vital for community participation [17].

Data Measures and Interview

Setting and Participants

An in-depth interview topic guide was utilized to investigate issues related to the study objectives. The interview topic guide was developed based on a detailed literature review. The interviews were conducted by the study research associate (Namoos) either via phone or on-site (Mosque). Each interview took about 20 minutes to finish, and they were audio-recorded and transcribed verbatim for analysis.

The interview guide was developed by the study research associate (Namoos) and divided into four sections; each section with a specific question set: I.) The opening set of questions asked the participants to describe demographic factors (e.g., age, race, ethnicity, marital status, education level, etc.) and the duration they had been living in the U.S. II.) The second part explored knowledge about cervical cancer screening and attitudes towards the screening process. This section asked about cervical cancer screening experiences, including whether the participants had ever experienced any difficulties that prevented them from getting cervical cancer screening exams before and after marriage. III.) In this section, the participants were asked about their knowledge of HPV, general vaccination, and the HPV vaccines. IV.) The last section evaluated the sociocultural factors affecting the participants' decision to seek HPV vaccination for themselves and their children. The participants were given a brief lecture about the HPV vaccine. Then they were asked whether they would take the vaccine or give it to their children.

Data Analysis

Setting and Participants

The analysis was guided by the steps used in the Strauss and Corbin variation of the Grounded Theory [18]. Data coding was an iterative process and followed the steps of open, axial, selective coding, and developing a theory based on causal relations between concepts in the interviews [19]. No software program was used to analyze the data, and coding was completed manually. First, transcripts were read, main ideas identified, and initial concepts named. Then, through constant comparison, the open codes' dimensions and properties were identified. Finally, the codes were aggregated into themes and subthemes based on the relationships between the identified concepts. To ensure proper recording of the study participants' responses, we audiotaped and transcribed them verbatim (generating 40 pages of data). The integrity of data interpretation was maintained using strategies to ensure credibility (audiotapes), confirmability (inquiry audit), and authenticity (use of direct quotes).

Results

A total of 15 women were screened to participate in the study,

and 10 women gave consent and completed the in-depth interviews. Most of the participants were ethnically Arab with Middle Eastern origin. All of them lived in Virginia. The participants' ages ranged from 21 to 55 years, with a mean age of 30. Sixty percent of the women were married. Seventy percent of study participants had formal education above high school (forty percent with high school education and thirty percent with some college or bachelor's degree). Half of the participants were unemployed (Table 1).

Table 1: Socio-demographic Characteristics of the Study Participants

Variable		N	Percentage (%)
Religion	Islam	10	100
Race	White	1	10
	Other	9	90
Ethnicity	Non-Hispanic	10	100
Marital status	Married	6	60
	Divorced	2	20
	Single	2	20
Education level	Bachelor's degree	2	20
	Some college	1	10
	High school	4	40
	Below high school	3	30
Employment status	Employed	5	50
	Unemployed	5	50
Legal Status	American by birth	1	10
	Naturalized citizen	8	80
	Green card holder	1	10

Themes

The main concepts and themes extracted from the interviews are shown in Figure 1.

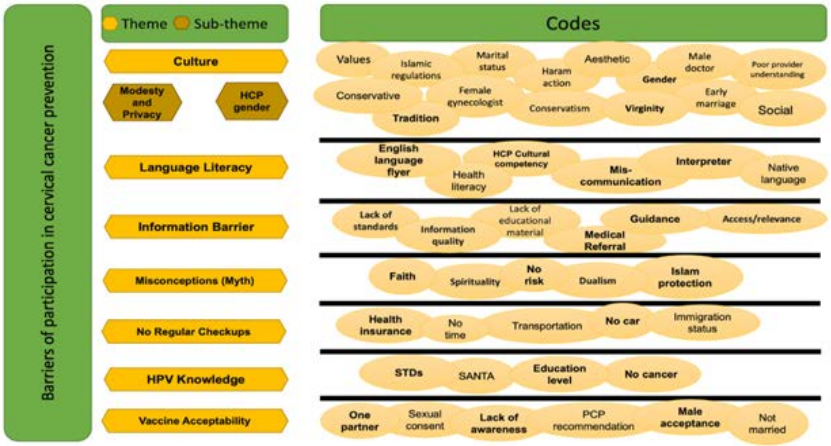

Figure 1: Themes Extracted from the Interviews

1. Culture Theme: All married and divorced women had an Obstetrics/Gynecology (OB-GYN) visit after marriage, while those who were single had zero visits. However, women who got married early, such as the one in the quotation below, mentioned that they did not need to visit the OB-GYN clinic because they were completely healthy. This participant also noted that it was her parents' decision not to take her to an OB-GYN visit before marriage, as they didn't see a reason for it. It might have resulted in unwelcomed questions about the modesty of the unmarried woman.

"P05: I got married when I was 18 years old. It was the first time I had been in the OB-GYN clinic. Okay, I had no problems before visiting a doctor. So, I think this is something related to the Arab culture that a person's family wouldn't let them visit the OB-GYN before marriage. This will cast doubts toward any virgin girl. I don't know if my mom didn't take me because of a traditional reason or not. But I believe it's just because she thinks I'm normal. And I never had any problems."

a. Modesty and Privacy Subtheme: Multiple participants discussed issues about modesty and how their families and commu-

nity perceived it. The previous quotation from P05 was a good example. In other examples, single women under 35 years old were not open to visiting an OB-GYN clinic.

"P03: I got infected before, and I do not know what the type of infection was. I was hesitant to discuss this issue with my mom because this would open many questions, and I did not want to go through this. Also, I used the Google engine to read more. I found that physicians needed to do an internal exam to know the type of infection by taking a biological sample. Therefore, I decided to practice good hygiene, and the itching disappeared after five days."

b. Healthcare Provider Gender Preference Subtheme: Participants had difficulties dealing with male healthcare providers. All women mentioned that they preferred female physicians, especially OB-GYN specialists. This issue seemed to be a major barrier to participating in cervical cancer screening. The quotation below shows how the thought of an examination by a male physician caused trauma to one participant and made her not go through with the examination.

"P01: I prefer to visit a female physician to be safe regarding the Islam regulations. In my periodic exam, I was always hesitant to go to the hospital after making an appointment. There is a high possibility of having a male physician. It happened to me before. I was very nervous and did not talk about my issues in detail."

2. Language Barrier Theme: Nine participants were immigrants, and all were able to speak, read and write in English, but almost all of them had negative experiences related to the limits of their language proficiency, especially early in their lives in the U.S. All women had heard about cervical cancer, but most of them didn't know about screening options. The source of information varied between friends/family (20%), school (30%), and flyers in the clinics (50%), as shown in the two quotations below. Some participants mentioned that they saw posters in the Women's Health Centers or OB-GYN clinics regarding cervical examination but the details were in English. They did not understand what they were supposed to do.

"P04: I have seen pictures in the clinic for the female genital system checkup, but I did not understand the English very well."
"P02: I had a flyer from a nurse before leaving the OB-GYN clinic, but she did not explain how to do a cervical cancer test while the interpreter was with me. She gave it to me after closing the phone with the interpreter. So, I could not understand what I was supposed to do. This was four years ago. Precisely, the first checkup for me in the U.S."

3. Information Barrier Theme: Participants stated that it was often difficult to get information about cervical cancer screening from their clinical providers (primary care and specialists). All women confirmed that they were asked questions regarding pap smears at the PCP clinic, such as in the quotation below. Fifty percent knew what the pap smear was for, but none knew how or where they could have the test. It was also apparent that some women did not know why or how often they were supposed to do the test.

"P07: I know I have to do a pap smear to check for cervical cancer, but I do not know where. My cardiologist told me to call the Women's Health Center, but I have not. No one goes into detail. That is why I have not done it yet."

Moreover, fifty percent of the participants mentioned that they did the pap smear test in their home country to prevent the need for further checkups in the U.S. One participant mentioned that she felt confused when she was asked about more details when talking to her PCP. She decided to say that she did it in her home country, while in fact, she had no information about what the pap smear was.

"P10: I don't know what the vaginal swab is for. I told my PCP that I have done it before to prevent more questions."

4. Misconceptions (Myth) Theme: Some participants had misconceptions about the risk factors of cervical cancer, such as the participant in the quotation below. Multiple women stated that cancer, in general, is a test from God.

"P06: There are no factors to get ill or get cervical cancer. I came to life, and my God wrote up my future. If I get cancer, that means my God loves me and is testing me."

One woman mentioned that she thought that getting vaginal infections multiple times would lead to cervical cancer.

"P09: I don't know what factors could lead to cancer, but I guess if I have not treated an infection multiple times, I could get it. In any way, if I get it, that means my God is testing my patience."

5. No Regular Checkup Theme: Large portion of the participants had done cervical cancer screening before, but they did not do it regularly. Four women had done the pap smear in their home country, but they had not been tested in the U.S.

"P07: I have done a vaginal swab once in Lebanon. It was normal. I have not done it again here. I feel more comfortable with my female OB-GYN. I do not know if I need to do a follow-up."
"P06: I was doing that regularly in my home country. For the last three years, I have not visited an OB-GYN. I do not have health insurance."

Two women had cervical cancer screening when they arrived in the United States years ago. They had not repeated the test.

"P08: I did one swab years ago; I was a new immigrant and had insurance. The caseworker in the refugee office helped me to do it."

6. Lack of Knowledge about HPV Theme: Most participants had not heard about HPV infection as the leading cause of cervical cancer. They didn't know that there was a virus that could lead to cervical cancer. We asked about the 'HPV' word in English and Arabic. Younger women had heard about HPV in high school, especially those educated in the U.S.

"P08: Yes, I know that HPV is a sexually transmitted disease. I

got this in grade knew this from grade 11 in high school, but I don't know what does cervical cancer have to do wth HPV.

Most of them knew the name "Santa", the Arabic name for genital warts.

"P05: I don't know. I'm probably okay. But to be honest, I don't know what HPV is. Okay, I know it's a virus, but I do not know about it.

Interviewer: Have you heard about 'SANTA'?
P05: Yes, sure. Well, this is the first time I know that the SANTA is the HPV infection. Oh, yes, I understand what you are referring to. SANTA will lead to a genital wart. My friend had it before. Hmm, she is completely fine; this is not cervical cancer."

7. HPV Vaccine Acceptability Theme: There was very little knowledge about the HPV vaccine; none of the participants were vaccinated. One of the participants mentioned that they had not needed to get the HPV vaccine since the virus was transmitted sexually.

"P10: I do know there is an HPV vaccine. From this conversation, I understand now that HPV is transmitted sexually. So, why should I get a vaccine while I have one husband? We are healthy and clean. I have to read more about this vaccine."

We tried to understand if women were against the concept of vaccination or just did not know about the HPV vaccine. Most women were very welcoming to get any vaccine to protect themselves unless this vaccine had any Haram (forbidden in Islam) chemical composition derived from pork or alcohol.

"P04: I would take any vaccine to prevent myself from getting sick. I would ask before if the vaccine does not contain any substances prohibited in Islam, such as pork. Other than that, I agree that everyone should get vaccinated."

One participant stated:
"P01: I would take the vaccine to protect myself, but to be specific, not the latest vaccine (COVID19). I feel unsafe taking it because of the media and everything we hear every day. However, back then, I never had this fear. Whenever I took my kids to get vaccinated, I never asked what I was doing because they told us we had to get vaccinated back home. But right now, I'm more afraid."

We asked all participants if they would take the HPV vaccine to protect themselves from cervical cancer. Fifty percent of the women agreed to take it without going into details.
"P08: Yes, why not. I will take any vaccine recommended by PCP or an expert."

"P01: I don't know anything about this vaccine. I might have got it in my home country, and I don't know. But I am happy to take it if there are no side effects."

The other fifty percent of the participants wanted to ask their families or husbands first and check if they needed it or not.

"P10: Hmm, I don't have information about this vaccine. I guess I am hesitant. I would ask my husband. He is a pharmacist. Probably he knows more than me."

The last question was whether the participants were willing to vaccinate their children (boy/girl) with the HPV vaccine. Two women stated that they would not give it to their male children. Most participants agreed that they would not provide the HPV vaccine to a female child before marriage. They might do it after marriage.

"P02: My daughter (15 years old) does not need this vaccine. She is a virgin, she doesn't have any relationship outside marriage, she will not get infected, I will not give her permission to take this vaccine, and the same for her dad. If she gets married, we may think about it."

Discussion

This study aimed to narrow the gap in the literature about the influence of religion and sociocultural elements on the knowledge, attitude, and behavior related to cervical cancer screening and HPV vaccination among Muslim women in Virginia, USA. Our findings align with the results of previous studies on Muslim women's understanding of cervical cancer screening and HPV vaccination. Most participants had very limited information about HPV, cervical cancer, vaccination, or screening programs, not to mention how these relate to each other. In our study, younger participants had more knowledge of CC and HPV from school, while older ones heard of them when their clinical providers inquired about their information on the topic. Most women stated that they would do regular screening and vaccination to protect themselves against cervical cancer. This finding is significant because it shows that women would seek screening if they had the proper knowledge. In addition, this reflects the burden on each healthcare professional who encounters these women at all stages of their lives.

One identified barrier to screening and vaccination was that most participants never visited an OB-GYN clinic before being married, so there was no chance to initiate screening. Any offer for an exam/swab is perceived as invasive, especially for unmarried Muslim women. Another discussed contributing factor was the presence of only male healthcare providers, which caused more hesitancy.

The language barrier is also a major element in understanding vaccination and screening hesitancy among Muslim women, as many are immigrants and new to the healthcare system. This would constitute a challenge as an interpreter adds a layer of privacy concerns, possibly failing the prevention process. The language barriers present in our study are consistent with those reported in other studies of similar communities in the USA and Australia [11, 20, 21].

Some misconceptions were found regarding the causes of cancer, as multiple participants believed that cancer was a test from God, therefore there was no point in prevention and screening. One study of Somali Muslim women in Minnesota identified cancer as punishment from God, so the stigma of being diag-

nosed with cancer explained their lack of screening [20]. Interestingly, a UAE study by Khan and Woolhead examined the role of religion and culture in screening and HPV vaccine uptake among Muslim women in Dubai, UAE. Participants did not consider religion as a barrier. Instead, they blamed cultural norms, such as the subservience and modesty of women [22].

Regarding HPV vaccine uptake, our participants stated that if they or their daughters were not married, the vaccine would have no benefit. Many agreed to take it when initiating sexual activity or recommended by their doctors. Again, this highlights the importance of health education customized for this group to enable and encourage younger generations to understand why prevention is essential and adopt a more informed decision-making process. Several studies explored how healthcare providers can effectively communicate information about HPV vaccination and cervical cancer screening. A brief discussion about the vaccine and its components' Halal status (approved by Islam) would impact the choice of adolescents and their guardians to receive the HPV vaccine and gain more trust in the vaccination program [23].

One aspect to be addressed for future research is the level of knowledge and acceptance of the Patriarch (father or husband) figures in Muslim families, as these men make most decisions. Our participants' responses highlighted this notion as many of them mentioned asking for their partner's opinion.

Study Limitations

The small sample size is certainly a limitation of this project, but its qualitative nature combined with limited resources did not allow a larger sample size. Even with the limited sample size, the project provided valuable information about Muslim American women's knowledge, attitude, and behavior related to cervical cancer screening and HPV vaccination. On the other hand, the interviewer reached the sample saturation and covered the research question. This information will guide further studies on the topic.

The interviewer noticed the response bias during the interview. The participants might have answered questions based on their expectations instead of the truth. To avoid this, the interviewer made sure that the interview settings were private and reassured the participants multiple times that the interviews were anonymous. The social desirability bias was also part of the limitations. Muslim women are not compassionate about sexuality and consider it as a very sensitive topic. Therefore, participants tend to answer in ways that make them look good in the eyes of others. Regardless of the accuracy of their answers research team also faced problems arising from leading questions and wording biases. Since the participants knew that the interviewer spoke Arabic, they mixed Arabic and English in the discussions. They sometimes requested to ask a question in their native language to understand it better. The translation was not prepared ahead of time; it happened ad-hoc on the spot, creating the potential for unknowingly wording the question in Arabic in a way to lead the participant to give a biased answer.

Research quality largely depends on the researcher's skills; a Muslim interviewer is a double-edged weapon. It could influence and expedite the recruiting process positively. Nevertheless, it can also create bias as participants are more easily influenced by the researcher's personal biases and idiosyncrasies.

Conclusion and Future Research

This project established our community partnership with local Mosques and proved that we could reach community members to recruit them for our research study. We will cultivate this partnership by providing educational resources to the community and asking for input to fine-tune further research questions. This project offered useful qualitative information, which will be used to design a more extensive scale mixed-method survey study. The new research project will use validated questionnaires to investigate further behavioral issues related to cervical cancer prevention.

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