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Identifying and Examining Disparities in Cervical Cancer Screening and Healthcare-Seeking Behavior among Arab American Women

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An abstract of

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University

in partial fulfillment of the requirements for the degree of
Master of Public Health
in Behavioral Sciences and Health Education

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Abstract

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By Sumayah Nuhaily

The primary objective of this research was to assess cultural, religious, and psychosocial factors related to perceptions of cervical cancer, cervical cancer screening, and human papillomavirus among Arab American women. We hoped to identify specific beliefs and processes that may inhibit or encourage Arab American women from obtaining regular cervical cancer screening, including interpersonal relationships, cultural influences, knowledge of and firsthand and secondhand experience with Pap screening, and overall perceptions of Pap screening. This was accomplished by conducting in-depth interviews with a sample of 16 Arab American women living in urban San Diego, California. Interviews were transcribed verbatim and coded using constructs from Social Ecological Model as well as salient themes that were found in transcripts. The majority of participants demonstrated limited knowledge of Pap testing, screening guidelines, and routine gynecological care recommendations. Some participants cited other women's negative experience as a reason for choosing not to obtain a Pap test. Immediate family members, specifically mothers and sisters, were viewed as important facilitators in obtaining a Pap test. Participants generally reported a lack of trust in healthcare providers' ability to provide culturally appropriate and high-quality healthcare. In conclusion, interpersonal factors appear to be important in the context of cervical cancer screening for Arab American women. Further research is needed to investigate cervical cancer screening attitudes and behaviors within this population.

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INTRODUCTION

Public Health Significance

Cervical cancer is a cancer that forms in tissues of the cervix. It is almost always caused by a human papillomavirus (HPV) infection, although not all woman infected with an oncogenic strain of HPV will develop cervical cancer during their lifetime (National Cancer Institute, 2010). Approximately 0.7 percent of women living in the United States will be diagnosed with cervix uteri cancer at some point during their lifetime. In 2011, there were an estimated 249,632 women living with cervical cancer in the United States (National Cancer Institute, 2010). While rates of cervical cancer and cervical cancer mortality are relatively low and stable in the United States due to consistently high rates of screening, it is still an issue that has not been appropriately studied and addressed among particular ethnic minorities within the United States, particularly with regard to women whose religious or cultural beliefs and values may affect their level of access to obtaining regular cervical cancer screening services (National Cancer Institute, 2014).

Cervical Cancer Screening

Before cancer appears in the cervix, the cells of the cervix go through changes known as dysplasia, in which abnormal cells begin to appear in the cervical tissue. Over time, the abnormal cells may become cancer cells and start to grow and spread (National Cancer Institute, 2014). Cervical cancer may be screened with a Papanicolaou (also known as Pap) screening test, during which a scraping of the cells of the cervix is examined for changes in the cervical cells that may be indicative of dysplasia or cancer. The HPV test determines whether or not a woman has contracted various strains of the HPV virus that may eventually evolve into cancer. Thus, cervical cancer is considered preventable and curable if detected early (National Cancer Institute, 2014). Both the Pap test and the HPV test can screen for indications that a woman may be at risk for cervical cancer. Those who are at a particularly high risk of developing cervical cancer are women who smoke regularly, initiate in vaginal sex at a younger age, have had multiple sexual partners, have used oral contraceptives, and/or have given birth to many children. In particular, women who do not screen regularly for HPV and abnormal cells in the cervix are at an increased risk of developing cervical cancer (National Cancer Institute, 2014).

According to the United States Preventive Services Task Force, the recommended screening guidelines for cervical cancer are that women should begin screening for cervical cancer at age 21, and that women between the ages of 21 and 65 should have a Pap test every three years, while women over the age of 65 with no past abnormal Pap results do not need to be screened regularly. These recommendations still stand for women who have had an HPV vaccine at some point in their lives (United States Preventive Services Task Force, 2012) due to the fact that the various types of HPV vaccine do not protect against all strains of HPV.

Many women living in the United States, particularly those who are at a disadvantage with regard to access to healthcare, fail to meet the recommended screening guidelines and are therefore typically diagnosed at later stages of cervical cancer than women who have regular access to healthcare. Disadvantaged populations are a particular group of interest in the study of preventive medicine, due to the fact that the identification of barriers to healthcare paves the way to interventions being staged among these populations. With regard to cervical cancer, we do see some ethnic disparities that may be explained by lack of access to healthcare and health education: Black and Hispanic women, in particular, are at an elevated risk of developing cervical cancer when compared to White women; while approximately seven White women per 100,000 are diagnosed, nine Black women per 100,000 are diagnosed, and 10 Hispanic women per 100,000 are diagnosed (National Cancer Institute, 2014). It is important to note, however, that the categorization of cervical cancer rates and screening practices by race and ethnicity often falls short with regard to appropriately addressing the potential underlying cultural differences within each racial and ethnic group.

Arab Americans are people with ethnic roots stemming from one of the nations included in the Arab League who currently live in the United States. While the Arab American population is rapidly growing each year, there is little data on rates of cervical cancer and its screening practices among Arab women living in the United States (Shah, Ayash, Pharaon, & Gany, 2008). Arab Americans are typically classified by default as White race for survey and research purposes, thus making it difficult for researchers to appreciate their specific public health needs and diminishing this population's relative capacity to seek specialized healthcare and research funding (Ajrouch & Jamal, 2007). Recently, Dallo & Kindratt (2015) proposed the disaggregation of Arab Americans from the non-Hispanic white population as a way to address health needs that may be specific to Arab American communities. The present study sought to identify beliefs and attitudes specific to the experiences of Arab American women that may inhibit or facilitate healthcare-seeking behaviors and receipt of timely cervical cancer screening services.

REVIEW OF THE LITERATURE

Cultural and Religious Perceptions of Illness in Arab Communities

Within the Arab American community, there is a wide range of religious backgrounds. Arab beliefs regarding illness in general may be based more on traditional and religious values rather than medicine and its scientific practices (Azaiza & Cohen, 2008; Shah et al., 2008). Arabs living in the United States generally trust physicians and often feel privileged to have access to American healthcare. However, many deeply ingrained cultural beliefs may inhibit these individuals from obtaining timely care and/or preventive services. For example, Arab preconceptions regarding the cause of disease are often based on knowledge that has no scientific basis (i.e. the evil eye, the combination of certain foods, exposure to drafts, punishment from god, etc.), and may serve as a barrier to engaging in appropriate preventive measures (Kridli, 2002). It is not yet understood how these beliefs may influence Arab American women's perceptions of and attitudes toward seeking timely and appropriate female reproductive healthcare services.

Culturally-Ingrained Views on Female Modesty in Arab Communities

It is well-understood within the Arab culture and the majority of Arab communities that Arab women cannot discuss certain female health issues, such as menstruation, child-bearing, childbirth, and menopause, with their male relatives, including husbands, brothers, and sons (Kridli, 2002). Males within the Arab culture are typically not involved in the labor and childbirth processes; they will usually have limited knowledge of menstruation and menopause, knowing only enough to understand their wife's menstrual cycle due to religious regulations on acts of sexual intercourse during menstruation; and they will typically never be involved in a discussion of breast, cervical, or other female sex-specific disease during their life (Kridli, 2011).

Within the Arab culture, women are also generally expected to abstain from engaging in sexual intercourse prior to marriage, which highlights a much deeper issue in terms of screening for cervical cancer: if a woman who is not married obtains a Pap test, she may be viewed as having deviated from her cultural and religious norms. Thus, any woman who is unmarried is simply assumed to be sexually inactive and abstinent from any sexual act that could pose a risk for sexually transmitted infections and diseases. This potentially presents a problem from a public health standpoint, because surely this blanket expectation of sexual abstinence does not always function as a scientific determinant of susceptibility to diseases such as cervical cancer (Kridli, 2002).

Furthermore, Arab women are typically expected to see a female physician for nearly all their healthcare needs, but particularly with regard to issues that relate to their gynecological health needs. More broadly, however, some research has indicated that American women generally report preferring to see a female physician for their gynecological care needs, which may point to a correlation between patient gender and subsequent provider gender preference rather than a culturally-imposed standard of gender preference within this population (Zuckerman, Navizedeh, Feldman, McCalla, & Minkoff, 2002). However, the expectation of seeing a female healthcare provider, when enforced, may still serve as a barrier to obtaining timely and routine care.

Cervical Cancer Screening Rates in Arab American Women

Research on the behaviors, attitudes and beliefs related to cervical cancer and its screening practices among Arab American women is generally limited (Salman, 2012). To our knowledge, there have been three studies conducted that surveyed cervical cancer screening rates among Arab American women. One study examined Arab American women over the age of 50 years living in Michigan by utilizing data from the Michigan Special Cancer Behavioral Risk Factor Survey, and found that while Arab American women's breast cancer screening rates were approximately the same as the general population of women in Michigan, they fell behind in regular cervical cancer screening (at least one Pap in the past three years) rates at 76.9%, while the general population had regular Pap screening rates of 86.5 percent. Moreover, the study found that among this population, women belonging to older age groups were less likely to receive timely Pap screening services when compared to their younger counterparts (Darwish-Yassine & Wing, 2005).

Another study examined specific disparities in foreign-born Arab American women with regard to vaccinations and cancer screening by utilizing five years' worth of data from the National Health Interview Survey, and found that Pap screening rates were significantly lower among foreign-born Arab American women than in White women living in the United States. Based on these findings, it was concluded that further investigation was needed to examine the cultural context surrounding such health behaviors in Arab American women (Dallo & Kindratt, 2015).

The third study investigated health practices related to cancer screening among Arab American women living in an urban community in Pennsylvania, and found that only

50% of women in the study had obtained a Pap during the past year. The study investigator proposed that cultural standards and expectations played a vital role in shaping Arab American women's healthcare-seeking behaviors, and concluded that customized health education could prove to be an effective tool in increasing Pap screening rates within this population (Salman, 2012). The literature in this field may point to significant barriers to accessing gynecological healthcare services, as well as overall low patient engagement in seeking regular cervical cancer screening services within this population.

Cervical Cancer Screening Beliefs and Attitudes in Arab Women

In non-American Arab women across the Middle East, some studies illustrate the need for education regarding cervical cancer and its screening practices. We also see that knowledge of cervical cancer and its screening practices is often limited among Arab women (Bakheit, 2004; Bener, Denic, & Alwash, 2001). A study conducted in Kuwait found that only 52.3% of women within the sample demonstrated correct knowledge of what a Pap test was, while a Qatari study found significant differences in knowledge based on marital status and age, with older, married women demonstrating more correct knowledge overall (Al Sairafi & Mohamed, 2009; Al-Meer, Aseel, Al-Khalaf, Al-Kuwari, & Ismail, 2011). A qualitative study of Israeli Arab women also pointed to a general lack of knowledge of cervical cancer screening practices; conversely, participants in this study were knowledgeable about breast cancer and its screening practices (Azaiza & Cohen, 2008). These findings highlight the importance of conducting research that may help healthcare professionals and public health practitioners to better understand why there is a gap in knowledge specifically with regard to cervical cancer and Pap screening. The present qualitative study sought to identify and examine this gap in knowledge by conducting in-depth interviews with and administering surveys to Arab American women in order to obtain information-rich data on their beliefs, attitudes and knowledge regarding cervical cancer and its screening practices.

METHODOLOGY

Participants

Characteristics and Number of Participants

Sixteen in-depth interviews were conducted with self-identified Arab American adult women living in urban San Diego, California.

Research Design and Methods

Description of Research Design

Overview. This study utilized a cross-sectional qualitative design. Individual in-depth interviews were conducted with a total of 16 Arab American women. The study investigators attempted to recruit a sample that included both women who have immigrated to the United States and those who were born in the United States in order to access diverse points-of-view with regard to cervical cancer and its screening practices.

Inclusion Criteria. To be included in the in-depth interviews, participants must have: (1) self-identified as Arab or Arab American; (2) been 18 years of age or older; (3) been English-speaking; and (4) been able to provide informed consent.

Recruitment. Flyers advertising the study were posted at mosques, churches and community centers attended by Arab American women (Appendix 1). The flyers provided information in the English language, as one of the participation criteria stated that participants must be English-speaking. The flyers instructed potential research participants to contact a trained research assistant by telephone in order to obtain more information about the study. However, significant difficulties were faced when the study sample was being recruited by way of paper flyers. No efforts were made on behalf of community members to contact the research assistant by telephone. Recruitment efforts and strategies were most successful when a lay community member was hired on a volunteer basis to recruit participants via word-of-mouth. When recruited by a familiar community member, participants appeared to be more willing to participate in the study. When a participant utilized the contact information they were given by the community member and contacted the research assistant, the research assistant explained the objectives and components of the study as well as the study inclusion criteria over the telephone and asked the participant if she wished to schedule an appointment to participate in an in-depth interview. Additional recruitment efforts included flyers being distributed to women who had already participated in the study in order to create a snowball recruiting effect as well as asking participants to provide information regarding the study to other acquaintances (i.e., mothers, sisters, friends) who may qualify for the study.

Theoretical Framework. The Social Ecological Model was used to examine factors related to cervical cancer beliefs, attitudes and knowledge in female immigrant and non-immigrant Arab Americans (Bronfenbrenner, 1983; Centers for Disease Control and Prevention, 2013). This model examines the way in which an individual is connected with interpersonal, organizational, community and policy factors, and how this influences one's own personal beliefs, attitudes and knowledge (Centers for Disease Control and Prevention, 2013). It has also been associated with individual and community health promotion programs as a way to examine the relationship between an individual's major activity settings and his/her life domains, and to identify the ways in which the two are interdependent (Stokols, 1996).

Data Collection. Upon obtaining approval from the San Diego State University (SDSU) Institutional Review Board, in-depth interviews were conducted with 16 women from the Arab community in San Diego using a standardized interview guide developed specifically for this study. Two trained research assistants conducted the interviews between October 2013 and December 2015. This sample size fell within an approximate estimate of the number necessary to achieve theoretical saturation (Morse, 2015). The Social Ecological Model primarily provided the framework for these questions. One of the principles of ecological models of health behavior is that often, multiple types of environmental influences affect health behavior (Centers for Disease Control and Prevention, 2013). Building upon this, the study investigators asked specific questions that sought to tease out and identify these types of environmental influences, which may be family, friends, community and/or religious organizations, or any other influence in each participant's day-to-day environment. Research activities took place at the Cancer

Disparities and Cancer Communication Lab at SDSU. Study participants were engaged in an informed consent process where they were provided with information on the study and its various components, potential benefits and risks. Those who indicated that they wished to participate were asked to provide informed consent after being given the opportunity to review the informed consent form (Appendix 2). Following completion of the informed consent process, the research assistants then conducted the in-depth interview with each participant. Following this, participants were asked if they would like to complete the optional written self-report survey and demographics form, and then given the $20 gift card incentive. The interviews were audio-recorded and transcribed verbatim at a later time. The de-identified files were saved on a password-protected computer on SDSU property, in a locked room inside a locked office suite at the Cancer Disparities and Cancer Communication Laboratory within the Department of Psychology.

Participant Involvement. Participants first completed informed consent procedures, participated in an in-depth interview, and then were given the option to complete the optional self-report survey and demographics form. The in-depth interview took approximately between 20 to 30 minutes to complete. The self-report survey and demographics form consisted of 19 multiple choice and short answer format questions, and took approximately 10 to 15 minutes to complete.

Research Instruments

The self-report survey and demographics form consisted of 19 multiple choice and short answer format questions. (Appendices 3 and 4). The form was optional, and aimed to obtain more information in terms of each individual woman's attitudes, beliefs and experience with HPV vaccines and Pap testing, as well as to gather information regarding the participants' basic demographic information such as age, place of birth, native language, and marital status. The oral interview attempted to examine the health attitudes, beliefs and knowledge in regards to cervical cancer and its screening practices by utilizing constructs from the Social Ecological Model.

Data Analysis

The principal study investigator read all interviews to determine whether theoretical saturation was achieved. Once it was determined that a sufficient number of interviews had been conducted to achieve saturation, the in-depth interviews were analyzed using constructs from the Social Ecological Model to determine the initial themes and subthemes for the analysis. The analysis also allowed for emerging themes which were not included in the Social Ecological Model. After reading all interviews, a codebook was developed by the study investigator in order to define and categorize themes found in the interviews. All themes and subthemes and their corresponding codes were refined and modified as the study investigator read and applied the codes to each interview. The principal study investigator then independently summarized the most salient themes and codes into a data analysis summary, drawing upon the relative number of times that each code was applied and supplementing the data analysis summary with participant quotes that illustrated each notable code or theme.

All self-report survey and demographic data were entered into a Statistical Package for the Social Sciences (SPSS) database and then transferred to a Microsoft Excel spreadsheet for analysis (Britannica Online Academic Edition, 2015; IBM, 2015).

Demographic information from the self-report survey and demographics form was analyzed with the use of descriptive statistics, particularly means, standard deviations, and frequencies. Microsoft Excel was utilized for purposes of obtaining descriptive statistics on the participants' age, total years of education, number of years spent in the United States, and other demographic information. The principal study investigator reviewed the self-report surveys in order to ascertain the number of participants who had received a Pap test, those who planned to obtain a Pap in the future, and other pertinent information, and recorded total counts in Microsoft Excel.

RESULTS

Participant Demographics

The mean participant age was 27.56 years (SD=10.18 years), with six participants reporting that they were currently married, and five participants reporting that they had children. Thirteen participants reported English as being their primary language, or the language in which they currently communicated most, with one participant reporting Arabic as her primary language, and two listing "Other" as their primary language. With regard to native language, six participants listed English, seven listed Arabic, and three reported "Other" as the language that they first learned to communicate in. The average number of years of education among this sample was 16.27 (SD=2.09 years). Eight participants reported being currently employed for pay outside the home. Participant demographic information is summarized in Table 1.

Self-Report Survey Responses

With regard to personal experience with the HPV vaccine and Pap test, 11 of the 16 participants reported having heard of HPV in general, while 12 had heard of an HPV vaccine at some point. Four participants reported having been offered an HPV vaccine, while eight responded that they had not, and four declined to respond. Three participants had actually received an HPV vaccine, five reported not having received it, and four were unsure whether they had received it. The remaining participants declined to respond to this question. A total of five participants reported having received a Pap test at some point, while 10 said that they had not, and one participant was unsure whether she had received a Pap. Generally, participants were receptive to the idea of obtaining and receiving a Pap test in the future. Eleven participants stated that they would get a Pap, with one participant saying that she would not, and four reporting that they were unsure.

In-Depth Interview Results

Acquiring Health Information

Almost all study participants stated that they would first and foremost trust their doctor to provide health information. Participants reported feeling confident in their healthcare providers' knowledge and ability to provide reliable and valid information. Most participants reported relying on Internet research for their health information and questions, with many mentioning specific websites (WebMD, MayoClinic, Centers for Disease Control and Prevention) as being particularly reliable. When asked how one could reach more Arab American women with information on Pap testing, eight participants mentioned flyers, brochures and pamphlets as being good sources of reproductive health information to women, while eight participants viewed classes and school settings as particularly good venues to provide Pap test information, and four participants mentioned social media as a far-reaching and informative source of health information.

Access to Care

More than half of study participants reported firsthand or secondhand experiences which indicated that either they or someone they knew had experienced difficulties in accessing healthcare due to limited monetary resources. Many participants also acknowledged the fact that although they did not personally experience such issues, other women in the community clearly did, and that it had a direct impact on their ability to access high-quality treatment for both general and feminine healthcare. Less than half of participants mentioned language barriers as a difficulty for many immigrant Arabs living in the United States; some participants mentioned that these language barriers placed patients at a higher risk of receiving substandard healthcare or misinterpreting medical advice or information. One participant stated,

> *"I have family who don't speak English and they are scared to go to doctors because they don't know how to communicate to them about their body."*

Five participants mentioned that a lack of access to health insurance could potentially conflict with the receipt of timely and adequate healthcare services, two participants proposed that transportation difficulties could affect a woman's ability to seek and obtain proper healthcare services, and an additional two participants mentioned time constraints as possible barriers to accessing and receiving proper healthcare.

Quality of Care

Nearly half of all participants reported feeling that their healthcare provider did not provide them with adequate or excellent care; however, only two participants voiced a negative perception of the specific healthcare setting in which they had previously or currently received healthcare services. With regard to negative experiences with healthcare providers, one participant mentioned a secondhand experience that had affected her view of nurses:

> *"Well, I didn't face this but I know that two of my friends changed their doctors because their nurses were kind of tough or hard or made faces when [they] saw something that [they] didn't like."*

Half of the participants had a positive perception of the healthcare setting in which they had previously or currently receive healthcare services, while seven participants mentioned that they had a positive perception or view of their past or current healthcare provider. Many participants had specific ideas as to what could potentially improve their and others' experiences with regard to receiving healthcare services in medical settings, mentioning more time dedicated to them and a positive social interaction with a healthcare provider as possible improvements to the quality of care that they or others received. For example, one participant spoke directly to how doctors could improve their delivery of healthcare services to other Arab American women, noting that

> *"it is important to make the patient feel comfortable and just from the start be open to what they have to say instead of scaring them."*

Perceptions of Pap Screening

Perceptions of the Pap test were generally negative, with six participants explicitly stating that they believed a Pap test would be embarrassing, awkward or painful, and four participants giving conflicted opinions on their perception of a Pap. Of the negative perceptions, embarrassment and awkwardness were particularly prevalent preconceptions with regard to the Pap, with one participant stating that

> *"if it's an awkward state and an awkward situation, I think it's less likely maybe that [the patient will] come back again."*

This participant is expressing that reproductive health follow-up care could depend, to some degree, on a woman's perception of the Pap test as being embarrassing or generally negative. Contrastingly, four participants viewed Pap testing positively, with one saying,

> *"I would encourage every woman to get it done because it is very important."*

Such positive messages generally framed the Pap test as being an excellent preventive measure against cervical cancer and female reproductive diseases in general. Perceptions of the Pap test were viewed as ambivalent when a participant reported both positive and negative perceptions that may have conflicted with one another. Quantitative data on perceptions of cervical cancer screening among participants are provided in Table 3.

Cultural Influences

A major theme that was observed throughout most interviews was that of modesty and chastity as social constructs that had a direct or indirect impact on the quality of gynecological care that Arab American women received. Most participants mentioned preferring a female doctor, reporting feelings of embarrassment and discomfort at the idea of being treated by a male doctor for their feminine health issues and regular care. Many interviewees regarded virginity before marriage as a necessary expectation within the Arab culture:

> *"In my culture, it's a huge taboo to get a Pap smear before you're married because it basically conflicts with your virginity."*

Some participants reported refusing a Pap test for fear that it would touch their hymen, while others simply stated that maintaining one's virginity was an important component of Arab women's lives. Many misconceptions with regard to what could or could not puncture a hymen were mentioned by participants. One participant relayed a secondhand experience of a friend, saying:

> *"[My friend had] got[ten] poked and lost her virginity and the doctor who did it…ended up apologizing and everything, but that was a mistake."*

Seven participants reported having experienced or noted some broad cultural expectations within the Arab American culture that they felt may have influenced their and others' attitudes toward women's reproductive health and access to reproductive healthcare. One participant noted that "male dominance" within the Arab culture played a role in the way that Arab American women viewed themselves and their sexual health. Additionally, the participant reported that this patriarchal cultural ideal had a direct impact on the ways in which Arab American women subsequently sought healthcare services. More detailed information on cultural influences is provided in Table 2.

Interpersonal Facilitators and Barriers to Pap Screening

Many participants mentioned interpersonal relationships in the context of both facilitators and barriers to obtaining a Pap. Thus, many of the participants who guessed that these interpersonal relationships could help guide an Arab American woman in obtaining cervical cancer screening also hypothesized that in some cases, these relationships could serve as inhibiting factors to obtaining Pap screening. The majority of participants stated that close friends and immediate family members, particularly mothers and sisters, could aid an Arab American woman in accessing and obtaining a Pap test. One participant mentioned her sister and mother as being important facilitators, stating:

> *"[Mothers and sisters] draw out the importance of it and they'll be supportive and [say], 'Oh, we'll do it with you,' or 'We'll go with you.'"*

Few participants mentioned extended family as a possible support system in obtaining a Pap test. Seven participants viewed immediate family as being possible barriers to getting a Pap test, while four participants mentioned that extended family members could potentially serve as barriers. One participant reflected on her extended family as a potential barrier to preventive care, saying,

> *“I know a lot of Middle*-*Eastern families, specifically talking about my family, they are kind of stubborn [and] they think that they are medically stable or fine, and if I bring something up, like you should get this checked out…they say ‘No, you’re fine.’”*

Four participants also reported that friends could serve as barriers to seeking and obtaining a Pap test. Most participants who spoke to the ways in which these barriers affected a woman on an individual level linked it closely to cultural influences and expectations being projected onto an Arab American woman in her day-to-day life. Quantitative data on interpersonal barriers and facilitators can be found in Table 2.

Experience with Pap Screening

Three participants reported having had a positive firsthand experience with a Pap test, while one participant had heard about a positive Pap experience from a family member. Conversely, seven participants reported having heard negative secondhand experiences of the Pap test from friends, reporting accounts of feeling embarrassed or awkward and/or experiencing pain during the examination. One participant relayed a story of a friend who had recently received a Pap test:

> *“A friend of mine just did it a couple of months ago, and she said that it was really painful and…she was not comfortable for a couple of days after that.”*

Four participants reported having heard negative secondhand experiences from family members, particularly from sisters or mothers. Two participants reported personally experiencing a painful, embarrassing or generally unpleasant Pap test at some point.

Theme and sub-theme counts with regard to experiences with Pap screening among participants can be found in Table 3.

Knowledge of Pap, Screening Guidelines and Gynecological Care Needs

Knowledge of Pap tests, screening guidelines and gynecological care recommendations was limited among participants. Less than half of all participants had correct knowledge of the frequency with which a woman had to visit a gynecologist for routine care. Fourteen participants demonstrated incorrect knowledge of what a Pap test was and what purpose it served, while 13 participants had incorrect knowledge of Pap screening guidelines. The number of participants who had incorrect knowledge of these topics can be found in Table 4.

DISCUSSION

Following the data collection and analysis procedures, several salient themes were identified, including general gaps in knowledge of routine gynecological care, cultural concerns with regard to obtaining a Pap, and overarching healthcare system barriers. Interpersonal factors such as familial support were particularly influential in participants' attitudes and beliefs regarding cervical cancer and its screening practices. Most participants who reported being unmarried demonstrated an overall lack of knowledge with regard to their own sexual health. Embarrassment and modesty were frequent barriers to receiving Pap tests among Arab American women. The concept of virginity was prominent throughout many participants' interviews, suggesting that it may be linked to perceptions of Pap screening and routine gynecological care. Many participants also reported negative secondhand experiences, which was correlated with intent to comply with screening guidelines. Conversely, mothers and sisters were generally viewed as most likely to facilitate receipt of Pap testing among participants. Finally, several participants voiced concern with regard to the trustworthiness of their healthcare providers, indicating that there was an overall lack of trust in providers and their ability or willingness to provide high-quality and culturally appropriate care.

The findings from this study align with the literature on Arab American beliefs regarding illness and reproductive healthcare. Modesty and virginity are important constructs in examining Arab American women's attitudes toward the receipt of routine health services, such as cervical cancer screening (Kridli, 2002). Participants' lack of correct knowledge of Pap testing, screening guidelines, and routine gynecological care recommendations may support the view that Arab cultural beliefs regarding medicine may stem from sources other than empirical science (Mellon, Gauthier, Cichon, Hammad, & Simon, 2013; Shah et al., 2008). Furthermore, the importance of secondhand experiences and familial support in shaping participants' perceptions of such screening measures highlights the significance of interpersonal relationships in these women's lives (Stokols, 1996). Finally, the lack of trust in healthcare providers that was common among participants underscores the need for further research and interventions for healthcare professionals in order to equip them with tailored approaches in dealing with Arab American women in gynecological care settings.

Public Health Implications

This research may highlight the relative importance of fostering a culturally sensitive patient-provider relationship between Arab American female patients and their healthcare providers, specifically with regard to female reproductive healthcare. It is vital that healthcare providers investigate and appreciate the potential barriers and facilitators to obtaining gynecological care services that an Arab American woman may face due to culturally and/or religiously specific beliefs and processes. A lack of understanding of such beliefs and processes may contribute to overall lower cervical cancer screening rates within this population, thus posing a health risk to Arab American women failing to adhere to cervical cancer screening guidelines.

Future intervention efforts within this population may benefit from a female-to-female approach due to stringent cultural standards of modesty and of sharing personal information with a member of the opposite sex. Interventions modeled in a way to encourage Arab American women to engage friends, family members and other community members would likely succeed in stimulating discussion of female reproductive health issues and in addressing possible barriers to accessing care. Additionally, data from this research on the importance of familial bonds in accessing and receiving female reproductive healthcare suggest that women within this population would respond to intervention approaches that seek to remind women of the importance of engaging in preventive healthcare in order to live longer and healthier lives with their families as well as experience fewer negative reproductive outcomes with regard to pregnancy and childbirth.

Strengths and Limitations

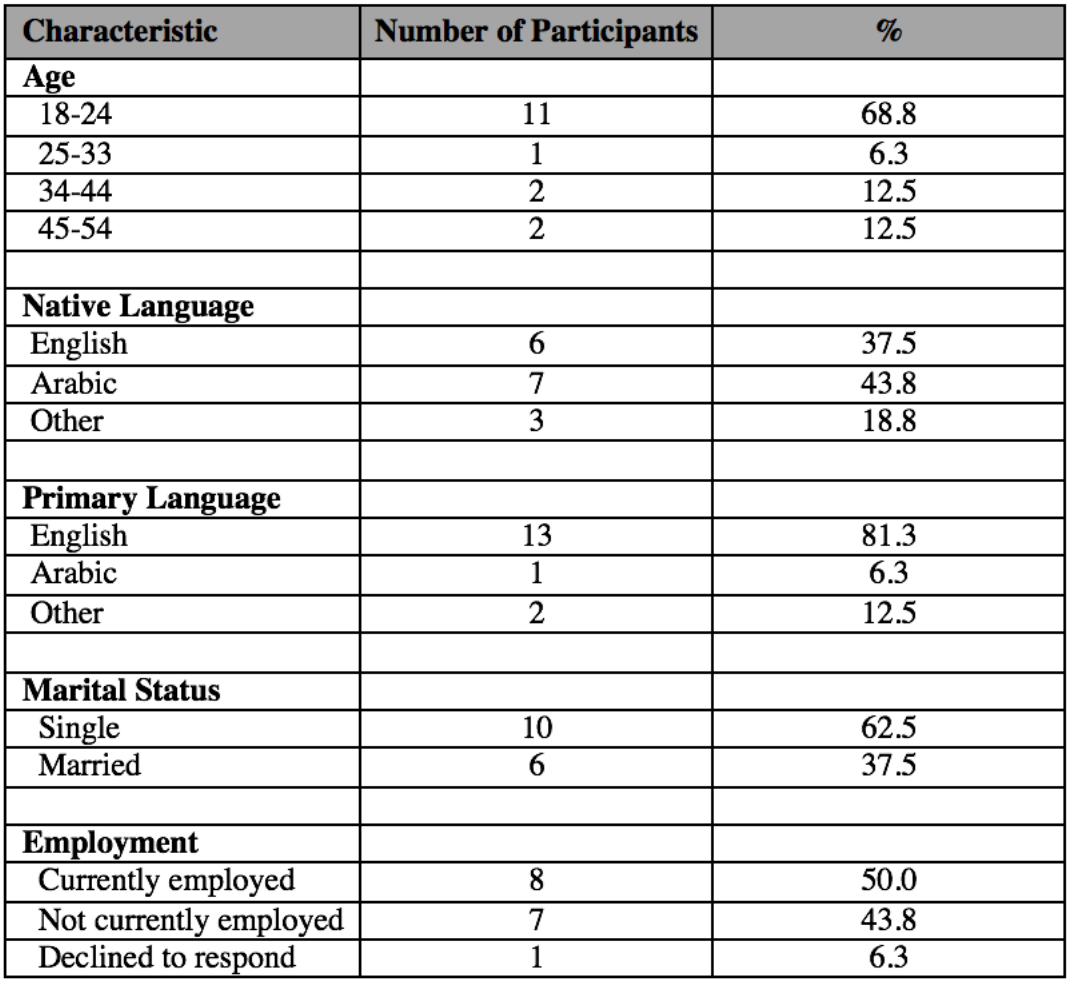
The findings of this research contribute to the limited research on the attitudes, beliefs and behaviors regarding cervical cancer and its screening services among Arab American women. The present study may yield results that benefit the Arab American community and create awareness of issues such as low Pap screening rates within this population. However, due to the small sample size and qualitative nature of the study, these findings may not be generalizable to Arab American women living in rural areas of the United States, or to Arab women living in the Middle East. Significant barriers to efficient recruitment may limit generalizability to non-Arab American women as well. Additionally, the relative rarity of information-rich data within this sample, perhaps due to culturally-ingrained views on sharing information regarding female reproductive health, may have limited the scope of the present study's results. Finally, the lack of a second person being involved in the coding process may have had a significant impact on the validity of its findings.

Future Directions and Conclusions

It is vital that healthcare providers engage Arab American women with regard to providing them with tailored support and assistance in learning more about the benefits of cervical cancer screening and in obtaining cervical cancer screening services in a timely manner. This research identifies potential areas that healthcare providers may choose to address in order to create a more effective and culturally sensitive approach to treating Arab American female patients in gynecological care settings and promoting the receipt of timely cervical cancer screening services. Further research is needed in order to assess predictors associated with cervical cancer screening among Arab American women and to investigate the implications of conducting an intervention within this population. Future research may also build upon this study's findings and further investigate the multi-faceted relationship between the Arab American culture and attitudes toward cervical cancer and its screening practices as well as attitudes regarding routine gynecological care.

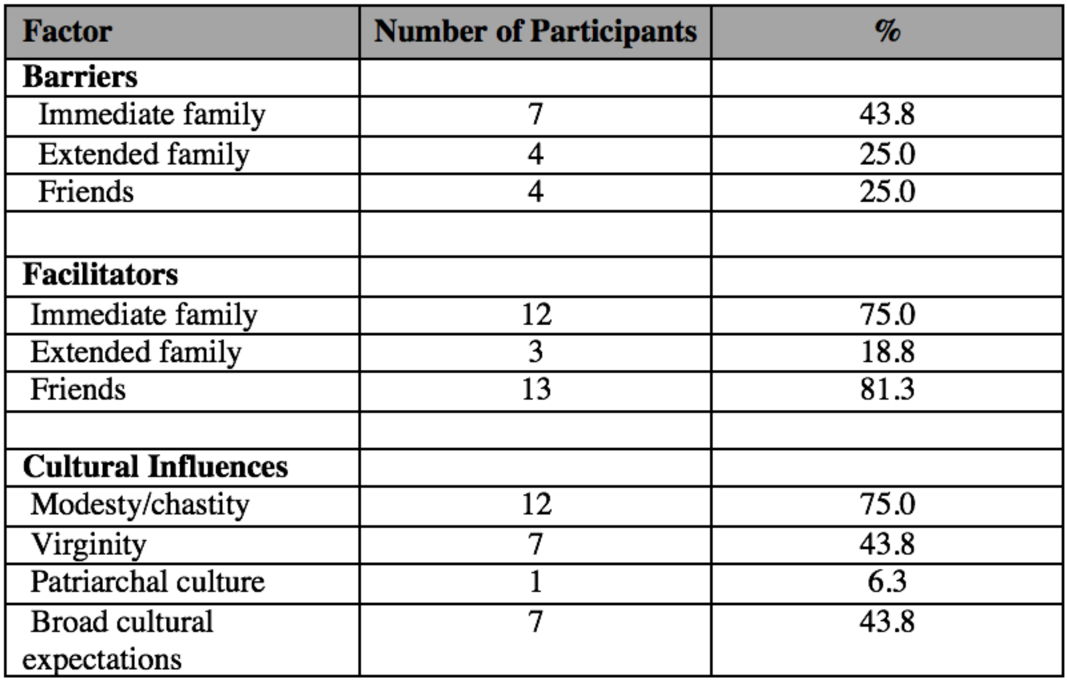
TABLES

Table 1. Participant Demographics



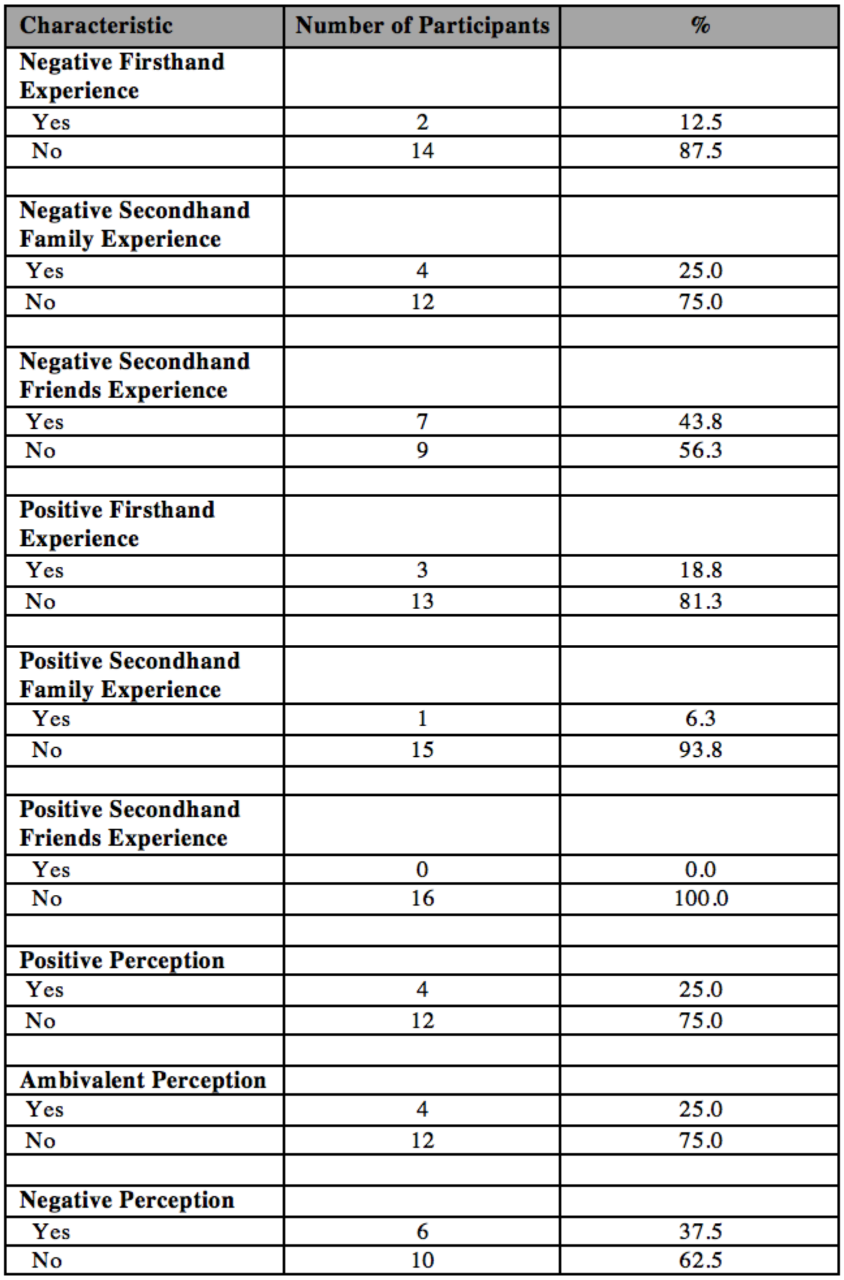
Characteristic	Number of Participants	%
Age		
18-24	11	68.8
25-33	1	6.3
34-44	2	12.5
45-54	2	12.5
Native Language		
English	6	37.5
Arabic	7	43.8
Other	3	18.8
Primary Language		
English	13	81.3
Arabic	1	6.3
Other	2	12.5
Marital Status		
Single	10	62.5
Married	6	37.5
Employment		
Currently employed	8	50.0
Not currently employed	7	43.8
Declined to respond	1	6.3

Table 2. Participants who Mentioned Barriers, Facilitators and Cultural Influences with Regard to Cervical Cancer Screening



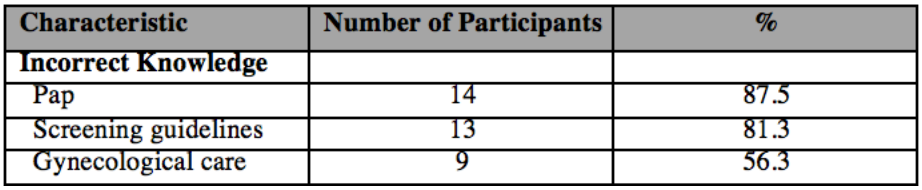
Factor	Number of Participants	%
Barriers		
Immediate family	7	43.8
Extended family	4	25.0
Friends	4	25.0
Facilitators		
Immediate family	12	75.0
Extended family	3	18.8
Friends	13	81.3
Cultural Influences		
Modesty/chastity	12	75.0
Virginity	7	43.8
Patriarchal culture	1	6.3
Broad cultural expectations	7	43.8

Table 3. Participants' Experiences with and Perceptions of Pap Screening



Characteristic	Number of Participants	%
Negative Firsthand Experience		
Yes	2	12.5
No	14	87.5
Negative Secondhand Family Experience		
Yes	4	25.0
No	12	75.0
Negative Secondhand Friends Experience		
Yes	7	43.8
No	9	56.3
Positive Firsthand Experience		
Yes	3	18.8
No	13	81.3
Positive Secondhand Family Experience		
Yes	1	6.3
No	15	93.8
Positive Secondhand Friends Experience		
Yes	0	0.0
No	16	100.0
Positive Perception		
Yes	4	25.0
No	12	75.0
Ambivalent Perception		
Yes	4	25.0
No	12	75.0
Negative Perception		
Yes	6	37.5
No	10	62.5

Table 4. Knowledge of Pap Test, Screening Guidelines and Gynecological Care Needs



Characteristic	Number of Participants	%
Incorrect Knowledge		
Pap	14	87.5
Screening guidelines	13	81.3
Gynecological care	9	56.3

APPENDICES

Appendix 1. Recruitment Flyer

Research Participants Needed

You can help make a difference in your community!

Purpose

Our research study examines the attitudes, beliefs and knowledge of cervical cancer in Arab American women

Why you should participate

It could help promote the future health of other Arab American women

Who can participate?

Arab American women, aged 18+

SAN DIEGO STATE UNIVERSITY

Sumayah Nuhaily

Dr. Kristen Wells, M.P.H., Ph.D.

$20 gift cards will be provided to participants of this study

For more information, please contact us at [redacted]

or e-mail us at

[redacted]

Appendix 2. Consent Form

San Diego State University

Consent to Act as a Research Subject

Researching the Cervical Cancer Screening Attitudes, Beliefs and Practices of Arab American Women Living in the United States

You are being asked to participate in a research study. Before you give your consent to volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators

The people who are in charge of this research study are **Sumayah Nuhaily and Kristen Wells, Ph.D.** Sumayah Nuhaily is an undergraduate psychology student at San Diego State University. Dr. Wells works in the Department of Psychology at San Diego State University. These people are called the **Principal Investigators**.

Purpose of the Study

- The purpose of this study is to gather information about cervical cancer screening among Arab women living in the United States.
- You are being asked to take part in this study because you are an Arab American woman over the age of 18.
- We are asking approximately 30 women to participate in this study.

Description of the Study

- If you take part in this study, you will be asked to take part in an interview with a member of our staff.
- The interview will last about 30 to 45 minutes.
- During the interview you will be asked questions about cervical cancer and its screening practices. We will also ask you some questions about yourself.
- The information that you share with us is important. It will help us understand the needs of Arab American women better.
- If it is all right with you, we will audio record the interview. The interview will be audio recorded to make sure that we remember what you tell us.
- Audio recordings will only be accessed by research staff, will be used for research purposes only and will be kept in strict confidence. Audio files will be kept on a computer at San Diego State University for five years and destroyed after the five-year period.
- To find out if you are eligible to take part in this study, you will be asked your age. If your age is between 18 and 65, you will be asked to take part in the interview for the study. If you are not eligible to take part in the study, the information that you provided about your age will not be included in the study and will be shredded to protect your privacy.

What Is Experimental in This Study

- None of the interviews done in this study are experimental in nature. The only experimental part of this study is the gathering of information for the purpose of analysis.

Risks or Discomforts

- This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day.
- The main risk is that the information that you provide to us may be shared with other people.
- We will not use your name in our research but will assign a number to the audio files, interview transcripts, the notes, and surveys. We will lock up all of the paper and computer files. Only the study staff will be allowed to access the study records. If we use something that you say in a report, a published paper, or a presentation, we will not include any information that can identify you.
- If you do not feel comfortable while you are taking part in the study, you can stop being part of the study at any time.

Benefits of the Study

- The information that is gained from the study may help other women get better healthcare and know more about cervical cancer. In other words, your participation may help women in your community improve their health.
- We cannot guarantee, however, that you will receive any benefits from taking part in this study.

Confidentiality

- We will keep your study records private and confidential. Confidentiality will be maintained to the extent allowed by law.

- Research files (surveys) and audio tapes will be kept at San Diego State University. These will be kept in a locked filing cabinet and on a computer that has a password protecting it.
- The audio files and any computer data will be kept on a password protected computer for five years after the study ends. After five years, they will be erased. You will not be allowed to review and edit the audio file before it is used for publication.
- After five years, the paper surveys will be shredded.

Incentives to Participate

- We will provide you a $20 gift card for the time you volunteer while being in this study. You will receive the $20 gift card after you complete the interview being done in this visit.

Costs for Participation

- It will not cost you anything to be part of the study.

Voluntary Nature of Participation

- Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with San Diego State University or San Diego State University Research Foundation. Information about your participation will not be shared with healthcare providers. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty.

Questions about the Study

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact Sumayah Nuhaily at [redacted] or Dr. Kristen Wells at [redacted].

If you have any questions about your rights as a participant in this study, you may contact the Division of Research Affairs at San Diego State University ([redacted]).

Consent to Participate

The San Diego State University Institutional Review Board has approved this consent form, as signified by the Board's stamp. The consent form must be reviewed annually and expires on the date indicated on the stamp.

Your signature below indicates that you have read the information in this document and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this consent form. You have been told that by signing this consent form you are not giving up any of your legal rights.

____

Name of Participant (please print)

Signature of Participant Date

Signature of Investigator Date

Appendix 3. Interview Guide

INTERVIEW GUIDE

Introductions

Interviewer:

Good morning/afternoon. My name is ________________________________. The purpose of this interview is to learn your thoughts about women's health. I am also interested in your views about getting an annual woman's exam, which is also known as a Pap test. Your answers to these questions will help us learn what makes it easier or harder for women to get this type of care.

Your ideas and opinions are important as we learn new ways to help other women get the healthcare they need. We want to learn from you.

Our interview today will last about 30 to 45 minutes. It is informal, and there are no right or wrong answers. Your participation is voluntary. If you feel like you need a break or want to stop, please let me know.

The information that you tell me today will be kept private. A final report will be prepared using the information that you give me, but your name and other identifying information will not be used. We hope that you feel comfortable to speak freely.

During the interview, I have a number of questions to ask you. We know that your time is important, so we want to be sure to keep you only for the time that we promised. To make *that happen, I may ask you to finish your thought or sentence and then move on to another topic or question.*

I will ask if I may tape record our conversation so that I can pay more attention to you and what you have to say instead of trying to write everything down. We will transcribe our interview from this tape. Do I have your permission to record?

[If permission given, begin recording.]

Date:________________________________ **Interview #: _______**

Thank you so much for taking part in the interview. Are you ready to begin? First, I am going to ask you some questions about getting the healthcare you need.

1. How do you like to get information about health? (Individual)
2. Who or what is the best source of information about your health? (Relationship, Community)
3. Why does this person/clinic/organization provide the best information? (Community)
4. Do you have a regular doctor or clinic where you get healthcare? Tell me about the place or person who provides healthcare to you. (Community; Relationship)
5. What makes this clinic/person (name of best source of information about health; name of place/person who provides care) trustworthy? (Community; Relationship)

Now I want to ask you specifically about the women's exam. I am going to ask about the part of the exam called "Pap test."

6. In your own words, what is a Pap test? (Individual)
7. What is the purpose of the Pap test? (Individual)
8. Why is it important to ________________ (use participant's words regarding why it is done)? (Individual)
9. Have other people told you about their experience having a Pap test? Who? What did they tell you? (Relationship; Community; Society)
10. If a Pap test finds something is wrong or abnormal, what does that mean? (Individual)
11. Please tell me some of the things that a woman needs to know to get a Pap test. Tell me some of the things that a woman needs to be able to do to get a Pap test. What are the steps that a woman must go through to get a Pap test? (Community; Individual)
12. How often do you think a woman needs to get a Pap test? (Individual)
13. What would you say makes it hard for a woman to get a Pap test? (probe for money, language skills, access to phone, knowledge of clinic, fear of results, fear/discomfort during exam) (Individual; Community; Society)
14. Are there people in a woman's life who could help her get a Pap test? How could they help? (Relationship)
15. Are there people who make it hard or discourage a woman from getting a Pap test? Tell me about that. (Relationship; Community; Society)
16. How could a clinic or doctor help a woman get a Pap test if she wants one? (Relationship; Community)

17. Is there anything about clinics or doctors that makes it hard to get the Pap test? Tell me about that. (Community; Relationship)

So you said that ______________________ *(use participant's words) make(s) it easier (and then follow with same question using difficult) to get a Pap test.*

18. What could be changed to make it easier for a woman to get a Pap test every two to three years? (Individual; Relationship; Community; Society)
19. What could make a woman more comfortable with having a Pap test? (Individual; Relationship; Community; Society)
20. What could make a woman have a better experience? (Individual; Relationship; Community; Society)
21. How can we best let other women know about Pap tests? Where should information be provided about Pap tests? Who should tell women about Pap tests? How would you like to hear information about Pap tests? (Individual; Relationship; Community;)
22. Is there anything else that you would like to tell me about getting a Pap test? (Individual; Relationship; Community; Society)

Thank you so much for taking part in the interview. I am going to stop recording now.

Appendix 4. Demographics and Self-Report Survey

Instructions: Please choose the best possible answer to each question. If you feel uncomfortable answering a question, please skip it and complete the rest of the survey to the best of your ability. All of your answers will be strictly confidential, and we will never share your information with anyone.

1. What is your age?

________________ years

2. Are you married?
   1. Yes
   2. No
3. Do you have any children?
   1. Yes
   2. No
4. Where were you born? (country, region) _____________________ (*if born in the United States, skip to question number 6).*
5. How many years have you lived in the United States? ___________
6. What is your primary language (language in which you can communicate the most)?
   1. English
   2. Arabic
   3. Other: ________________
7. What is your native language (the first language that you learned/spoke)?
   1. English
   2. Arabic

    3. Other: ________________

8. How many years of education have you completed?

    ______________ years

9. Are you currently employed for pay outside the home?

    1. Yes

    2. No (*skip to question 12*)

10. How many hours do you typically work per week?

    ___________ hours

11. What type of work do you currently do?

    ____

12. Have you ever heard of HPV (human papillomavirus)?

    1. Yes

    2. No

13. Have you ever heard of the HPV vaccine?

    1. Yes (*Go to question 14*)

    2. No (*Go to question 16*)

14. Have you ever had the HPV vaccine?

    1. Yes

    2. No

    3. Not sure/don’t remember

15. Have you ever been offered the HPV vaccine?

    1. Yes

    2. No

16. Have you ever had a Pap test?

    1. Yes (*Go to question 17*)
    2. No (*Go to question 18*)
    3. Not sure/don't remember (*Go to question 18*)

17. How long has it been since you had your last Pap test?

    1. 12 months or less
    2. 13-24 months
    3. 25-36 months
    4. 37-48 months
    5. 49 months or longer
    6. Not sure/don't remember

18. Do you plan on having a Pap test in the future?

    1. Yes (*Go to question 19*)
    2. No (*Go to end of survey*)
    3. Not sure/undecided (*Go to end of survey*)

19. When do you plan on having your next Pap test?

    1. Within the next 2 months
    2. Within the next 3-6 months
    3. More than 6 months from now

This is the end of the survey.

Thank you very much for your participation today! We appreciate your time and effort.

ACKNOWLEDGMENTS

The author would like to thank the women who participated in interviews for purposes of this study. Additionally, the guidance, contributions and support of Drs. Wells and Sales, as well as those of Ms. Pan, are greatly appreciated.

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