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RESEARCH ARTICLE

Impact of Cultural Beliefs About Cervical Cancer Screening on Clinical Practice: A Qualitative Study of Asian Indian Women in Texas

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ABSTRACT

Background: Asian Indians, primarily through immigration, are among the three fastest growing Asian minority populations in the United States. Sadly, Asian Indian Women did not meet the Health People 2020's the 93% cervical cancer screening goal of 93%. Cervical cancer screening rates among Asian Indian Women were 70.5% compared to 82.7% among non-Hispanic Whites. A systematic review revealed the need for qualitative studies to explore influences of cultural beliefs on cervical cancer screening (pap smears) behaviors among Asian Indian Women applying symbolic interactionism theoretical framework.

Purpose: To explore the influence of cultural beliefs on cervical cancer screening behaviors among Asian Indian Women.

Method: A qualitative descriptive ethnographic design used descriptive ethosemantic semi-structured questions to investigate cultural impact on cervical cancer prevention behaviors among a purposive sample of 15 Asian Indian Women between the ages 21 to 49 years of age. Data analysis used inductive analytical methods.

Findings: Five themes influenced cervical cancer screening: locus of control, concept of health, 'no sex before marriage,' awareness, and body image. A healthy internal locus of control, sense of being healthy, awareness, and positive body image supported cervical cancer screening behaviors. An external locus of control, belief that health is not a priority, "no sex before marriage," and low body image were barriers to cervical cancer screening behaviors. Additionally, the concept of "no sex before marriage" influenced timing of the first pap smear. Notwithstanding their cultural beliefs, employment, health insurance, and recommendations from their providers had a positive impact on cervical cancer screening.

Conclusion: Findings from this study have implications for both health policy and clinical practice. Health policy influences funding for basic screening and preventive services. Clinical practice implications encompass fostering partnerships within the community to promote prevention programs and cultural sensitivity training for providers. Future community-based participatory research should address interventional studies to increase compliance for cervical cancer screening and prevention behaviors among Asian Indian Women.

Introduction

Asian Indian women (AIW) make up one-fifth of the population of the world's women. They comprise the second-largest Asian minority group in the United States[1,2]. Disaggregating data specific to AIW is challenging to obtain because most studies combine Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPI) or combine AIs and Pakistanis as an ethnic group. Although AIs/Pakistanis have a low (4.2%) cervical cancer incidence compared to other Asian minority groups, mortality rates for cervical cancer among AANHPIs have remained high compared to other Asian groups and non-Hispanic Whites[3]. Limited studies on cervical cancer screening (CCS) (defined as Papanicolaou smear or pap test) among AIW reveal that they consistently fall short of the recommended Healthy People 2020 CCS goal of 93%, with rates averaging nearly 50%[4,5].

Cervical cancer rates have declined in the United States by more than 50% over the last three to four decades because of screening and prevention efforts. AIW engage in CCS behaviors in disproportionately small numbers despite high education levels and employment[6]. CCS among Asian women in aggregate is 73.6%, compared to non-Hispanic Whites (81.3%) and Hispanics (79.3%), and foreign-born women had lower screening rates than U.S.-born women, regardless of their stay in the United States[6]. CCS rates among AIW were 70.5% compared to 82.7% among non-Hispanic Whites[3]. Low rates of CCS among AIW renders them vulnerable to higher incidences of invasive cervical cancer and its related health complications.

Studies that explored CCS behaviors among AIW in the United States indicate the top factors influencing CCS behaviors are: (1) having lived in the United States for more than ten years (effects of acculturation); (2) higher education; (3) employment; (4) health insurance; (5) knowledge about the importance of CCS; (6) being married; and (7) physician recommendation. Barriers to CCS include (1) healthcare provider of the other sex and or different ethnicity; (2) lack of access to healthcare, regular healthcare provider, health insurance, time, and transportation; (3) language barriers; (4) unmarried status; and (5) cultural beliefs[7-13]. The researchers in these studies identified cultural beliefs worthy of exploration and expressed a need exists for culturally sensitive educational interventions to improve CCS among AIW[7-14].

This qualitative descriptive ethnographic study aimed to explore the cultural facilitators and barriers to CCS behaviors among AIWs. The significance of this study is to (1) explore the cultural beliefs influencing CCS among AIW, (2) underscore the health disparities of the target population regarding cancer screening, (3) serve as a foundation for developing culturally sensitive educational interventions in the AI community, and (4) reduce the cost of invasive cervical cancer treatment through early and routine screening. The specific aim of the study was to (1) Explore cultural beliefs about autonomy in making health decisions as applied to CCS experiences of AIW in the United States, and (2) explore the cultural facilitators and barriers that influence CCS behaviors among AIW in the United States.

Design, Sample, and Methods

According to the Centers for Disease Control and Prevention (CDC), the rate of new cases of cervical cancer in the United States increases significantly from age 20 to 49, peaks between ages 40 and 44, and gradually declines after age 50[15]. The United States Preventive Services Task Force (USPSTF), along with the American Cancer Society, American Medical Association, and American College of Obstetrics and Gynecology, recommends screening for cervical cancer every three years with cervical cytology (pap test) alone in women aged 21 to 29, and either screening every three years with cervical cytology alone or every five years with high-risk human papillomavirus (hrHPV) testing alone in women aged 30 to 65[16]. Following the USPSTF cervical cancer screening recommendations, this descriptive ethnographic study included participants between 21 and 49 years of age. It excluded women younger than 21 or over 49. All participants spoke English, which eliminated the need for translation services.

The PI recruited participants through notifications in the local university newspapers and AI associations and flyers at cultural and community-based events. Also, event planners for the cultural events posted the recruitment flyer on their personal Facebook pages and the event's Facebook pages. Snowball sampling was also used by giving each participant a flyer to recruit future participants. The sample size was determined to be adequate when new informants revealed no new findings, and meanings from all previous narratives became redundant (i.e., data saturation) (Spradley). For this study, the researchers recruited a purposive sample of 15 AIWs, aged 21 to 49. Thirteen participated in one interview, and two participated in 2 interviews, which lasted between 35 and 75 minutes. Each participant received

monetary compensation for their time with a $15 gift card to a local grocery store.

Participants signed consents and completed a demographic questionnaire prior to the interviews, which occurred in the participant's homes, university student centers, or coffee shops. Spradley's *The Ethnographic Interview*[17] guided the formulation of the interview questions. The interview questions addressed cultural influences of values, beliefs, and behaviors related to CCS. They contained broad questions about the participants' beliefs about health, the importance of reproductive health, causes and prevention of cervical cancer, and specific questions addressing cultural beliefs related to pap smears and HPV vaccination. Questions evolved during the interview and observation process as meanings, concerns, and practices emerged from various perspectives. The interviews were audio recorded on two recording devices and transcribed via an online transcription service, after which the PI compared the transcriptions for accuracy against the audio recordings.

Data collection and data analysis occurred concurrently. For instance, after the first two interviews, the PI identified central domains, sub-categories, and important meanings (semantic inclusions) and explored relationships between each informant's earlier experiences and the current situation. Future interview questions were refined based on the previous interviews. Because the questions evolved during the interview, the questions did not require validation. However, the PI met three times with one of the participants (key cultural informant) and another for member check-in and to confirm that the findings and themes represented the Asian Indian culture. The PI met with other researchers throughout the data analysis process to discuss the evolution of the codes, sub-categories, categories, sub-themes, and themes. The written summary (Excel) showed connections between meanings within and across stories. Based on the taxonomic structure, sub-categories, important shared meanings, and exemplars derived from data analysis, the central domains and cultural themes directed responses to the specific aims of this study.

Trustworthiness

Measures to foster trustworthiness included recruiting participants who spoke English and eliminating the need for a translator or interpreter. As an AIW herself, the researcher understood the participants' cultural beliefs and words. Direct quotes from the participants capture the meaning in the participant's voices, thereby increasing credibility. In addition, one participant, the "cultural informant," met with the researcher three times toward the end of the content analysis to verify and confirm if the findings and themes represented the AI culture to the participant's satisfaction.

Results

Thirty-one percent of the participants were aged 21–30 and 41–49, and 38% were aged 31–40. Participants were Hindus (46.2%), Muslims (23.1%), Christians (15.4%), and Jains (15.4%). A high percentage had an education higher than high school (92.9%), had health insurance (92.9%), were employed (77%), or were married (69.2%). Two had annual incomes below $35,000, and nine earned $35,000 to $75,000, and one more than $75,000. Four participants had lived in the United States for less than ten years, three between 11 and 20 years, and six participants for more than 20 years.

Descriptive findings and analysis of the interview data revealed five themes related to cultural beliefs of AIW living in the United States: (1) concept of health, (2) locus of control, (3) 'no sex before marriage', (4), awareness, and (5) body image. Subthemes and categories emerged from these themes, as reported in Table 1.

Table 1: *Themes, Subthemes, and Categories*

Theme	Subtheme	Category
Concept of Health	Concept of Health	Importance of health 'Don't go to the doctor'
Body image	Body Image	Negative body image Restrictions during periods or menarche No restrictions during periods or menarche Celebrating menarche
Awareness	Awareness About Cervical Cancer and Pap Smears	Lack of knowledge/misconceptions about cervical cancer and pap smears Knowledge about cervical cancer, pap smears
No Sex Before Marriage	No Sex Before Marriage	No sex before marriage No pap smears before marriage Sexually active before marriage
Locus of Control	Internal Locus of Control	Responsibility and decision maker Defiance Preference for doctor
	External Locus of Control	Doctor's recommendations Parental control Patriarchal family values We don't talk about it: reproductive issues (periods, pap smears, reproductive cancers, other) We don't talk about it: sex Limited conversations about reproductive issues, sex, talking to the other sex.

Theme 1: Concept of Health

Participants described their concepts of health, reproductive health, why they believed they were healthy or unhealthy, and why some preferred not to visit their doctor. The women who considered themselves healthy reported annual physicals and screenings and identified both mammograms and pap smears as examples of screenings. The favorable results of annual physicals and screenings reinforced beliefs that they were healthy and motivated them to continue with these behaviors.

Importance of Health: I Am Healthy: Physically, Mentally, and Spiritually

The women rendered holistic views of physical, mental, and spiritual health. They were physically healthy because they (1) felt healthy, (2) had no medical issues or problems, (3) did not need to see the doctor often, (4) never had surgeries or hospitalizations, (5) had regular menstrual cycles, (6) normal cholesterols and blood pressure, and (7) were doing things that were good for their bodies. They did not feel tired and could do their daily work and function thoroughly. The women believed they were relaxed and happy, maintained good relationships, and enjoyed their lives and families. Irrespective of their religion, praying fostered spiritual well-being. The women who perceived themselves as healthy either felt they did not need to see a doctor and therefore did not obtain pap smears or considered participating in screening behaviors essential for good health.

> "*I would say I'm mostly healthy. I guess, with the measures I use, I would say I don't really go to the doctor as much, but that's because I think I mostly feel really healthy.*"

However, participants indicated that at work, they only sometimes ate healthy foods and did not exercise, leading to problems maintaining a healthy weight. Participants mentioned current medical conditions, such as irregular periods, thyroid problems, and recurrent yeast infections, as reasons for not considering themselves healthy.

> "*But sometimes if a woman is working and not able to concentrate on eating healthy things – they're eating stuff from outside and not taking proper precautions and all those things, then it will obviously impact the health and reproductive organs.*"

Importance of Reproductive Health

For most women, reproductive health is essential for peace of mind, given that it is part of their bodies and sex hormones affect all aspects of one's health. Overwhelmingly, the women attributed childbearing to reproductive health. They believed that to guarantee the ability to become pregnant and have healthy babies, it was important that their reproductive organs were healthy and functioning

correctly. In some families, childbearing is considered a legacy. In contrast, women who had children did not consider childbearing a priority.

> *"As a woman, your reproduction kind of decides your general health because . . . either it's entering a menstrual cycle or it's getting out of a menstrual cycle and it's regulating everything else in your body. It's regulating your weight gain; it's regulating your weight loss."*
>
> *"I'm not concerned about this one. I have two kids, I'm happy with it."*

Benefits of Pap Smears

The pap smear is an essential aspect of CCS. Knowledge of the benefits of paps is a motivating factor for getting the test. Some of the benefits mentioned by the women included but were not limited to ensuring cervical cancer prevention or catching it early, having peace of mind, and detecting any condition that could interfere with childbearing. A previous HPV positive result was also a strong motivation for having regular pap smears. Interestingly, four of the fifteen participants mentioned that they were HPV positive and knew this because they had screenings. Three of these four actively sought a pap smear even when the doctor had not recommended it to them at that time. Participants commented much like this: "*I mean this is something that you do towards your health. So, I guess it's the uncomfortness [discomfort] that sometimes discourages women to get a pap smear*." Another said, "*So, I wanted to make sure that I didn't have any kind of STD, I didn't have any kind of health abnormality, any kind of cancerous problem, really just any health abnormality*."

Eleven women stated that their "*annuals and screenings results were normal*," and all participants were cancer-free at the time of the study. A normal pap smear result was associated with being healthy. However, four women revealed that they had an abnormal pap smear result and considered reproductive issues as a "stigma."

I Don't Go to the Doctor

The concept of health influenced the need to visit a doctor. The women who grew up in India mentioned that AIs choose not to go to the doctor unless a significant problem occurs. As such, they preferred to treat themselves with home remedies or homeopathy. Other reasons for not visiting the doctor are that they do not want to hear that they have a medical disease and fear that doctors order unnecessary and expensive tests. One participant mentioned that in India, women who visited the gynecologist were stigmatized and looked down upon, so many chose to ignore any reproductive problems.

> *"But for our generation, for the most part, the mentality is, 'Nothing is wrong. Why should we go to the doctor? They'll just charge you for unnecessary things.' That's the biggest thing that will come up in your mind. When you go, they'll order some unnecessary test and then you have to pay for it. Half of the time the visits are discouraged because of the fear that, "we'll have to pay for something which is not necessary. Why should we waste money?" You know, that's what it is."*
>
> *"Back in Pakistan or India, wherever they grew up, they didn't have a lot of woman's help. It was looked down upon I guess."*

Theme 2: Body Image

Negative Body Image

The participants confirmed that while growing up, they received negative messages from family about their bodies, especially at or after menarche. For example, having periods is shameful; reproductive parts are dirty and impure during periods; therefore, they were not allowed to touch many things because they would contaminate everything they touched. The women had many restrictions imposed on them during their periods, such as being in seclusion, being denied entry to the kitchen or pooja (prayer) rooms, not being allowed to participate in religious celebrations, touch or read from any holy books, or to pray. Some women were not permitted to go to school during periods or menarche:

> *"It's the idea that when you're menstruating, you're dirty. And that's why when you touch something, it'll probably contaminate whatever you're touching. And that makes me really angry, because how is this dirty? This is a part of you."*

More importantly, possessing a low body image negatively influences CCS behaviors. In particular, the women do not seek help for reproductive health issues, are unaware of protective behaviors, and are unwilling or unable to discuss their health concerns. However, some women reported that they did not experience any restrictions during menarche or periods and believed that periods were a normal part of their bodily functions. Any restrictions imposed on women during periods or menarche are associated with an external locus of control and how women view themselves—either dirty and impure or the condition is part of normal bodily functions. In turn,

these beliefs and practices explain the influence on their overall concept of reproductive health.

> "*Maybe it's culture. But I think it could also be a body-confidence thing. I've heard more and more about-- I've spoken to friends in India who've moved here. And people, in general, people here are a lot more body-confident. But girls in India are not as much.*"

Theme 3: Awareness

Lack of Knowledge/Misconceptions About Cervical Cancer and Pap Smears

While some women indicated that they had never heard of cervical cancer or its causes, only a few confirmed that they had heard about it after coming to the United States. They attributed the lack of knowledge to never having anyone in their family with this type of cancer or never having discussed women's issues within their families.

Some women believed that the more pap smears they had, the higher the likelihood of having cervical cancer because it "changes the cell." If a girl engages in intercourse before age 16 or within one year of menarche, they have a higher risk of getting cervical cancer. Therefore, they associate the act of having premarital sex to the development of cervical cancer.

> "*I was reading about it and read that if a girl has sex before the age of sixteen or within one year of her menstruation cycle. Then there are high chances of getting cervical cancer and otherwise, it's more about age of fifty.*"
>
> "*Probably not being neat and hygiene. If you're not taking showers. If you're not keeping it clean. Like whenever you go to the bathroom and you're not rinsing properly, there's a chance you might develop some sort of cancer.*"

Knowledge About Cervical Cancer, Pap Smears, and Prevention

Some women credited the cause of cervical cancer to HPV. The other causes of cervical cancer include genetics, sexually transmitted diseases, radiation, menstrual health, menstrual hygiene, multiple sex partners, family history of cancer, smoking, and others. These women believed in a proper diet, regular exercise, good hygiene, having a single partner or few partners, safe sex, birth control pills or hormonal pills, and abstinence. Not smoking and avoiding high-risk behaviors such as drinking alcohol, and drugs can also prevent cervical cancer. They also included regular screenings, pap smears, and receiving the HPV vaccine.

Variation in Timing and Scheduling of Pap Smears

Most women revealed that their first pap smear occurred after marriage, usually during their first pregnancy. In contrast, a few women who were sexually active before marriage had pap smears early when they requested it when visiting their doctors for birth control. The intervals between paps ranged from every two to more than six years.

> "*Then when I was going to have my daughter that's when I had my first pap smear. I think I was twenty-seven.*"
>
> "*So, I got my first pap smear done when I was 30 when I came to U.S.*"

Theme 4: No Sex Before Marriage

An overwhelming number of women revealed that while growing up, it was taught and implied that there should be "no sex before marriage." This creed influences decisions about health, the importance of pap smears and HPV vaccines, and CCS among AIW. Women from conservative households were taught not to have intercourse before marriage, and topics regarding reproductive organs were taboo and not discussed. Women who had arranged marriages stated that it was vital that they were virgins at their weddings.

> "*So, the idea has always been that if you're taking birth control, then you're having sex. And if you're having sex and you're not married, this is completely inappropriate and not something that they want to be supporting. And so, the messages were always just if we're supporting this, then that means that we're supporting our child having premarital sex. And so, there just weren't really any discussions around even that type of language was never really used to say why birth control shouldn't even be considered. It was just no; this is not something that is going to be allowed in our household.*"

We Don't Have Pap Smears Before Marriage

The women explained that when having a pap smear before marriage, the instruments (i.e., the speculum) would break the hymen, and they would no longer be virgins. Thus, the women had pap smears after marriage, most at the time of their first pregnancy.

> "*I'm pretty sure I refused to have a Pap before I got married. This must have been after.*"
>
> "*I thought it (pap smear procedure) would break the hymen and I was a virgin.*"
>
> "*Right. I…back home…I don't remember ever getting it done before wedding.*"

I Was Sexually Active Before Marriage – I Did Not Tell My Parents

Four participants were sexually active before marriage and did not tell their parents ("*Oh, my goodness, no. My mom would probably have me married that day. No.*"). Three participants requested pap smears before marriage, and the remaining participant did not have a pap smear because she did not want her parents to know that she was sexually active then. One participant did not clearly state if she was sexually active during the interview. However, she indicated that she had never had a pap smear. Although her doctor recommended a pap smear, she did not want to have a pap smear before marriage. She did not feel right to do this because her father would see the medical bill and assume she was sexually active.

> "*To me that's that doesn't make sense for me to, I mean, I wouldn't want to go and pay out of pocket or something. My dad sees every single bill that comes through our house. He would know it. It's illogical, so I have to go conquer the fear and just tell him.*"

The remaining ten participants had their first pap smear during their first pregnancy after marriage. The cultural belief of "no sex before marriage" leads to no pap smears. Women who confirmed that they were sexually active before marriage did not tell their parents. The women born in India and later arriving in the United States confirmed that they had never had pap smears or had ever heard of pap smears while in India. The women also indicated that in India, no doctor recommended pap smears, and they were told that paps are not recommended until age 40.

Theme 5: Locus of Control

Ammirati and Nowicki state the assumption that individuals with an internal locus of control are more inclined to participate in actions that result in health consequences, whereas a person with an external locus of control credits success to chance or destiny, godsend, or accident, or other factors in the environment[18].

Internal Locus of Control

I Am Responsible for and Make Decisions About My Health

Participants overwhelmingly indicated that they were responsible for and made all decisions about their health. To this end, they engage in healthy behaviors, such as adequate hydration, eating healthy, avoiding fad diets, and exercising. Other healthy behaviors include being clean, living in a clean environment, having good living habits, getting enough sleep, and avoiding things in the environment that can cause cancers. Some participants also mentioned annual checkups and screenings such as mammograms, pap smears, and blood tests.

Some participants voiced that it was essential to visit the doctor to ensure they were healthy. One participant stated, "You go because you will make sure nothing is wrong with you, and that's the reason why we get our physicals and urine and stuff."

A few participants mentioned that their doctor did not recommend pap smears even though the reason for their visit was to seek birth control.

> "*Whenever I've gone to the healthcare center, I'm mostly only going there for birth control. But I can't recall if they've ever asked when my last pap smear was or if I was planning on having one any time soon.*"

Defiance

An internal locus of control motivates women to rise above their cultural beliefs and practices. Having grown up in India and now living in the United States, these AIW questioned several cultural beliefs and practices, such as why pap smears in India began at age 40. They defied some practices enforced by mothers, grandmothers, or mothers-in-law during their periods. Two participants stated the following:

> "*I don't understand the strategy behind it. I don't know what the 'after 40' early means in this case. Because if it has to happen, it can happen since you're sexually active. So, I don't know where that 'after 40' comes from in India.*"

Participants challenged their mothers' statements that their holy book includes various practices to be followed during periods. One young woman questioned her Hindu priest about these practices, and the priest told her that no such passages were in their holy book, which upset her mother. Overcoming these beliefs and practices motivated some AIWs to defy tradition, culture, or messages from parents and make decisions for themselves.

At least five of the fifteen participants stated that they were sexually active before marriage and did not tell their parents. These women questioned if their religion indeed stated this or if it was a commonly held conviction of their parents. Because of this, these women advocated for themselves by obtaining the HPV vaccine and birth control, requesting a pap smear, and believing that they would instead teach their children about safe sex practices versus being virgins.

Preference for Doctor

The participants made conscious choices about the gender and ethnicity of their doctors. Most women selected female physicians of Indian origin because they felt that the physician understood them better. Some women felt that Indian physicians were judgmental, treated them with biases, and were often rude. Women who preferred non-Indian female physicians expressed that talking to them about birth control and reproductive health was straightforward because they were more open-minded and nonjudgmental. Comfort and trust in their physicians positively influence CCS, as does seeking care for other reproductive issues.

External Locus of Control

A strong internal locus of control positively influenced CCS. External locus of control can positively and negatively influence CCS behaviors. Some examples of external locus of control were (1) physicians' recommendations ("*My doctor tells me what to do*"), (2) parental control ("*My parents make decisions for me*"), (3) growing up in patriarchal families, and (4) having little or no discussion about reproductive issues, sex, and talking to the opposite sex.

My Doctor Tells Me What to Do

Even though the women were responsible for and made decisions about their health, their doctors made decisions for them. Only when the doctor recommended a pap smear or other screenings would they have the screening done. They believed they were healthy because the doctor said so. Some women never had a pap smear because their doctor did not recommend it for them or their daughters, who were at the recommended age (21 years).

My Parents Make Decisions for Me

Parental control is an external locus of control that is not limited to childhood but to adulthood when independent decisions are vital. One participant stated it this way:

> "*Whereas if I was younger or in college or anything like that and if I wanted to get any kind of health, I would have to go through my parents or a guardian, but not now.*"

Parental control also influences CCS. The women responded that they would only allow their daughters to have pap smears after marriage. Growing up in India, they understood that women over age forty had pap smears. However, some women were open to having their daughters have a pap smear early. When a doctor recommended a pap smear, one woman asked her father, and her decision was not to have the pap smear.

Parental control also included decisions regarding whom they would marry, including arranged marriages. Parents insisted that their daughters remained virgins until marriage. This negatively influenced CCS behaviors.

Growing Up in Patriarchal Families

Growing up in a patriarchal environment was one of the strongest external loci that influenced decision-making and choices for the women, and they did not want their children to grow up with the same beliefs and practices under which they were raised. Some women preferred to protect their daughters by ensuring they have regular pap smears. A common thread in most patriarchal families is that beliefs and practices associated with reproductive issues, such as menarche, periods, sex, or reproduction, are not discussed, leading to a lack of awareness that may impair the woman's decision-making ability concerning their reproductive health.

> "*My grandfather had a lot of influence over what the women in the house did. So, he had two daughters-in-law and then he also has brothers who have daughters-in-law, but he would basically be their deciding authority. And my grandmother would just follow without question. She wouldn't object to anything. I do have one uncle who is very, very patriarchal like that and he decides what his daughter ought to do about things.*"

We Don't Talk About It: Reproductive Issues and Sex

Parents and mothers felt uncomfortable teaching their children the correct names for their reproductive parts. From an early age, the child feels embarrassed about his or her body parts. The women concurred that their parents did not talk to them about their body changes as they entered puberty or how their reproductive organs functioned. Some women did not know what was happening to their bodies every month during their periods. Instead, they learned about this from sex education, their older sisters or cousins, or books and women's magazines.

The women indicated they did not know about cervical cancer, what caused it, or how to prevent it because no one, males or females, talked about it. They did not discuss or talk about their gynecological health with their husbands. Some women were embarrassed to tell their husbands they had an appointment for a pap smear. It was unusual for the women to discuss everything with their husbands.

Most participants seemed to agree that they were not comfortable talking about sex with their mothers, other family members, or their friends. For one thing, it is private and not done in AI culture. One participant stated that talking about sex is taboo: "*I remember asking my mom what a period was. And my mom got really upset that I asked. She said, 'It's something you don't need to talk about.'*"

Limited Conversations About Reproduction, Sex, and Talking to the Opposite Sex

The women acknowledged minimal conversations about reproductive issues or sex with their mothers and other female family members or friends, but this was rare in their culture. In contrast to their upbringing, these AIWs were open to discussing pads or tampons with their daughters, nieces, and cousins.

Women in arranged marriages expressed that they did not know much about sex. More specifically, they had minimal conversations with their mothers or female relatives about what to expect on their wedding nights. However, most expressed that they did not want to raise their children the way they were raised but wanted to communicate openly with them. They acknowledged that times and technology have changed. A considerable amount of information is available on the Internet for this generation of young girls and women. They also expressed a need to stress at a young age the importance of a positive body image and being healthy.

> "*I don't know what the words to say. Going into the actual sexual process too, I think girls have to be informed about how it works, reproduction, how it works. This is something I'm talking about because I personally have been born and brought up in India when this has been such a taboo topic.*"

Discussion

Although the findings from this study cannot be generalized, it is interesting to note that 93.33% of AIW in this study met the Healthy People 2020's goal of having a CCS within the past three years of 93%. Eight first-generation and four second-generation participants of this study had at least one pap smear at the time of the interview. In comparison, the Healthy People 2020 data reported that only 72% AIWs met this goal compared to 82% of Whites.

This study's findings are inconsistent with the limited studies on the CCS behaviors of AIW, who continually fall short of the recommended Healthy People 2020 CCS goal with rates averaging ~50%. Some reasons for the increased percentage of the participants obtaining CCS are that 92.9% of participants were highly educated, 69.2% were married, 92.9% had private or another type of health insurance, 77% were employed full-time or part-time, 83.3% had an income ranging higher than $35,000 to more than $75,000, and 69.3% lived in the United States more than ten years.

Relationship of the Themes with the Specific Aims

Specific Aim 1: Explore cultural beliefs about autonomy in making health decisions as applied to CCS experiences of AIW in the United States. Several themes, subthemes, and categories address autonomy in making health decisions as it applies to CCS behaviors. Participants overwhelmingly confirmed that they were responsible and made decisions about their health, demonstrating a strong "internal locus of control." As such, they engaged in many healthy lifestyle behaviors, such as avoiding smoking, maintaining a healthy diet, drinking water, exercising regularly, and being active. They also made appointments for annual checkups ("*annuals*") and screenings (mammograms and or pap smears). Most of these women had a pap smear as part of an annual checkup.

The participants in the study preferred either Indian- or non-Indian physicians who were female. The preference for female Indian physicians was that the physicians would understand their culture. In contrast, others preferred non-Indian physicians because they felt these physicians would be unbiased in their care and recommendations. The women also felt they could talk to these physicians without any reproach. Trinh et al. described similar findings where differing cultural beliefs on cancer screening and fear of potential physician biases prevented Asian Americans from participating in cervical, colorectal, and prostate cancer screenings[19]. Having female physicians of the same ethnic background or country of origin perform the pap test was a strong motivator[20-23]. Participants who preferred non-Indian female or male physicians indicated that their physicians recommended paps without regard to their marital or sexual activity status.

Participants who defied traditional cultural beliefs and engaged in sexual activity before marriage advocated for themselves by requesting pap smears from their providers. These women indicated that their healthcare providers did not recommend pap smears, so they made the decision themselves.

Other categories undermined autonomy in cancer screening behaviors, such as "*my doctor tells me what to do*," "*my parents make decisions for me*," and patriarchal family values. Women noted that

they had pap smears only because their doctors recommended it. If their doctors did not recommend pap smears, the women did not obtain them.

Women who lived in patriarchal families explained that their fathers, husbands, or fathers-in-law made many personal and health decisions for them. Patriarchal, conservative family values negatively influenced CCS because it led to a lack of awareness and impaired the woman's decision-making ability. Despite this, being employed and having health insurance motivated these women to participate in CCS behaviors as part of their health insurance benefits. In such cases, the healthcare system promoted CCS.

Specific Aim 2: Explore the cultural facilitators and barriers that influence CCS behaviors among AIW in the United States. The themes that emerged from specific aim 2 include locus of control, concept of health, self-awareness, "no sex before marriage," "we don't talk about it," and body image. The importance of reproductive health to their overall health and the belief that they are healthy were facilitators for CCS. Women with normal pap smear results believed they were healthy; therefore, they continued to have regular pap smears. An abnormal pap test result was a strong facilitator for continued, regular screening behaviors. Participants who received an abnormal pap smear result recalled its devastating impact on them because most were unmarried and sexually active. Because they had not told their parents they were sexually active; the women did not want to tell their families about the abnormal pap smear (HPV positive) results. However, they underwent further testing and treatments without any support from their families. As McCaffery et al reported[24], women described shock, distress, worry about cancer, the stigma of having an STD, anxiety about disclosing this to their partners, and fear of transmitting the viral infection to others.

Women who are aware of cervical cancer, its causes, and the current schedule of pap smears tend to participate in regular CCS. On the contrary, never having heard about cervical cancer and a lack of knowledge or misconceptions about the causes of cervical cancer are barriers to CCS. Most participants said they heard about cervical cancer and pap smears only after coming to the United States. Also, parental decision-making and patriarchal family values can undermine women's autonomy in health decision-making and remain barriers to CCS. Lack of knowledge about cervical cancer is a common barrier to CCS among many ethnic minority women[21-22,25-30]. In contrast, the study by Yoo et al, demonstrated that knowledge about cervical cancer did not significantly increase the odds of having a pap test. Instead, being older, being born in the United States, and being comfortable with the pap test increased the odds of having a pap test[31].

Women who had "no [religious] restrictions" during menarche went to school or places of worship. Conversely, women who grew up with negative messages about their bodies, especially at menarche or shortly after, grew up with a negative body image. These women can develop a negative concept of their bodies, reproductive parts, and health, leading to neglect, refusal, or ignorance of CCS behaviors.

The cultural expectation of "no sex before marriage" and a negative body image are barriers for CCS and prevent many women from having a pap smear before marriage. It was also quite crucial for many participants to remain virgins until their wedding days. Consequently, they believed that the speculums used during pap smears would take away their virginity; these women also believed that using tampons would take away their virginity and, therefore, only used pads during their periods. While "no sex before marriage" appears to be a barrier to CCS, participants had pap smears after marriage and continue to have pap smears per current recommendations.

Reproductive health was a priority only for childbearing and fertility, and the women understood that healthy reproductive organs were necessary to ensure giving birth to healthy babies. Recognizing this, the women in the study obtained pap smears to ensure the health of their reproductive system.

The participants also indicated that recommendations from their doctors motivated them to obtain pap smears. Nevertheless, several women indicated that their physicians never recommended pap smears; consequently, they did not obtain pap smears, even though they were sexually active. Few studies have supported the idea that physician recommendations are a facilitator for CCS[22,27,32-34].

Some cultural beliefs or reasons why many AIWs do not visit their doctor include the lack of significant health issues, preference to avoid knowledge of ominous diagnoses, preference for home remedies and homeopathy, or fear of unnecessary tests and related payments. The participants indicated that going to a gynecologist was looked down upon by their families and neighbors, and previous horrible experiences with doctors prevented them from visiting doctors unless a significant health issue existed. Studies with Chinese American women found that women preferred to use traditional medicine to cure an illness before trying Western medicine or visiting the doctor[29,35].

These cultural beliefs negatively impact the prevention of cervical cancer. Women from countries with limited preventive services might not know the importance of pap smears. For most AIs and minority populations, prevention is not a priority[29,36-38]. Other Asian subgroups, especially the Chinese, use home remedies, and the use of herbs and traditional medicine is valued[35].

In addition, the subtheme "we don't talk about it" negatively influences CCS. Many participants considered conversation on topics related to reproductive issues such as periods, pap smears, or sex as taboo. The participants remembered not knowing what was happening to them during menarche because they "never talked about it," and they did not know about the work of their reproductive system until years later. Limited qualitative studies on cultural beliefs among women from other minority groups explore the influence of CCS, and the few available studies fail to address the concept of "we don't talk about it."

Implications for Health Policy and Clinical Practice

Findings from this qualitative descriptive ethnographic study demonstrate that cultural beliefs among AIW influence CCS, and thus, has many implications for health care policy and clinical practice. Three of the five themes that emerged from the interviews—awareness, "no sex before marriage," external locus of control, and the subtheme "we don't talk about it" impact CCS among AIW and overall cervical cancer incidence and mortality from this disease.

The American Cancer Society, the American College of Obstetricians and Gynecologists, and the United States Preventive Services Task Force separately had slightly different CCS guidelines, with multiple pages of algorithms to select the suitable screening recommendation for an individual woman. Nevertheless, recent efforts to streamline all CCS recommendations into one based on age should be uncomplicated and straightforward for all clinicians to follow[16]. While these screening guidelines are helpful, clinicians must be sensitive to the distinctive cultural needs of AIWs.

Federal and state government funding for basic preventive services is essential in the fight against cervical cancer. For instance, continued Medicaid, Title X (i.e., federally funded program for CCS), and Planned Parenthood funding have been vital. These resources are used by many women, including minority populations, seeking preventive services like pap smears[39]. In 2018 and 2019, at the national level, Planned Parenthood performed 255,682 pap tests and treated 70,032 women whose cancer was detected early or had abnormal pap results[40]. However, in August 2019, Planned Parenthood withdrew from the Title X program, thus losing more than $286 million in funding[41-42]. Interestingly, the Biden-Harris administration ended the Title X gag rule in October 2021 and increased funding to Planned Parenthood[43].

The Gynecologic Cancer Education and Awareness Act of 2005, also known as Johanna's Law, is a national campaign to provide information to the public on request and make public service announcements to encourage women to discuss their risks with their physicians[44]. The announcements should include early warning signs and risk factors concerning cervical cancer. Translation of these announcements to other languages, including languages used by Asian Americans with low-English proficiency, such as Hindi, Gujarati, Tamil, Mandarin, Vietnamese, and Korean, is essential to meet the needs of women from minority groups with high incidence and mortality rates of cervical cancer. The CDC has since joined this campaign and published numerous resources for the public and clinicians to increase awareness of cervical cancer, HPV, and CCS[45].

On January 15, 2019, the CDC conducted a Public Health Grand Rounds presentation, "Preventing Cervical Cancer in the 21st Century." Streamlining CCS guidelines was a notable change. In addition, to accelerate control of cervical cancer in low-resource settings, the National Cancer Institute encourages an increase in coverage through single-visit, "screen and treat" programs, reduction in unnecessary referral to treatment, and integration of HPV vaccination and CCS[46].

Implications for Society

AIs are a heterogenous group, and it is evident that not all AIWs have the same cultural beliefs about CCS. By exploring the various cultural beliefs of AIW, healthcare providers can circumvent stereotyping and address relevant interventions for the women they serve. While cervical cancer incidence and mortality rates have decreased in developed countries, the rates remain high. According to GLOBOCAN 2020, there were 13,545 new cases in the United States, making it the 20th-most-prevalent cancer. More than 5700 women in the United States died in 2020 from cervical cancer[47]. Healthy People 2020 focused on the nation's health, but many minority groups are overlooked in terms of resources and thus continue to have higher cervical cancer rates. The CDC's Public Health Grand Rounds on the prevention of cervical cancer held in January 2019 identified barriers to cervical cancer prevention: low HPV awareness (similar finding in this study), poor

understanding of HPV/cancer link (similar finding in this study), cultural issues (the focus of this study), poor screening uptake and compromised follow-up[46].

This study also elucidated that educating young females about reproduction is essential, even before attaining menarche. Some participants said they would not discuss this with their children and hoped the school systems would cover it. Sex education information sheets should be culturally sensitive, and those with low English proficiency can request copies in their native languages. Educational campaigns could also be posted online for young girls and women on various social media platforms. A solid social media presence of the CDC's " Inside Knowledge: Get the Facts about Gynecologic Cancer" campaign in many languages is crucial.

Suggestions for Future Research

Findings from this study inform future research that includes developing culturally sensitive, personalized educational interventions to advance awareness of CCS. For instance, the impact of religious beliefs on CCS should be investigated further along with cultural beliefs specific to women from different religions because participants acknowledged that their beliefs were rooted in tradition, culture, and religion. Future interventional studies can include recommendations from female AI providers because the participants here expressed their comfort with such providers and obtained pap smears based on their physician's recommendations. It is vital to compare AIW who do not participate in CCS behaviors to those who do and closely examine the differences in the characteristics between the two groups.

Cultural beliefs, such as "no sex before marriage" and "no paps before marriage," could have less impact because of the new, streamlined CCS based on age than sexual activity. As a result, future studies may focus on the longitudinal impact of the updated cervical cancer recommendations, the endorsement of the 9-valent, two-dose HPV vaccine, and the impact of the CDC's campaign to increase cervical cancer awareness in minority populations.

Most studies discussed promoting the development of culturally sensitive strategies and policies to address CCS among Asian American women and women from other minority populations. Several factors must be considered, such as ethnic community size and geographic location, cross-cultural similarities, and dissimilarities, targeting unmarried young women and their close referents, use of trusted resources within social networks[31,48], and heterogeneity of the Asian American subgroups[34]. In addition, public health outreach and cancer education should be a priority for Asian American women who are recent immigrants to the United States and have minimal access to healthcare[37].

Conclusion

This qualitative descriptive ethnographic study was the first step in a research program focusing on decreasing health disparities based on cultural beliefs and providing a firm foundation for future studies. A sense of cultural defiance, employment, healthcare insurance mandates, prior awareness about CCS, and physician recommendations functioned as cultural facilitators for CCS. Growing up in patriarchal families, becoming secluded during menarche, avoiding conversations related to reproductive issues and sex, and believing in "no sex before marriage" were cultural barriers to CCS behaviors. In healthcare practice, policy, and future research, the findings of this study inform the development of culturally sensitive, personalized educational interventions to advance awareness of CCS in AIWs.

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