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The "Area Down There:" An Exploration of Cervical Cancer Screening Attitudes and Behavior Among South Asian 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
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2011

Abstract

The "Area Down There:" An Exploration of Cervical Cancer Screening Attitudes and Behavior Among South Asian American Women

By Zunera Mirza

Background: Asian American women are less likely to seek a Pap test within the past three years compared to other racial and ethnic groups in the United States. Therefore, cervical cancer is a major cause of death for women among this fast growing population.

Objective: The purpose of this study is to identify the perception of cervical cancer screening among young unmarried South Asian American women in the Atlanta area and to generate an understanding for approaching perceived barriers and benefits to seeking gynecological care.

Methods: Qualitative data were collected through 20 in-depth interviews in Atlanta, Georgia. Interviews were coded and organized in NVIVO qualitative software. The Health Belief Model, social constructivist theory, and the decisional balance construct from the Transtheoretical Model provided a conceptual model for interpreting results.

Results: The research found that the primary cue to action for cervical cancer screening was through a doctor's advice (to receive a Pap smear). Another cue to action involved participants engaging in sexual activity and/or experiencing pain, abnormal menstruation, etc. (feminine issues) that would cause the individual to seek general gynecological care and become influenced by the doctor to receive a Pap smear. Major barriers to seeking cervical cancer screening were limited understanding of what gynecological care was for, low perceived susceptibility, taboo of sexual topics, and stigmatizing cultural beliefs.

Discussion: The findings from this study suggest that cervical cancer screening programs in the United States could be more effective if South Asians were targeted with dialogue and education around the preventive services provided by a gynecologist and the risk factors to cervical cancer. This study has several recommendations. One key recommendation is for healthcare providers to educate themselves and strategically address aspects of perceived susceptibility among young South Asian women (such as risk), since doctors are a trusted source of information and authority.

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ACKNOWLEDGMENTS

> In many ways, Asians are still below the radar . . . it’s a huge mistake to keep generalizing as we do about Asian American students and to treat them as a monolithic group that doesn’t need attention.”
>
> -Pedro Noguera, Ph.D., “The ‘Other’ Gap,” *Education Week* (February 14, 2007)

To Professor Kegler and Professor Escoffery: Thank you for taking me on as your thesis student and for your valuable feedback.

To all my other Professors (and Cami!) at the Rollins School of Public Health: I wouldn’t know the first thing about qualitative research, survey methods, or how to navigate OPUS without you.

To Linda and Diamond: The time you spent helping me code was invaluable. You are amazing and wonderful!

To my friends and family: Always for your love and words of encouragement, even when I thought I couldn’t type another word. I love you.

To Isaac Foster: Thank you for being phenomenal and my own personal coach, chef, and therapist. I love you too.

And, of course, to all of the participants who shared their stories and insight with me. I couldn’t have done any of this without you.

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CHAPTER I: INTRODUCTION

BACKGROUND

STATISTICS ON ASIAN AMERICANS IN THE UNITED STATES:

Asian Americans (AA) are among the fastest growing racial and ethnic groups in the United States. In 1960, there were fewer than 900,000 Asian Americans in the United States, representing less than 1 % of the US population at the time.[1] Yet, from 1960 to 2006, immigration rates from Asia to the United States increased by 1700%, leading to a total population of 14.7 million Asian Americans.[2] By 2050, the Asian American population is predicted to increase to 8% of the total U.S. population, or 33.4 million persons.[3] They are also a very diverse group. Asian Americans, including US-born and immigrant communities, are defined by the US Census Bureau as individuals with origins in "any of the original people of the Far East, Southeast Asia, or the Indian subcontinent. Asian groups are not limited to nationalities but include ethnic terms as well, such as the Hmong".[4]

STATISTICS ON ASIAN AMERICANS IN GEORGIA:

From 1990-to 2003, Census data ranked Georgia among the top two states with the fastest growing AA population (29%), second only to Nevada.[5] Early in March of 2011, the Census Bureau released 2010 demographic data for Georgia which revealed a huge growth of the Asian populations over the past 10 years, from 2.1% in 2000 to 3.2% in 2010.[6] Moreover, from 2000 to 2010, the state-wide Asian population grew 81.6 percent in comparison to the overall population growth of 18.3 percent.[6]

Almost three-quarters (73%) of Asian Americans in Georgia live in the 10 counties that make up Metro-Atlanta: Cherokee, Clayton, Cobb, DeKalb, Douglas, Fayette, Fulton, Gwinnett, Henry and Rockdale counties, including the city of Atlanta.[6,7] The Asian and Pacific Islander American population grew 77 percent in metro-Atlanta alone. The county with the highest concentration of Asian Americans is Gwinnett County, with 10.7 percent (including Pacific

Islanders), followed by Fulton (5.6%), DeKalb (5.2%), Clayton (5%) and Cobb (4.5%). In the ten-county metro Atlanta area, Asian Americans represent 5.7% of the metro population, up from 3.8% in 2000.[6]

Atlanta's Asian Americans are a diverse population consisting of both refugees and immigrants from many countries including Korea, Vietnam, Cambodia, Afghanistan, Laos, India, Burma and Bhutan. Asian American Justice Center data[8] indicates that 29% of Atlanta's AA homes are linguistically isolated. Linguistic isolation, poverty, and significant cultural differences mean that health outreach, prevention and education programs must be tailored to each group's unique needs and circumstances.[9]

HEALTH DISPARITIES FOR ASIAN AMERICANS:

Asian populations are extraordinarily diverse with respect to country of origin, time since immigration, socioeconomic status, languages and dialects spoken, religion, and many other characteristics that affect health. It is, therefore, not surprising that the various Asian American ethnic groups differ with respect to cancer and other chronic diseases.[10,11] However, despite the upsurge of Asian Americans in America, conversations regarding health disparities largely do not include the health challenges faced by many Asian Americans in the United States. For instance, cancer is a major public health problem among all racial and ethnic groups in the United States. Although Asian Americans and Pacific Islanders have lower incidence and mortality rates from all cancers combined than all other racial/ethnic groups[12], the pattern of cancers within Asian American ethnic groups is distinctive and is an important cause of suffering and death.[10] More importantly, Asian Americans and Pacific Islanders are the only major US racial/ethnic group for which the annual number of deaths from cancer exceeds that for heart disease.[13] Although Asian Americans are at lower risk for cancers of the lung, colon and rectum, breast, and prostate, they have higher rates of cancers related to infectious conditions, particularly tumors of the cervix, stomach, liver, and nasopharynx.[14]

In addition, there are little to no cancer data collected on AAs and if there are data, Asians are collapsed together into one category. Overall, there is very little health research focusing on AA women as a whole, let alone as separate heterogeneous groups. In the state of Georgia, there are limited specific cancer services that are culturally and linguistically appropriate for reaching out to Asian American populations. Whether it is public perception that cancer is not a serious issue among AA or the constant lumping of all "Asians" into one category, it is detrimental to the AA community to be omitted from cervical cancer prevention research. The aggregation of data across diverse AA populations has partly led/or has been due to the "model minority" myth in which AA are always seen more healthier/wealthier than other ethnic/racial groups in the USA.[15] To counter the "model minority" myth and the imprecise "Asian" label: geographically, AA reside in all 50 states and have disparate poverty rates, educational levels, and other socioeconomic characteristics (example: an average of 14% of "Asians" live in poverty, but rates are much higher for Cambodians (43%), Hmong (64%), and Laotians (35%)).[16] Furthermore, there are significant subgroup differences in health behavior between different AA groups; for instance, a California survey from 1990-1991 reported that the rate of smoking was 35.8% for Korean American men, 20.1% for Japanese Americans, and only 19.1% for Chinese Americans,[17] while the national reported average of smoking rate for "Asians" in 1990 was 13.9%.[18,19]

CERVICAL CANCER AND THE PAP TEST:

Cervical cancer is the second most common cancer for women in the world, affecting nearly 500,000 women each year. Its incidence rate is only less than that of breast cancer and it is a leading cause of cancer-related death in women in underdeveloped countries, causing nearly 190,000 deaths annually in the world.[20,21] Cervical cancer not only causes a substantial life loss but also creates a big burden on society's economy. The most effective way to reduce life and economic loss is to diagnose and treat cervical cancer at an early stage. Early screening and treatment programs have been effective in preventing precancerous cells from becoming pathological. The Papanicolaou test, colloquially known as a Pap smear or Pap test, is a cytology screening test that detects precancerous anomalies in the cells around the around the opening of the cervix (*cervical os*). The Pap test has dramatically reduced cases of cervical cancer; in some developed countries the test has reduced the disease burden by 80%.[22]

Specific to the United States, evidence also suggests that annual Pap smear screening is related to lower cervical cancer rates for women in the US.[23,24] Despite this, the latest cancer incidence and mortality patterns among specific AA groups indicate that cancer is the leading cause of death for AA women;[25,26] and cervical cancer is the most common cause of death for Southeast Asian and Vietnamese women.[25-28] We also know that prevalence of cancer screening in AA women is among the lowest cancer screening rates of all racial groups in the United States.[29,30] In 2003, 67.8% of Asian American (not including Pacific Islander) women reported having a Pap test within the past three years compared to 79.1% of White women, 82.8% of Black women, and 84.3% of Native American women.[31] Other statistics in the literature show that 22%-81% of different ethnic groups of Asian American women over 18 years of age reported receiving a Pap smear in the last 3 years.[32-35] Thus, the cervical cancer screening rates for Asian women fall short of the Healthy People 2000 guidelines, which aim for 85% of US women to receive Pap smears in the last three years and Healthy People 2010 which aims for a 97% screening rate.[35-37]

POSSIBLE BARRIERS TO SEEKING GYNECOLOGICAL SERVICES:

Asian American women seem to experience similar barriers to Pap screening as other minority groups such as inadequate knowledge and lack of sources of usual care.[38-40] However, given that a majority of Asian Americans are foreign born, or have foreign-born parents/guardians, they are likely to experience unique linguistic and cultural barriers to Pap screening.[8,39,40] Currently, very few resources for gynecological services are available that are linguistically and culturally accessible by many recent immigrants and/or refugees in the United States. Thus, while it is common knowledge for many people that gynecological screenings are effective in preventing/detecting cervical cancer before it spreads, this knowledge may not be relayed to the diverse Asian American community where cultural beliefs and linguistic isolation are common barriers. In fact, according to "Diverse Communities, Diverse Experiences: The Status of Asian Americans and Pacific Islanders in the U.S.," an analysis of Census 2000 data published by the Asian and Pacific Islander American Health Forum, 73 percent of Asian Americans spoke a language other than English in their homes.[41] This rate is four times higher than the national average of 18 percent and more than 12 times the rate for Whites.[41] Prior research also shows that Asians have different views and practices in health care than Whites.[40,42-44] For example, traditional Chinese emphasize self-care and believe that illness is a result of personal fate or luck. Moreover, we do not specifically know why Asian groups are not getting screened. Data are either lacking or studies contradict each other.[35,38-40,43,45]

SPECIFIC AIMS:

The purpose of this study is to assess the knowledge, attitudes, and behaviors related to the Pap smear test among South Asian American women. South Asian, for this study, included people from Bangladesh, India, Pakistan, and Afghanistan [See Appendix A]. Primary qualitative data collected in Atlanta, Georgia will be analyzed to generate themes and recommendations for future research. This thesis will:

1. Review existing literature on cervical cancer and screening rates in Asian Americans
    a. Highlight screening rates, screening methods, and barriers/facilitators to screening.
2. Utilize social construction, the decisional balance construct from the Transtheoretical Model, and constructs from the Health Belief Model to understand the barriers and benefits to receiving Pap tests.
3. Explore themes related to barriers and facilitators in seeking gynecological exams for South Asian American women-a group that has been largely excluded from cancer research in the United States.

RESEARCH QUESTIONS:

Specific research questions include:

- What is the *worldview* of South Asian women regarding cervical cancer?
    - Specifically, how do young unmarried US-Born South Asian women perceive their vulnerability and susceptibility to cervical cancer?
- What do young, unmarried, US-born South Asian women see as the *pros/cons* of getting gynecological exams?
- What barriers and facilitators exist for young unmarried South Asian women to getting gynaecological exams?

SIGNIFICANCE AND RATIONALE FOR THIS STUDY:

Research is needed to determine the cervical cancer screening practices of young unmarried South Asian American women. It is necessary to assess their screening rates and identify potential barriers to being screened, should they exist, since cancer is a major cause of death for Asian women.[12,46,47] This is important to examine because sex before marriage is a taboo subject in South Asian culture. If people in the South Asian community knew that young unmarried women received a Pap smear test before marriage, this could lead to stigmatization of these women. Gender roles of women, as dictated by culture, make it so that young unmarried women in the South Asian culture are not "touched" before marriage. Culture seems likely to play a role in how and when these women would seek out Pap smear tests; in that, sexual activity is viewed as the only reason to seek gynecological care.

This study may have clear implications for designing a social marketing campaign for Pap smear tests that is both culturally appropriate and relevant to South Asian women in the United States. This study will provide information on "pros and cons" of getting a Pap smear test as well as understanding barriers to getting the test. It will provide information on how South Asian American women view Pap smears and whether cervical cancer is a major problem in their communities. It may identify strategies that young unmarried South Asian women believe are key to increasing receipt of Pap smear tests in their population (such as religious-related activities, normalizing dialogue on cervical cancer and gynecological exams inside and outside of their communities, etc).

Additionally, findings from this study may indicate to what extent research is needed on young unmarried South Asian American women to design necessary interventions and messages to motivate increased uptake in accessing and receiving Pap smear tests. The results may also indicate important perceptions regarding cervical cancer and Pap smear tests that future research could investigate and refine.

FOR FUTURE RESEARCH:

Findings from this study may indicate to what extent research is needed on young unmarried Asian American women to design necessary interventions and messages to motivate increased uptake in accessing and receiving Pap smear tests. The results may indicate important perceptions regarding cervical cancer and Pap smear tests that future research could investigate and refine.

CHAPTER 2: LITERATURE REVIEW

LITERATURE REVIEW

INTRODUCTION:

Cancer is the second leading cause of death after heart disease and is responsible for one in four deaths in the United States.[48] It is estimated that there were 1,529,560 new cancer cases and 569,490 deaths in the United States in 2010.[49] When deaths are aggregated by age, since 1999 cancer has surpassed heart disease as the leading cause of death for persons younger than 85.[50]

Cervical cancer is the second most common cancer to afflict women in the world; its incidence rate is only less than that for breast cancer. It is a leading cause of cancer-related deaths in women in underdeveloped countries. Worldwide, approximately 500,000 cases of cervical cancer are diagnosed each year and about 190,000 die annually, about 78% of which occur in developing nations.[20,21] Even though widespread cancer screening programs and education have reduced the prevalence of cervical cancer in the US, it remains a significant health threat to American women. In 2010, the American Cancer Society estimated 12,200 new cases of cervical cancer would be diagnosed and 4,210 new deaths would occur from cervical cancer.[48]

Cancer is also a significant health problem in Georgia. It is estimated that there are 33,500 newly diagnosed cases of cancer and about 13,910 deaths from cancer annually in the state. Cancer is the second leading cause of death among adults and the third leading cause of death for children between the ages of 1 and 19 in Georgia.[51,52] Troublingly, one in two men and one in three women in Georgia are expected to be diagnosed with cancer in their lifetimes. Due to this high incidence rate of cancer, it is possible that cancer has touched virtually every Georgia family.[53]

In Georgia, cervical cancer is one of the main threats to a woman's health. During the years of 1990 to 2000, over 410 cases of cervical cancer were reported annually to the Georgia Comprehensive Cancer Registry and from 1997 to 2001, about 120 Georgia women died each year from cervical cancer.[54] In 2004, the incidence rate of cervical cancer in Georgia was 9.6/100,000, which was slightly higher than the national average of 9.2/100,000.[55] The mortality rate of cervical cancer was 2.8/100,000 which was also slightly higher than the national average of 2.7/100,000.[55] Therefore, cervical cancer can be considered a serious public health issue in Georgia.

BIOLOGY OF CERVICAL CANCER:

THE UTERUS AND THE CERVIX

The brief discussion of the anatomy of the uterus and the cervix allows for further understanding of cervical cancer. A normal uterus is thickly walled and hollow, with the cervix comprising almost one-third of its structure.[56] The cervix is located at the lowest part of the uterus and is made up of dense tissue.[56] The cell types in the vagina (squamous epithelium) and those in the uterus (columnar epithelium) meet at the external cervical os, in the area known as the squamocolumnar junction (SCJ). This area is the focus of interest here, because 99.7% of cervical cancers originate from the SCJ.[56]

As a woman goes through puberty, the SCJ becomes exposed to the exocervix. As she ages, the SCJ moves inward and creates an expanding transformational zone. Pre-cancerous lesions originate in this area as it is most susceptible to infection while cells go through this natural transformation. Moreover, the SCJ in postmenopausal women receded into the endocervix making visual inspection ineffective.[56]

CAUSES OF CERVICAL CANCER

It is well established that infection with certain strains of HPV is one of the strongest risk factors for cervical cancer. This cancer, linked to infection with HPV, can be detected in its early stages with several methods and is considered largely preventable to a degree.[56] There are three steps of cervical carcinogenesis. Primary prevention, with the use of a condoms or the HPV vaccine, targets the first step by blocking the initial infection of the cervix with HPV. Secondary prevention, such as screening, occurs at the second and third stages when pre-cancerous lesions are detected and removed. Precancerous cells can regress spontaneously into normal cells unless the infection is persistent and leads to invasive cancer.

HUMAN PAPILLOMAVIRUS VIRUS (HPV)

HPV infects the genitalia through direct skin-to-skin contact-infection can be facilitated through an increase in epithelial microabrasions. Risk factors for HPV infection are listed below in Table 1. Biologically-based risks are often from co-infection with HIV. Behaviorally-based risk factors include sociocultural and economic factors.

Table 1: Risk Factors for HPV Infection and Persistence (adapted from Dempsey, 2008, pg. 3)[57]

BIOLOGICALLY BASED	**BEHAVIORALLY BASED**
Host Factors	**Sexual History-Related Factors**
Immunosupression	Lifetime number of sex partners
HIV infection	Recent new partner
Coinfection with other STDs	Older sex partner
Micronutrient deficiencies	Oral contraceptive use
Genetic polymorphisms	Pattern of condom use
Age at exposure to HPV	Parity
Age at first menarche	Partner's number of partners
	Marital status
Viral Factors	**Substance Use-Related Factors**
HPV type	Heavy alcohol use
Coinfection with multiple HPV types	Sex while impaired by alcohol
Viral load	Current or previous cigarette use
	Current or previous illicit drug use

HIV, human immunodeficiency virus; HPV, human papillomavirus; STD, sexually transmitted disease

HPV Types

Out of over 100 types of HPV identified in humans, approximately 30 to 40 have been found in mucosal epithelial, the majority of which are considered low-risk.[58] There are 14 oncogenic, or cancer causing types of HPV. The most prevalent (HPV-16) causes squamous cell carcinoma and accounts for more than half of all cervical cancers. HPV-18 causes adenocarcinoma- a deadly form of cervical cancer that still remains largely undetected by cytology and visual screening methods. HPV-18 alone accounts for 20% of cervical cancers. Less common types (HPV 31, 35, and 45) are thought to make up around 30% of the cervical cancer burden in the United States.[58] Understanding the types of HPV and their individual contribution to cervical cancers can inform the physical and educational aspects of primary prevention. Educating the public on the low probability of detecting type 18 with secondary methods of prevention (i.e., screening) until it has become invasive may inspire them to seek a primary method of prevention, such as condom usage or use of the HPV vaccine.

Prevalence

HPV is the most common sexually transmitted infection (STI) worldwide. Kahn (2009) estimates 80% of the U.S. population will experience an HPV infection during their lifetime and that more 24.9 million women are currently infected with at least one type of HPV.[59] Studies demonstrate that an infection is present in 25% to 30% of women 14-59 years old, with prevalence peaking around 24 years of age.[58,60] Other studies found similar levels of prevalence for all types of HPV, but the high-risk types HPV-16 and HPV-18 were found in only 1.5% and 0.8% of study populations.[61] The key element of infection with high-risk types is not their prevalence, but the persistence of those infections that can cause precancerous lesion leading to subsequent cervical cancers.[58]

Incidence

Transmitted through both sexes, the highest incidence of HPV infections fall on women through the manifestation of cancers and warts. Winer et al., (2003) followed 603 female university students at the University of Washington between 1990 and 2000. At four-month intervals, vulvovaginals samples were collected and tested for HPV DNA. At 24 months, the incidence of first-time infections was 32.3%.[62] The authors found that the cumulative risk for women with only one male sexual partner started at 28.5% in the first year and increased to almost 50% by the third year, suggesting that most sexually active people are at risk for some type of HPV infection regardless of their number of partners.[63]

Prevention

HPV infections of the cervix are frequently asymptomatic, leading the general population to have a decreased concern for preventive screenings, but prevention efforts can decrease the incidence of any HPV infection.[64] A nested study by Winer et al. looked at condom use and the risk of HPV infection among 82 women who had their first partner within the timeframe of the study or two weeks prior to the study. The authors found that the incidence of 37.8 per 100 patient-years at risk for women whose partners used condoms all of the time. For women whose partners used condoms less than 5% of the time, and infection incidence of 89.3 per 100 patient-years at risk was observed. The authors found that consistent condom use reduced the incidence of cervical and vulvovaginal HPV infection, although it did not provide absolute protection.[64] Prevention of HPV infection can decrease associated morbidity and mortality, but prevention efforts require more than just condom use and education to be fully effective.

HPV Vaccines

A vaccine against HPV infection provides primary protection. The Federal Drug Association has approved two vaccines that protect against HPV infection. *Gardasil* (by Merck) is a quadrivalent vaccine that protects against HPV types 6, 11, 16, and 18. The vaccine provides protection against 70% of cervical cancers and 100% against genital warts (by including types 6 and 11). *Cervarix* (by GSK) is a bivalent vaccine that protects against types 16 and 18. Both vaccines are administered in a 3-part series that occurs over nine month period. In terms of efficacy, both vaccines have been shown to be “effective” in preventing around 92-98% of infections of HPV types 16 and 18.[65]

Due to the relative newness of these vaccines, the length of protection against HPV infection is unknown, though the current evidence shows at least five years effectiveness. Olsson et al., in a subset of 241 women ages 16-32 years enrolled in a placebo-controlled trial, performed an anamnestic challenge to antibodies to the quadrivalent vaccine out to 61 months and showed a sustained antibody response.[66] Studies are currently pending on the effectiveness of one or two administrations out of the three of the vaccine with the potential to reduce the number of required doses. Despite the recent release of these vaccines, the American College of Obstetricians and Gynecologists (ACOG) recommend the vaccination against HPV for all women ages 9-26 years old.[58]

THEORETICAL ORIENTATION

SOCIAL CONSTRUCTIVIST THEORY:

Although Asian groups are heterogeneous (especially in regards to language, culture, and religious beliefs), common norms regarding the central position of family, family influences, respect for elders, etc. tie them closely to one another. Literature and personal experiences have proved that most Asian women's worldviews are shaped largely by culture, religion, and their language.[67] Thus, studies addressing populations other than those of interest (South Asian women), may be helpful in informing future research.

Community-based-participatory-learning work by the World Bank, UNDP, WHO, and Aga Khan University all have proved that "subordination of women was linked to religion and 'culture'; controlling her movements, beliefs, and actions."[68-70] In addition, this work found that a South Asian women's knowledge about health and health issues came from talking to their friends and family, rather than from doctors, personal exploration, or other health "official;" and that their husbands were ultimate deciders for their health decisions.[70] Therefore, as culture may play a large role in shaping these women's beliefs and perception, as might language, the Social Constructivist theory allows for exploring regardless of brute facts. According to Patton, "Social Construction, or constructivist philosophy, is built on the thesis of ontological relativity, which holds that all tenable statements about existence depend on a worldview, and no worldview is uniquely determined by an empirical or sense data about the world" (Patton, 2002, pg. 97).[71] People's beliefs and worldview's are socially engendered. For instance, that a river is a *river* (as opposed to just another undifferentiated mass of water) is socially engendered, and not a "brute" fact. That the concept of a river is almost universally present in all human languages reflects an almost universal consensus, but this does not make it an objective reality. This goes for all other "real" objects and events: trees, rain, accidents, etc. Thus, this leads to the view that all reality is social construction based on a narrative (discourse rooted in consensus).

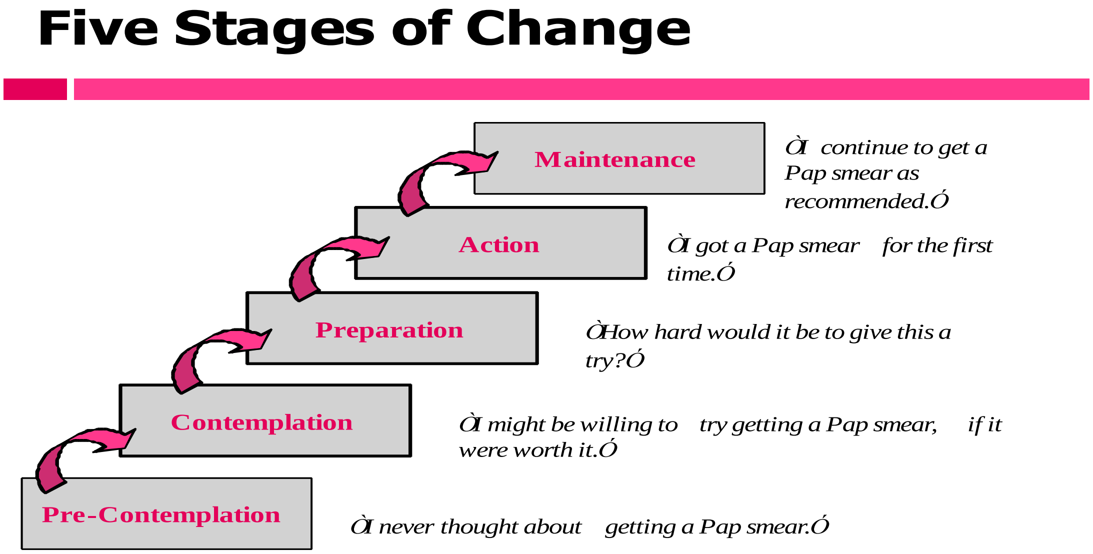
The benefit of this theory is that it allows for "capturing and honoring multiple perspectives; attending to ways in which language as a social and cultural construction shapes, distorts, and structures understanding; how methods determine findings, and the importance of thinking about the relationship between the investigator and the investigated, especially the effects of inequitable power dynamics---and how that relationship affects what is found" (Patton, 2002, pg. 98).[71] Essentially, this theory allows for the inclusion of culture and language; and for uncovering the ways in which individuals *perceive* their social reality.

THE TRANSTHEORETICAL MODEL:

The Transtheoretical Model (TTM), also known as Stages of Change Model, states that behavior change occurs in a series of incremental stages.[72] The "stages of change" are core constructs within this model, and represent how individuals attempt to make decisions and "changes" in their behaviors (see Figure 1). Since the TTM has been historically examined in the context of addictive behaviors, such as smoking, the stages and the process behind moving across/relapsing to stages have been touted as conscious or unconscious strategies that enable individuals to enact behavioral change.[72] However, it has also been used extensively to study health promotion behaviors such as exercise, colon cancer screening and mammography use.

For mammography and Pap smear use, the TTM has been utilized to look at readiness to change, pros/cons to the behavior (i.e., getting screened for cancer) and at factors weighing decisions to the behavior (i.e., getting screened for cancer).[73] This is a unique approach to looking at Asian women (as a whole) because Asian Americans have rarely been included in cancer studies.

Figure 1: The Stages of Behavior Change (adapted from Prochaska, et al., 1992 p. 148)



Integrated into the TTM's stages of behavior adoption is the decisional balance construct, which refers to an individual reviewing both the positive and negative aspects of a behavior and identifying expected gains and losses that would result from a behavior change. These positive and negative aspects are referred to as ‘pros’ and ‘cons’, which are similar to the Health Belief Model's concepts of perceived benefits and barriers. Decisional balance is a summary index derived from two variables: the pros (benefits) minus the cons (barriers) of the target behavior. Studies have found significant correlations between perceived benefits and barriers and mammography use and, to some extent, with Pap smear tests in East Asian women.[43,74-76] Additionally, perceived benefits, perceived barriers and perceived risks have been found to be associated with the stage of mammogram adoption.[76]

Therefore, the decision to take action to change is based upon the relative weight given to pros (advantages of changing behavior) and cons (negative aspects of changing behavior; i.e., obstacles to change). Decisional balance can be visualized as a scale, with the negative aspects of changing (costs) on one side and the positives of changing (benefits) on the other.[77] If the sides are equally balanced, the scale will not “move” (i.e., make a change). On the other hand, if you add more weight to either side, an imbalance will occur and the side with the most weight will drop down. In the pre-contemplation stage of change, the cons always far outweigh the pros because people do not even recognize a need to change at this point. As they become more aware of the advantages of changing in the contemplation and preparation stages, the pros gradually increase in importance until they eventually outweigh the cons prior to taking action.[75,77] At the maintenance stage, it is important to keep decisional balance weighted toward the pros to prevent a relapse (e.g., a reversion back to not receiving Pap smear tests).

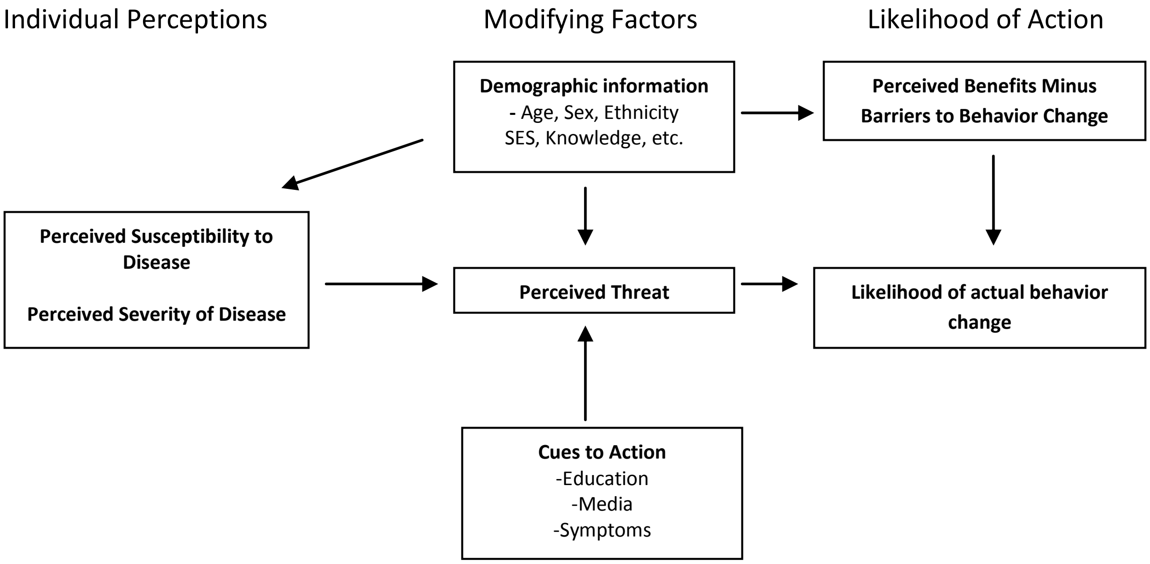
THE HEALTH BELIEF MODEL:

The Health Belief Model[78] (HBM) is a psychological model that has been used since the 1950s to explain and predict health behaviors. It was originally created by social scientists working with the US Public Health services to understand why people sought x-ray examinations for tuberculosis, but has been used to explain mammography and other health behaviors for a variety of ethnic and racial groups.[78-81] The Health Belief Model is made up of three categories: Individual Perceptions, Modifying Factors, and Likelihood of Action (see Figure 2 for an image of the HBM). These categories are used to describe the constructs that affect a person’s likelihood of seeking care. In addition, the HBM proposes that a person’s health-related behavior depends on the individual’s perception of four critical areas:[78]

- The perceived severity of the potential illness;
- The perceived susceptibility to that illness;
- The perceived benefits of taking (preventive) action; and,
- The perceived barriers to taking the (preventive) action.

A person’s health behavior would be influenced by person’s perception of a threat posed by the health problem and the value associated with actions aimed at reducing the threat.

Figure 2: The Health Belief Model (adapted from Rosenstock ,et al. 1974)



COMBINATION OF THE TTM, HBM, AND SOCIAL CONSTRUCTIVISM:

Studies showed that the TTM was useful and applicable to understanding Asian women's (Korean, Chinese, Malaysian, Vietnamese, Burmese, and Indian) stages of Pap smear adoption,[74,75,83] while other studies denied their applicability.[32,33,44,79] All the studies stated that the TTM may be more efficacious in explaining stages of Pap smear adoption or other cancer screening adoptions when paired with another theoretical framework (HBM), or when combined with a culturally sensitive theory, such as social construction. Thus, to get at understanding adoption to cervical cancer screening, the TTM provides a basic framework, but it may not capture cultural sensitivities without the help of other theories. For this reason, there is a focus on three separate but complementary theories. In light of the combination of theories, this study will use qualitative methods to effectively get at understanding adoption of cervical cancer screenings in South Asian women. The proposed research may also be used to explore the usefulness of HBM constructs and the construct of decisional balance from the TTM, in an ethnically diverse and culturally diverse population.

INTRODUCTION TO MAMMOGRAPHY AND CERVICAL CANCER SCREENING STUDIES

It is important to look at mammography and breast health practices for Asian Americans, since breast and cervical cancer are among the top cancer illnesses that affect Asian women.[25] Since most of the studies that examine Asian American health behaviors are recent, it can be difficult to find research and literature that focuses solely on Asians and Asian subgroups in the United States. For instance, the study published in 2009 by Wu and colleagues was one of the first studies to ever look at mammography-related beliefs using the TTM by four separate groups of Asians.[83] In addition, a small number of studies have been done to examine the degree to which South Asian American women understand cervical cancer practices, and less than a handful of studies have utilized theoretical frameworks (such as TTM and HBM) to study this specific population and cervical cancer screenings.[84,85] Therefore, research on mammography screenings and cervical cancer screening that focused on non-South Asian groups were also included in the literature review.

TRANSTHEORETICAL MODEL AS A FRAMEWORK:

Much of the literature dealing with Asian Americans and barriers to health screenings (particularly breast cancer) makes use of the TTM as the theoretical base. For example, Wu et al. applied the TTM to examine the relationships between stages of mammography adoption and mammography-related beliefs while controlling for socio-demographic factors. The study consisted of a convenience sample of 315 participants from four populous Asian ethnic groups in Michigan (109 Vietnamese, 51 Chinese, 36 Koreans and 119 Filipinos). To determine each participant's stage of mammography adoption, the study utilized the five stages of mammography adoption (defined previously by other studies): (1) pre-contemplation—women with no prior mammogram and are not planning to get one in the coming year, (2) contemplation—women with no prior mammogram and are planning to have one in the coming year, (3) action—women who had a prior mammogram with age-specific interval and are planning to have another one in the coming year, (4) maintenance—women who had two or more mammograms on schedule and are planning to have another one in the coming year and (5) relapse—women who have had one or more mammograms in the past but are not planning to have one in the coming year.[83] Common barriers for this sample of Asian participants included lack of recommendation from doctor, limited access to transportation, lack of insurance, and modesty issues. The study was cross-sectional, and was therefore unable to provide any significant information on the relation between risk perception of the disease, attitudes towards breast cancer, and of perceived barriers/costs and benefits to mammography. Nonetheless, this study represents one of the first attempts at assessing differences in mammography-related beliefs in Asian ethnic groups.

Tung et al. examined cervical cancer screening in Vietnamese American women.[74] They were interested in finding the Pap smear screening behaviors of Vietnamese-American women, and also to examine whether constructs (stages of change, self-efficacy and perceived benefits/barriers) from the TTM were applicable to Vietnamese-American women relative to Pap testing. They did find significant results of differences on self-efficacy across the stages; surprisingly, self-efficacy was higher in pre-contemplation stage than in later stages- suggesting that this usage of the TTM may not be suitable in studying cervical cancer in Vietnamese American women. Yet, their cross sectional design, small sample, and method of sampling (snowballing) limited the generalizability of the results.

To get at understanding adoption to cervical cancer screening, the TTM provides a basic framework, but it may not capture cultural sensitivities without the help of other theories. So little is known about barriers in getting a Pap smear test for South Asian women that it is important to examine *how* and *why* they choose/choose not to get a Pap smear. This involves the construct of decisional balance from the TTM.

THE HEALTH BELIEF MODEL AS A FRAMEWORK:

According to the HBM, health behavior is a function of knowledge, attitudes and perceptions.[78] This theory states that there are two important factors that determine the likelihood of a person adopting the recommended health behavior. An individual's belief in his/her susceptibility and severity of the disease leads to health positive behavior. The other factor that controls possibility of behavior change is the person's belief that benefits of positive health behavior, in this study, getting a Pap smear, outweighs the barriers. Understanding South Asian American women's views regarding benefits of screening and barriers to getting screened will help in planning necessary interventions.

Few studies have been done to examine the degree to which South Asian American women understand cervical cancer practices, and even fewer studies have utilized the HBM to study this population and cervical cancer.[84,85] Thus, this literature review includes studies that focused on mammogram screening practices for South Asian Americans.

Several studies documented the knowledge, beliefs, and attitudes of Asian American women regarding breast cancer and screening for early detection.[86-89] The findings suggested that lack of time, knowledge, transport, embarrassment and inability to understand English language were some of the barriers. Higher socioeconomic level, a physician's recommendation to obtain a mammogram, longer duration of residency in the Unites States and greater acculturation were associated positively with screening. In a study of health beliefs and practices related to breast cancer screening in Filipino, Chinese and Asian lndian women, results showed strong influence of ethnicity on perceived susceptibility and seriousness.[90] The study also found that each ethnic group reported distinct barriers for getting mammograms. Chinese participants identified "I do not need mammogram if I feel ok" as a barrier. For Filipino women "waiting time is too long" was an important barrier, whereas for Asian lndian women" do not know where to get a mammogram" was a major barrier. This study involved 125 Asian American women out of whom 47 were Filipinos, 40 were Chinese, and 38 were Asian lndian women. A self-administered questionnaire was used to evaluate participants' knowledge, beliefs, and screening practices.

Studies that have utilized the HBM to also understand patient behavior around cervical cancer screening, specifically Pap smear receipt, have found that the HBM can serve as a good predictor of an individual's likelihood of getting screened.[91-93] The trend in the HBM literature is that *knowledge* is one of the best predictors of health-seeking behavior and that healthcare providers are one of the most important influencers in passing on that knowledge to their patients. For instance, in a study by Lee et al., eight focus groups with Korean women were conducted to understand their knowledge, attitudes, and barriers for cervical cancer screening using HBM as a framework. Focus group discussions revealed that there was a lot of misinformation and lack of knowledge about cervical cancer.[28] Participants stated that medical advice and education would influence them the most to undergo a Pap test.[28] Other structural barriers involved economic reasons and time factors along with language barriers.[28]

In another study by McPhee, et al. (1997) education levels were found again to be associated with cervical cancer screening in women.[94] Knowledge about cancer and preventative health was shown to be an important factor in predicting screening behaviors for Vietnamese American women. Participants who were less educated were less likely to be knowledgeable about screening practices, making them less likely to seek gynecological services or viewing preventive care as useful or relevant to their health.[94]

A cross-sectional study by Leung, et al. used a survey design with 385 Chinese women.[95] The study found results that support the HBM: women's knowledge on cervical cancer and risk factors affect their perception of the severity of illness and their own susceptibility to cervical cancer.[95] Such knowledge was shown to be significantly related to participants' engagement in screening. The authors recommended that health care providers take into account women's knowledge and health perception when developing a cervical screening program. The study by Leung, et al. also found that women educated to higher levels were more likely to have a better knowledge of cervical screening and cervical cancer, leading to their participation in cervical screening.[95] Additionally women with a higher level of education were more likely to gather new information by themselves, or have a quicker access to information.[95]

Generally, the literature on cervical screening that utilized the HBM identifies several components of the model that are pertinent to the study population. A few studies linked lower perceived risk of contracting cervical cancer with a lower perceived threat of developing cervical cancer as the main barrier to cervical cancer screening in women.[93,96] Other studies found that perceived benefits and barriers were more significant in predicting a woman's decision to get screened for cervical cancer.[86,97]

FACTORS THAT ASSIST WITH CANCER SCREENING IN ASIAN AMERICANS:

Historically, US based research examining health care and race or ethnicity mainly has been limited to four categories: White, Black, Hispanic, and other. Only in the last decade has there been research focusing on Asian Americans. However, most studies group all Asians together, despite the large socio-cultural and economic differences between subpopulations.

Asian communities face unique challenges in accessing and utilizing health care services. As stated in the introduction, language and other socio-cultural factors are barriers to learning about and seeking preventive health services.[8,10] The few studies that have looked at Asian populations have found several factors that tend to influence health-seeking behaviors for South Asians. In seeking preventive health services, such as a Pap smear, factors such as: education, knowledge, cultural barriers (taboos/stigma), availability to the usual source of care, and marital status were highlighted in the literature.

CULTURAL INFLUENCE ON HEALTH SEEKING BEHAVIOR

Culture is defined as the "thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups" (Office of the Ministry for Health, 2001, p.4). Literature suggests that South Asian immigrants to the United States have brought with them a strong sense of their native culture and customs.[99] In keeping with this, researchers have shown that South Asian ethnic identity development has tended to adhere to the "alternation model of acculturation".[100,101] In particular, this group has been noted to selectively acculturate by holding onto core values (e.g., family, food preferences, and religion) at home, but make concessions in the workplace (e.g., as noted by adopting Western clothing as opposed to wearing traditional garments).[102] Research also suggests that ethnic group approval plays a significant role in Indian, Pakistani, Afghani, and Bangladeshi families preserving their cultural identity.[103] In their interviews with women whose parents had immigrated to the United States in the 1960s and 1970s, Inman, et al. (1999) noted gender pressures experienced by these women in preserving their cultural identities.[103] For instance, being perceived as credible within the community was associated with maintaining and perpetuating traditional behaviors. The women felt that engaging in these behaviors would prevent "others [in the community] from pointing a finger at my family" (Inman, et al., 1999, p. 36).

Other studies have noted that communities with selective acculturation patterns and in-group support tend to have higher ethnic identity retention than communities without such patterns and support.[104] Traditionally, South Asian families have been greatly influenced by a patriarchal, joint family system, whereby grandparents and other elders play a significant role in socializing children into practicing culturally expected behaviors. South Asian parenting practices typically include authoritarian parenting styles[105] and familial bonds and solidarity (e.g., importance of family and respect for elders).[106] Because of the history of a caste system in the Asian Indian culture, marriage within the same community and religion is encouraged.[107] Dating is expected only as a step toward marriage, and premarital sexual relations are generally considered “unacceptable.”[107,108] Finally, because language is a means of transmitting cultural values, speaking Urdu, Hindi, or other South Asian dialects at home plays an important role in parenting practices.[105]

Research also suggests that, similar to other immigrant parents, South Asian immigrants continue to emphasize specific values and goals for their second-generation children—values that were instilled during their own upbringing (e.g., pride in cultural heritage, strong dependence on family, etc.).[107] However, through the process of immigration, South Asian parents may experience a sense of displacement when the comfort and confines of their original environment are at odds with the new environment.[109] For instance, South Asian parents who immigrated to the United States during the 1960s and 1970s might have been particularly susceptible to these dilemmas.[110] Living in a culturally incongruent community, first-generation parents perceive themselves as having the sole responsibility of imbuing cultural values to their children, which may result in restrictive behaviors by the parents.[100] Within this context, actively reproducing the traditional culture and establishing a cultural identity in their children become important parenting goals for these immigrants.[108] Dynamics surrounding immigration and family experiences could significantly influence how parents socialize their children.[110] Thus, understanding South Asian parents’ immigration experiences becomes imperative in contextualizing second-generation experiences and need to be included in any research or discussion around health seeking behaviors.

For example, cultural barriers have been shown to have a strong impact on breast health awareness.[40,82] Many Asian women have reported that they do not practice breast self examination due to the taboo about touching oneself,[82,111,112] embarrassment about discussing intimate parts of the body, or even by being examined by a male physician.[111] This is important, since symbolic meanings of the body may essentially be related to a person's experiences and perceptions of health, illness, and health care.[111-113] This may be the case with sexual organs such as breasts and cervix; in several traditional Asian cultures, sexuality, especially in women, is associated with taboos.[113] Pakistani women living in the UK and Pakistan were shown to regard breasts and other sexual organs, such as the vagina and cervix, as "hidden organs" that should not be revealed.[111] Thus, it would be considered taboo to openly discuss with anyone and personal modesty is expected.[111-113]

In an article about Korean American women's beliefs about breast and cervical cancer, Lee, et al. found that Korean women were aware of the cultural prohibition against openly speaking about their breasts or cervix.[86] It was also found that most of the women interviewed for the Lee, et al. study "identified the cultural practice of describing breasts in indirect and modest ways…and it is shameful to emphasize breasts or even to have big breasts" (Lee, et al., 2007, p.718).[86]

Two other studies looked at the inclination of Asian Americans to avoid "losing face" or shaming oneself or their families.[114,115] These studies found that Filipino Americans and other Asian American groups avoid "help-seeking behavior" due to loss of face.[114,115] This cultural influence goes deeper than it appears at the surface. In Chinese and Japanese, a wealth of linguistic data pertaining to countenance, emotions and *mianzi* (face in a figurative sense, as in losing face) abounds.[116] Wang and Fischer (1994) have tabulated more than 150 words for varieties of guilt, shame and embarrassment in Chinese, but only a few dozen at most in

English.[116] As stated earlier, the importance of language in transmitting the culture and how it ties to identity is important to understanding Asian populations in the United States and may be important to changing health education and health messages for Asian Americans.

EDUCATION AND KNOWLEDGE ON HEALTH SEEKING BEHAVIOR

Research that focused on health education to raise knowledge and awareness of Pap smear testing in Asian women provided interesting results. In a one-year prospective cohort study by McAvoy and Raza (1991), 737 randomly selected Asian women ages 18-52 years old in Leicester, England were assigned to four randomly assigned groups: they were visited and shown a video; visited and shown a leaflet and fact sheet; mailed a leaflet and fact sheet; not contacted at all. About 5% of the control group (not contacted) had a Pap smear compared with 11% of those who had just received a leaflet and fact sheet in their mail. Those who were visited and shown a video or a leaflet, about 30% who saw the video and 26% of the leaflet got a Pap smear test. Those who watched the video with the research assistant (41%) were more likely to get a Pap smear test than those who watched the video alone (64%). Therefore, it was shown that “personal instruction was the best form of education” (McAvoy, 1991, p. 835).[117] Mailing the fact sheet and leaflet was shown to have a really poor response rate, especially when compared to non-Asian populations.[117]

In a study by Lam and colleagues, a coalition of 11 organizations in Santa Clara County, California designed and implemented a media education (ME) campaign and a lay health worker outreach (LHWO) program to increase Vietnamese-American women's cervical cancer awareness, knowledge, and screening.[118] Ten lay health workers (LHWs) each recruited 20 women who were randomized into 2 groups: 10 to a Lay Health Worker Outreach program (LHWO)+ Media Education (ME) campaign, and 10 to Media Education (ME) campaign alone. Participants completed pre-and post-intervention questionnaires. Overall, at post-intervention, significantly more women in the combined LHWO+ME group understood that HPV and smoking can cause cervical cancer.[118] At pre-intervention, 32.8% of the LHWO+ME group had incorrectly selected heredity as a cause, and 67.2% had correctly not selected this item. By post-intervention, there was a net increase to 93.4% of those who did not select heredity. The change in correct answers versus incorrect answers was significant. By contrast, among the ME group at pre-intervention, 21.9% incorrectly selected heredity as a cause and 78.1% did not select it. At post-intervention, 66.7% did not select it. Only 8.6% changed their answers correctly, whereas 20% changed to incorrectly select it. In addition, the number of women who had obtained a Pap test increased significantly among women in both LHWO+ME and ME groups; however, substantially more sought a Pap smear in the LHWO+ME group.[118]

In conclusion, Lam et al. stated that, "the combined effects of the media education and lay health worker outreach increased women's knowledge about cervical cancer prevention, motivated significant numbers of women to obtain Pap tests, and motivated others to consider obtaining them. Media education alone was effective in raising women's general awareness about cervical cancer and about Pap tests, but was less effective at motivating women to obtain them." (Lam, et. al, 2003, p.521). These results were consistent with previous findings from three studies among Vietnamese Americans that media alone, while effective for increasing their recognition of, and intentions to undergo, cervical and breast cancer screening, was still less effective than a lay health worker intervention, for improving receipt and maintenance of screening.[118]

The literature thus far shows that a personal instruction or community-based approach may be effective in increasing the education and practice of cancer screening in Asian Americans.

ACCESS TO HEALTH CARE

Taylor, et al. did a meta-analysis of several studies that focused on Vietnamese women and Pap testing.[119] They found that Vietnamese women were less likely to seek preventive services due to health care access inequities.[119] According to Taylor et al, nearly any study "that examined the role of having a usual source of care and/or usual doctor in Pap testing among Vietnamese women had documented associations"(Taylor, et al, 2004, p.619). The authors also found positive correlations in studies that examined the relationship between having a female doctor and having a non-Vietnamese physicians.[119] In the case of not having a Vietnamese physician, it may tie back to cultural barriers of shame and stigma in discussing a private body part with someone of your own "community;" it may also be tied to "saving face.[119] Health insurance coverage in relation to Asian American women's pap smear testing were inconclusive.[119]

Through a survey, Kagawa-Singer and colleagues found that Vietnamese women who reported at least one doctor's visit over the last year were more likely to have also received a Pap smear test than those who did not report seeing a doctor within the last year (65% versus 43%, $p<0.01$).[120] This finding raised the idea that individuals who are more likely to seek any health care service, may also be more likely to seek preventive screenings or value their health more than others who do not seek health care services.

MARITAL STATUS ON HEALTH SEEKING BEHAVIOR

Several studies done on Asian women found that never married women had lower levels of screening participation than currently/previously married women.[44,75,84] For instance, in a study by Yi (1998), mail and telephone surveys were sent to college-aged Vietnamese women at the University of Houston to gather data on the prevalence of Pap smear screenings and to identify predictive factors that influence Vietnamese women to engage in cervical cancer screening behavior.[121] Of the respondents, approximately one-third (36.8%) reported having had a Pap smear. More than one-third (39.3%) of sexually active respondents reported never having had a Pap smear. After running a logistic regression model, marital status, sexual activity, and a belief that only married women should have a Pap smear were important predictors of prior reported Pap smear experience. These study findings suggest that some Vietnamese women appear to have the belief that cervical cancer screening is more important for married women than for unmarried women, regardless of their sexual activity.

This has also been noted in South Asian populations. For example, Chaudry et al. reported that South Asian women in the United States had greater odds of having had a Pap smear if they were married.[122] Never married women had lower levels of screening participation than currently/previously married women.[122] A mixed-methods study by Islam and colleagues in New York City also found that marital status was a significant predictor of receiving timely Pap tests.[85] This may be linked to a few things. In one study, it was found that Pakistani women who were unmarried were less likely to seek breast exams or to perform self-breast exams due to the fear of “finding out something was wrong”.[82] If a lump would be found and revealed, this would have a devastating impact on the unmarried women’s life-essentially, decreasing her marital prospects.[89] It may also be that many Asians view the gynecologist as a doctor for married and sexually active women, not for young un-married women. There were no studies that looked directly at whether that was true, but discussion sections of several articles mentioned it as a possibility.[82,84,85,89,111,112] Regardless, the existence of such misconceptions underscores the importance of offering culturally relevant cancer education that addresses related misconceptions.

BARRIERS AND FACILITATORS TO SCREENING WITHIN OTHER RACIAL AND ETHNIC GROUPS:

Studies conducted with other non-Asian racial and ethnic groups have pointed out barriers and facilitators to screening that may be similar to those experienced by Asian Americans. It is useful to examine this literature for two reasons. One, barriers to seeking cervical cancer screenings may be the same for many women, regardless of race and ethnicity in the United States. If this is the case, more research and efforts need to be carried out to address global concerns. Two, barriers to seeking cervical cancer screenings may not be the same across different races and ethnicities. Therefore, health professionals need to be educated on these differences to create and implement interventions that are culturally, linguistically, or otherwise tailored to specific populations in the United States.

Ogedegbe and colleagues (2005) conducted a qualitative study to elicit and explore the perceptions of barriers to and facilitators of colorectal, cervical, and breast cancer screening among minority women. The sample included 187 women, 44% were African American, and 51% were Latinas' with an age range of 50 to 69. To be eligible for the study, the participants had to be able to speak, read, and write in English, Spanish, or Creole, and have visited one of the community health centers. Participants were asked open-ended questions designed to explore barriers and facilitators of cancer screening behaviors. Each participant interview was divided into sections focusing on particular screening tests such as mammography, home fecal occult blood test (hFBOT), or sigmoidoscopy. Qualitative analysis of participant's response revealed three major categories of cancer screening behavior: 1) patient attitude and beliefs; 2) social network experience; and 3) accessibility of services.[123]

Results showed that attitudes and beliefs identified as barriers to cancer screening included a lack of knowledge about cancer screening or the disease cancer (patients never thought about screening, or heard of screening test) and a fear of cancer, and pain. Many of the participants indicated that part of their fear included the pain associated with the procedure, and this prevented them from having the exam or procedure. Also, the lack of symptoms (such as pain) was identified as a barrier to cervical cancer screening, and knowledge of someone who was harmed by cancer screening procedures, and discouragement from family and friends were also identified as cancer screening barriers. External barriers included cost, transportation, and location. The most commonly cited barriers to cervical cancer screening behaviors were the perception of the participant not needing the test due to good health, an absence of symptoms, and lack of knowledge. Other important barriers elicited from participant were the fear of pain, and the fear of having the test. Fear was the most commonly cited reason for not planning to have a Pap smear in the future.[123]

In another study of Latinas and African Americans by Bazargan, et al., a cross sectional survey was conducted with community-based random samples of 230 African American and Latina female heads of households chosen from three urban public housing communities in Los Angeles County, CA. The survey results found that 62% of the sample had received screening for cervical cancer within the past year.[124] Yet, 29% of the sample claimed that no health care provider ever told them that they needed a screening test for cervical cancer. For this study, 51% of Latinas and 22% of African Americans reported no screening within the last year.[124] Multivariate analysis of the data found that affordability, continuity of care, and receiving advice from health care providers regarding the Pap smear were significant predictors of up-to-date cervical cancer screenings.

We know that failure to screen with a Pap test, which often results from a lack of access to health care, is the most common attributable factor in the development of invasive cervical cancer.[24,38] Access to quality health care is often compromised among under-served minorities, particularly African-American women, Hispanic women, the uninsured, and older women.

Language, cultural and geographic factors have been identified as barriers to receipt of well-organized Pap screening services.[38] While race has been considered by some to be an important determinant of cervical cancer incidence and mortality,[125,126] some studies have argued that socioeconomic status, education, age, and other comorbidity have been shown to be better predictors of cervical cancer screening and outcome than race and ethnicity.[127-129]

One such study by Krieger, et al. included four racial/ethnic groups— Asian-Pacific Islander, African American, Hispanic, and White–demonstrated that the incidence of cervical cancer was inversely related to socioeconomic status in all four ethnic groups.[129] Another study that looked at a previous report from the National Health Interview Survey found that nearly 50% of older women (ages 50– 64 years) did not have a Pap smear in the previous three years.[130] The 2000 National Health Interview Survey reported that the lowest prevalence of Pap screening occurred among uninsured women (64.1%), recent immigrants (61.0%), and women without a usual source of health care (58.3%).[131] Disparities by level of education, family income, chronic disability, race, and ethnicity were also observed, though without as great a difference as those due to healthcare access and age.[131]

Although socio-economic status, level of education, and age may be important predictors of Pap smear use[129], cultural and attitudinal factors, such as fatalism, low acculturation, and lack of knowledge of preventive care have also been singled out as predictors to low Pap smear use rates among Hispanics, Native American, Latina, and Asian American populations.[1,10,24,41,97] Despite the argument that race and ethnicity may not be important or significant barriers to seeking cancer screenings, such as Pap smear tests, these studies may not accounting for the fact that it is difficult to separate race and ethnicity from cultural influences. As discussed earlier, cultural and linguistic factors are instrumental in shaping the identity of specific racial and ethnic minorities in the United States, such as South Asians. Thus, while

Krieger, et al. like to argue that race and ethnicity are “less significant” in predicting cervical cancer incidence[129] by treating race and ethnicity as separate categories from cultural or linguistic influences, the reality is that this demarcation is not so clear or simple.

For instance, low English language proficiency for Hispanics and Asian Americans has been consistently associated with low Pap smear use rates in several studies.[27,29,32,42,47] In addition, most Asian American populations are recent immigrants[100,102] to the United States and have reported greater ties to their culture and language than other racial or ethnic groups in the United States, with the exception of Hispanic women who also cited a strong identification to their cultural and linguistic roots.[132] In another study that looked at cross-sectional survey data from the Commonwealth 2001 Health Care Quality Survey, researchers measure cultural beliefs of Asians compared to non-Hispanic White women.[133] Non-Hispanic White and Asian American women (including Chinese, Vietnamese, Korean, Filipino, and Japanese) were included in the study. Eastern cultural views were measured by beliefs in the role of self-care and luck. Access factors (having health insurance, regular providers, and communication with providers) and demographics of patients and providers were measured. The outcome was receipt of a Pap test in the past 2 years. Asian American women had a lower rate of obtaining a recent Pap test (70%) than non-Hispanic White women (81%; $P = 0.001$).[133] More Asians believed in the role of luck and self-care and experienced access barriers than Whites ($P < 0.0001$).[133] Women with less Eastern cultural views are more likely to be recently screened than women with more (odds ratio, 1.08; 95% confidence interval, 1.00-1.16; $P < 0.05$).[133] Just this one study by Wang and colleagues (2008) illustrates how cultural beliefs and views can affect a group’s health seeking behavior.

PUBLIC HEALTH IMPLICATIONS AND SIGNIFICANCE IN STUDYING THIS ISSUE AND POPULATION:

It is important to look at South Asian American women for several reasons. One, Pap smears are effectively shown to lower cervical cancer rates in the U.S.[23,24] Two, prevalence of cancer screening in AA women is among the lowest cancer screening rates of all ethnic groups in the United States.[29.30] Three, although Asian American women seem to experience similar barriers to Pap screening as other minority groups (i.e., inadequate knowledge and lack of sources of usual care), they are likely to experience unique linguistic and cultural barriers to Pap screening.[38-41] Four, prior research has shown that Asians have different views and practices in health care than Whites.[42-44] For example, Pakistani women are less likely to go to the doctor for any ailment because they believe that "it is their duty to experience pain and suffering in silence"(Chaudhry, et el., 2007, p.373). Five, we do not specifically know why Asian groups are not getting screened.

Specifically, we know that "despite the high SES of South Asian women, their rates of Pap smear receipt were lower than national average" (Chaudhry, et el., 2007, p.377). There are little to no data on Pap smear rates for single/engaged South Asian women ages 18 years to mid-30s.[84,85] This has been attributed to the idea that only married South Asian women are getting screened, but there is no confirmation of this. Therefore, young married South Asian American women were excluded from this study because they would already be receiving gynecological services, as according to the data from the literature review.

CHAPTER III: METHODS

DESIGN AND METHODOLOGY

INTRODUCTION TO METHODOLOGY:

Asian Americans are a diverse group. Each one has its own culture, norms, and language, making it difficult to gather rich data when they are grouped together. Different barriers may exist for these groups to getting a gynecological exam. Immigrant versus first generation versus second, etc. also may have different experiences and beliefs towards cervical cancer and Pap smears. In addition, differences in age could also play a role in how these women experience a different set of barriers (i.e., older women may experience a different set of barriers than younger women). Because of the possible taboo linked to gynecological exams for single women and the scant information in the literature (scientific or otherwise), women's viewpoints and thoughts on the possible barriers/facilitators to cervical cancer screenings and perceived vulnerability to cervical cancer needed to be explored. This research was a qualitative study of women's perception of facilitator and barriers to screening. From reviewing the literature (and finding a gap), unmarried South Asian women born in the US between the ages of 18-30 years were chosen as the target study population.

QUALITATIVE OVER QUANTITATIVE METHODS STUDY:

This study used qualitative methods to effectively get at understanding adoption of cervical cancer screenings in South Asian women. Qualitative methods are better suited than quantitative methods in examining how South Asian American women view cervical cancer and Pap smear tests and understanding why they may, or may not, be receiving Pap smear tests. To understand this phenomenon it may be best to view it in its context. Therefore, little is known about the barriers and facilitators to getting a Pap smear test that quantification of Pap smear test rates is limited in nature; it is looking only at one small portion of a reality that cannot be split or unitized without losing the importance of the whole phenomenon. Qualitative methodology allows flexibility: rather than approaching measurement with the idea of constructing a fixed instrument or a set of questions, questions can emerge and change. This is important because, ontologically, there may not be a single unitary reality apart from perceptions. Since each person experiences life from his/her own point of view, each person experiences a different reality. Conducting research without taking this into account violates the fundamental view of the individual.

Understanding of individuals whose contextual factors consist of culture-bound norms and expectations is better explored through qualitative methods. The research purpose of this thesis is to explore how South Asian women view and perceive their health (specifically in relation to cervical cancer). This purpose requires data that goes beyond numbers and statistics. Qualitative methods can yield rich, in-depth detailed information that can be explored, uncovered, and understood. This approach is useful in gathering exploratory data, especially for a new area of research or with a previously unstudied/understudied population. Quantitative methods, at best, can yield correlations but cannot fully explain causes and effects. In other words, qualitative researchers are concerned with processes and "how *x* plays a role in causing *y*" while "quantitative researchers tend to be interested in whether and to what extent variance in *x* causes variance in *y*" (Maxwell, 1996, p.23).

STUDY PARTICIPANTS

Twenty South Asian American women participated in individual in-depth interviews. Interviewees were all recruited from the greater Atlanta metro area. Participants were recruited from several venues: religious establishments (such as mosques, temples, churches, etc.), South Asian shopping venues (specifically around Lawrenceville Highway in Atlanta) and at undergraduate and graduate institutions (i.e., Emory University, Georgia State University, Georgia Perimeter College). Religious establishments were chosen through internet-searches.

Personal contacts made at Asian focused community-based organizations, such as Raksha, were also tapped to recruit eligible women.

Participants chose to partake in the study by calling or emailing the PI after seeing a flyer posted for the study or hearing from others who took part in the interview. Persons who contacted the PI were screened over the phone for eligibility. Participant inclusion criteria were as follow: American-born; South Asian women; unmarried, not a widow, nor divorced; English-speaking; between the ages of 18-30 years old. Only South Asian American women were targeted for the study. South Asian, for this study, included people from Bangladesh, India, Pakistan, and Afghanistan [See Appendix A]. If eligible, the PI scheduled a date, time, and place for the in-depth interviews or called back to do so. The process was repeated until all 20 participants were recruited.

STUDY RECRUITMENT PROCEDURE

A convenience sampling strategy was used to recruit study participants. Data collection was confined to a time frame (2 months). Thus, other sampling strategies would have been more difficult to utilize. For instance, homogeneous sampling of South Asian American women would have required narrowing eligibility criteria down to religion, family city of origin, caste, economic level, etc. since there are distinct cultural differences in South Asians across these identifiers.[84] Typical sampling would have been difficult because there is not enough information or research that has been conducted in the literature to define the “average” young South Asian American woman who is not receiving a Pap smear (i.e., young, Pakistani-American, Muslim, with a boyfriend); we just know that South Asian women are less likely to receive a Pap smear test. Purposeful random sampling would also have made it difficult to recruit participants for this study. Due to the potential difficulty in getting enough participants who would be willing to talk about a sensitive topic, it was necessary to try and include all people who were eligible and willing.

Word of mouth and flyers were used as methods of recruitment. Word of mouth as a recruitment method has been used with success in studies targeting South Asians, especially as building/establishing a face-to-face relationship is necessary to engage in any dialogue with a "stranger."[101] Interestingly enough, four of the 20 participants for this study were recruited by word of mouth. Flyers were posted with information on the study (including what is the purpose of the study, length of the interview, who to contact, mobile phone and email address of the PI, and the address of Rollins School of Public Health (site of the interviews). Because of the taboo associated with talking about sex or anything related to it (including Pap smears), the initial description of the research purpose did not include the words "gynecological exam." Instead, it was framed around understanding South Asian American women's views on cervical cancer and related health behaviors, such as screenings and receiving vaccines. This was an appropriate method to recruit because: 1) the sensitive nature of the topic; and, 2) allowing for personally addressing questions/concerns about the study.

STUDY PROCEDURES

For this study, in-depth interviews were used gather data. In-depth interviews are useful for learning about the perspectives of individuals, as opposed to, for example, group norms of a community, for which focus groups are more appropriate. They are an effective qualitative method for getting people to talk about their personal feelings, opinions, and experiences. They are also an opportunity to gain insight into how people interpret and order the world. This can be accomplished by being attentive to the causal explanations participants provide for what they have experienced and believe and by actively probing them about the connections and relationships they see between particular events, phenomena, and beliefs. Interviews are also especially appropriate for addressing sensitive topics that people might be reluctant to discuss in a group setting; in this case, gynecological exams.

In-depth interview methodology allows for probing and clarifying of participant statements which other research methods may not allow. Sampling is controllable and face-to-face interviews allows for the researcher to pick up on nuances and behaviors that may not be captured through a survey. The length of the in-depth interview also allows for depth and richness of data to emerge that goes beyond standard survey methods or close-ended questioning.

The semi-structured in-depth interviews were administered in-person by the PI [see Appendix B]. Interviews were conducted over a 2 month period starting January 2011. All interviews were conducted in English. One to two days before the interview, participants received a phone call and an email reminding them of the appointment. No participant failed to show up for the interview. Consent for the interviews was collected verbally. The PI took notes on the dynamics of the participants during the interviews. The PI was the sole interviewer and notetaker for this study. Probing consisted of silent probing, repeating past comments for clarification, and asking follow-up questions (as necessary). Interview lengths ranged from 32 minutes to 57 minutes. After each interview, participants filled out a short demographic and health survey [See Appendix C]. No incentives were offered for this study.

The interviews began with a brief introduction where the participant was reminded of the purpose of the study. Participants' right to withdraw or to refrain from answering were also re-stated. They were then given a copy of an informed consent which was read to them for verbal consent. After going over the consent form, participants were asked if they had any questions prior to the interview [See Appendix A]. At the end of the interview, participants were thanked and allowed to ask questions or give suggestions on the interview guide. The rationale behind the flow of the guide was to ask directed questions on specific practices of the participant (allowing her to reflect and "tell stories") before moving to broader/more abstract questions.

The principal investigator conducted three practice interviews with young, unmarried South Asian women at the Rollins School of Public Health three days before the start of the actual study to determine if any changes were needed for the interview guide (note: no changes were suggested). Practice interviews were not included in the data collection or in data analysis of this study. Five interviews were conducted at the Rollins School of Public Health in private study rooms on the 1st floor. Thirteen interviews were conducted at the Decatur City Library private study room on the second floor. Two interviews were conducted at Emory University Woodruff Library in a private study room on the fourth floor. These locations were selected for several reasons: one, the privacy of the study rooms allowed for better confidentiality of the interviews; two, the noise-level in a library or a study room is considerably less than a coffee shop making it easier to record the interview and leads for easier dialogue between the interviewer and the interviewee; three, the participants and the interviewer were all familiar with these locations; four, they were all neutral spaces and less distracting than a personal home or coffee shop; and five, if participants were without a car, most locations were easily accessible by Marta rail and shuttle buses. Interviewees were all discouraged from leaving during the session, except if they decided to discontinue their participation.

MEASURES

Interview Guide

The interview guide included 11 open-ended questions. The interview was open-ended to capture the full descriptions of what 'cervical cancer' means to participants and what factors serves as facilitators or barriers to seeking cervical cancer screenings. Questions were based on eight domains [See Appendix B for specific interview questions]:

1. Young Unmarried US-Born South Asian women (Demographics)
2. Health Exam Behavior
3. Gynecological Exams
4. Social Stigma
5. Taboo
6. Barriers and Facilitators
7. Perceptions of vulnerability and/or susceptibility to cervical cancer
8. Pros and Cons

An example of how the domains served as a framework to the guide can be easily illustrated. Social stigma, as defined by Goffman (1963) is "The phenomenon whereby an individual with an attribute is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity." Thus, questions related to stigma (i.e., "Why haven't you gone to get an exam?"; "What barriers are there in getting these exams (if any)?"; "How much of a role does stigma play in preventing unmarried women in the South Asian American community to getting gynecological exams?"; and "How would you define it [cervix]?") were placed into the guide. In addition to questions about stigma, the interview guide included questions on the following topics:

BACKGROUND INFORMATION AND DEMOGRAPHICS- This section asked about a participant's family's country of origin and members of the family. Other information about the participant's age, religious affiliation, parent's country of origin, and marital status were asked on the short survey administered after the interview. All answers were self-reported.

HEALTH EXAM BEHAVIOR- This section asked participants to describe if they have ever sought any health exam/screening. They were also asked questions about how often they seek care at a doctor's office and for what issues do they seek a doctor.

GYNECOLOGICAL EXAMS- This section asked participants if they have ever received a Pap smear test or a pelvic exam or an HPV test. They were asked when did they seek this exam, how did they decide to get this exam, if anyone dissuaded them from getting the exam, how did they feel about getting the exam, what is their opinion towards these exams, what barriers exist in seeking these exams, etc.

SOCIAL STIGMA- These questions got at the role of stigma (if any) in seeking gynecological exams.

TABOO- Pap smears and gynecological exams are specifically reserved for married women because only married women should be having sex (taboo to have sex before marriage). These questions were designed to get at the extent to which taboo plays a role in seeking gynecological exams.

BARRIERS AND FACILITATORS- These questions asked participants to speak about the different ways in which they feel they are prevented from or promoted to seek gynecological exams. This included the influence of family, the role of peers, culture, stigma, taboo, the role of religion, access issues, etc. Interviewees were asked to discuss barriers and facilitators to better understand if they are relevant to South Asian American women in seeking preventive cervical cancer screening, and if so, how do they overcome these barriers and what facilitators do they have.

PERCEPTIONS OF VULNERABILITY AND/OR SUSCEPTIBILITY TO CERVICAL CANCER- This section included questions that fleshed out perceptions of vulnerability to cervical cancer in unmarried South Asian women born in the US: Are they aware of cervical cancer? How likely do they believe that they might receive a diagnosis of cervical cancer? Do they perceive cervical cancer as a major health concern that may affect them directly? If they do not perceive it as a health concern, what do they think is a bigger threat to their health? If cervical cancer is a threat to their health, why?

PROS AND CONS- Weighing of negative/costs and benefits/advantages. These questions asked participants about what they think are the pros and cons of getting a gynecological exam and what the perceived benefits and barriers would be to getting an exam.

Surveys

In an effort to enhance understanding of barriers/facilitators to seeking Pap smears among young South Asian American women, a short 19-question survey was included as part of the study [See Appendix C]. Some survey questions were directly lifted or tailored from three previous peer-reviewed published studies.[136-138] There were no extant data on any of the questions reliability and validity. Other questions on the survey were created by the researcher specifically for this study. The survey was pre-tested with three South Asian American women recruited from the Rollins School of Public Health and three staff members at Raksha. The survey was also developed as part of a course at Rollins School of Public Health and received feedback from a Professor. The survey included questions on these topics:

BACKGROUND INFORMATION AND DEMOGRAPHICS- Demographic measures included questions about a participant's place of birth (open-ended blanks for city and state), self-reported age, marital status (single, never married; single, divorced; engaged; married; separated; divorced; in a committed relationship; and widowed), ethnicity (Afghani; Bengali; Bhutanese; Burmese; Indian; Nepali; Pakistani; Sri Lankan; Maldivian; Tibetan; and Other Ethnicity), parent's country of origin (Afghanistan; Bangladesh; Bhutan; Burma; India; Nepal; Pakistan; Sri Lanka; Maldives; Tibet; and Other), and religious affiliation (Ahmedi; Baha'I; Buddhist; Catholic; Other Christian (non-Catholic); Hindu; Jain; Judaism; Mirzai; Parsi; Shiite Muslim; Sikh; Sufi; Sunni Muslim; Zorastrian; Atheist; Agnostic; Spritual; and Other). The first two questions were fill-in-the-blanks while the next three asked participants to circle one answer from a provided list. Ethnicity and parent's country of origin were drawn from how the literature defines South Asia and South Asian.[112] The list of religions was drawn from several resources that contain data on the top practiced religions in countries of South Asia.[122] All these questions were developed by the researcher.

KNOWLEDGE QUESTIONS- This section asked participants five questions to about their general knowledge on cervical cancer. The first question was modified from the original to ask how common cervical cancer is among gynecological cancers (least common; moderately common; most common).[136] Originally, this question was, "If you had to estimate, what % of gynecological cancers (e.g., uterine cancer, ovarian cancer, etc.) that affect women are cervical cancer?" and the answer choice was left open-ended. When asked what the major cause of cervical cancer is, respondents were asked to choose one answer from a list of options: Genetics; Infections; Environmental; and Behavioral.[136] Two other answer choices that were added to this question were: Other and Don't Know. The third question asked what organism causes cervical cancer (Bacteria; Virus; Fungus; and Parasite).[136] Two other answer choices added were: Other and Don't Know. The fourth question asked participants "If a virus can cause cervical cancer, which one is it?" (HIV; Rotavirus; HPV; Other; and Don't Know). The last question asked respondents to check off multiple risk factors for cervical cancer from a list of choices (Having an STD; General Infection; Lead Exposure; Family History; Use of Contraception; Multiple Partners; Poor Hygiene; Genetics; Early Age at First Coitus; and Being Sexually Active).[136] For this question, four answer choices were added by the researcher (Old Age; Smoking; Other; and Don't know).

OPERATIONALIZATION OF THE HBM- This section asked participants five questions about their perceptions on cervical cancer and HPV. Answers were on a 6-point Likert scale with a "Don't Know" option that was added by the researcher. Some questions asked were how likely they think they would get cervical cancer (Extremely Likely; Very Likely; Moderately Likely; A little likely; Not at all likely; Don't Know) and how terrible they think having cervical cancer would be

(Extremely Bad; Very Bad; Moderately Bad; A little Bad; Not Bad at all; and Don't Know). Three other questions were pulled directly from previous published studies. Two questions from Lopez and McMahon that were used asked: 1) "How likely do you think it is that minimizing your number of partner(s) will help you reduce your chances of being diagnosed with cervical cancer?" (Extremely Likely; Very Likely; Moderately Likely; A little likely; Not at all likely; Don't Know); and 2) "How difficult would it be to reduce your number of sexual partner(s) for the sake of preventing HPV infection?" (Not difficult at all; A little Difficult; Moderately Difficult; Very Difficult; Extremely Difficult; and Don't Know).[137] The question, "How confident are you in your ability to use a condom for protection the next time you have sex to prevent HPV infection?" (Not confident at all; A little confident; Moderately Confident; Very Confident; Extremely Confident; and Don't Know) was taken from a study that looked at condom use behavior**.**[138]

DETERMINING SCREENING RATE- This section asked participants three questions developed by the researcher. Participants were asked if they had ever received a gynecological exam, how old they were when they received their first gynecological exam, and the date of their last Pap smear. Answer choices for the first question were "Yes," "No," and "Don't Know." For the second question in this section, participants chose one answer from a provided list of age-ranges, and the third question was a self-reported year.

Table 2: Examples of Questions from the Survey

Topic Area	**Questions**
Population Demographics	• Age (In Years): ___ • Place of Birth (City, State) __________ • Marital Status
Knowledge Questions	• How common is cervical cancer among gynecological exams? • What is the major cause of cervical cancer?
Perceptions of Cervical Cancer and HPV	• How likely do you think it is that you will develop cervical cancer? • How bad do you think it would be to have cervical cancer?
Determining Screening Rate	• Have you ever received a gynecological exam, such as a Pap smear?

Due to the small sample size of the study, these surveys were primarily used to add more depth to the data from the interviews and exploratory [See Appendix D].

DATA MANAGEMENT AND MONITORING:

Electronic data was password protected and backed up on an external drive. All data were stored at the Rollins School of Public Health in a secured office in a locked over-head desk drawer. Digitally recorded interviews were downloaded onto i-Tunes software on a private password-protected laptop (that also contained a copy of the verbatim transcripts and a trial version of QSR-NVIVO- the qualitative software). In addition, voice recordings were destroyed immediately after they were transcribed and the transcriptions were verified. The back-ups (external drive), digital recorder were placed in the secure and locked drawer in the locked office at Rollins School of Public Health. The digital recorder was only taken out of the office when it was being used as part of interviewing the participants and was placed in the secure locked drawer in the office at Rollins School of Public Health after the completion of each scheduled interview. The only person with access to the hard data was the PI. For the codebook development, the other two coders only had access to hardcopies of the transcriptions. Transcriptions were not identified by any name but by numbers (1-20), and coded-links were not retained for the uniquely numbered transcripts and participants' names to ensure confidentiality. At the end of the study, all records (electronic data, interview notes, backups, coding notes, transcripts, etc.) were destroyed.

PROTECTION OF HUMAN SUBJECTS:

Verbal consent [See Appendix A] was obtained in person at the time of the interview. The PI (the sole interviewer for the study) went over the consent form with participants. Participants had time to ask questions before verbally agreeing to be part of the study. As part of the consent process, participants were informed that they can refuse to be in the study at any time (before, during the interview). Participants were also reminded at this time about the confidentiality of the data. By using verbal consent versus signed consent forms, this may have minimized the potential risk of breaching participant identification. A paper copy of study information was given to each participant.

Study related materials contained no identifiable information (i.e., no names, addresses, social security, full dates, etc.); even so, all data from the surveys and interviews were assigned a unique number. The ID Number was used for each transcript only, and not for the surveys. All files were kept confidential using a password-protected computer that was in a secure office on the 5th floor of Rollins School of Public Health. Participant names and other facts that identify a participant will never appear if this study is ever presented or published. All project related materials were properly disposed of to protect the confidentiality of the participants after all the data analysis was completed.

Given the sensitive nature of this topic, the PI compiled a list of resources in the Greater Atlanta area (including mental health providers, STI and gynecological services). If any participant became upset during the interview, the interview would have been terminated [See Appendix A]. This was not the case for any of the participants in this study. All participants received information on cervical cancer, where to seek care, and the general CDC guidelines to Pap smears. In thinking about ethical issues surrounding this study, while there may not have been obvious physical harm in conducting these interviews, the nature of the topics (cervical cancer and gynecological exams) may have made the participants' uneasy for several reasons.

Gynecological exams imply "sexual behavior," which is taboo in South Asian culture, especially for young unmarried women. Some of the participants may not have wanted to talk frankly about the subject for fear of someone in their community finding out about what they have said. The fear of social stigma (being labeled a "slut" or "unclean" or other similar terms) just for talking about receiving or seeking a gynecological exam is a major issue for young unmarried women within South Asian communities.[107] Talking to anyone outside of the immediate family about “private matters,” including anything that may seem innocuous to Americans (such as health), is highly discouraged in South Asian culture.[109]

The fear of “*nazar*”-the evil eye, is also common in most South Asian families regardless of education status, financial status, and religious affiliation. Thus, South Asian children may be advised to skirt issues by avoiding full disclosure of any topic with anyone (including those in their community and extended family). *Nazar* is a belief that people outside of your immediate family may place a curse on you to prevent good fortune or decide to harm you with ill will, especially if they are jealous.[139] It is also the idea that if you or someone in your immediate family had done something to displease another member of the community, that they have a better chance of harming you. For example, if Aunties (mothers of other children in the community that were not related by blood) ever asked a child how he/she was “feeling,” a child would answer that he/she is “fine” (even if he/she were actually sick). Therefore, a major ethical concern was privacy and confidentiality of the information discussed in the interviews. To address this issue, the researcher reiterated confidentiality promises to the participants and concealed participants’ identities (by numbering the interviews, using verbal consent instead of written consent, securing all data, and destroying all records after completing data analysis).

Talking about gynecological exams may stir up emotions, especially if the participant is relating her own experience to the interviewer. If the participant had a personal instance of cervical cancer in her family, friends, or others, or she herself had a diagnosis of cervical cancer, this study may have been emotionally charged. It may also be that the participant wanted to learn more about cervical cancer and risk factors. For this study, none of the interviewees had a personal experience with diagnosed cervical cancer. In addition, referral services comprising of mental health providers, informational sites, women's health providers, and other relevant resources were provided to all interviewees at the end of the interview.

Transparency was key to conducting these interviews. The topic of cervical cancer and gynecological exams may have been uncomfortable for the participants (perhaps causing them to end the interview early or refusing to answer questions), but the researcher believed that it was not in her interest to coerce or dupe participants into answering these questions. The primary data collection received exempt status from the Emory IRB. Lastly, all participants were treated courteously and respectfully.

TRAINING:

The PI included on this protocol was the interviewer and notetaker for the interviews. The PI is CITI-trained and is a public-health student who has taken courses and received training in interviewing techniques, probing for responses, and the consent process. The other 2 coders, Diamond Bruner and Linda Vo, are also CITI-trained and are public health students who have experience in qualitative analysis and in handling data.

ANALYTIC METHOD:

All interviews were audio-recorded, transcribed verbatim, printed out, and then coded by hand for data analysis purposes. Probing consisted of silent probing, repeating past comments for clarification, and asking follow-up questions (as necessary). Verbatim transcripts were also uploaded onto qualitative data software (QSR-NVIVO) for data management. Interview lengths ranged from 32 minutes to 57 minutes. After each interview, participants filled out a short demographic and health survey [See Appendix C]. Data from the surveys were put into tables [See Appendix D]. No incentives were offered for this study.

Overall, thematic analysis was the easiest method to organize the data: main ideas and conclusions could easily be extracted from across the transcripts. Analytic results may have also looked different if an entirely a priori, theoretically-driven approach had been used instead of an inductive approach, in which themes ‘emerge’ from the process of analysis. Thematic analysis allowed the researcher to examine themes without making judgment. It was easy to observe commonalities across the interviews and aid in looking at data in an organized fashion. Data could be dissected down to a fragment (sentence) or in units (one word). Identification and discovery of multiple relations between different themes made the 20 transcripts consistent and intelligible: 20 seemingly different interviews had overlap in themes that were generated by coding. Thematic analysis gave the researcher a detailed framework to explore the two main broad research questions and provided linkages for investigating and defining themes.

Using a ‘grounded theory’ approach[134], responses from the first 5 interviews were used to further refine the interview guide. Doing so ensured that any new major themes that emerged would be examined in subsequent interviews. The use of grounded theory informed the data analysis process by creating a framework of building theories that are “grounded” in the actual words and meanings of the data.[71,134] The process began with reading the transcripts and field notes several times and writing memos. The memos served as a place to store thoughts, flesh out themes or highlight questions that emerged from the data. For instance, when asked about “where else have you looked for information about gynecological exams,” many participants went into great detail about what strategies could be used to increase dialogue about cervical cancer and cervical cancer screenings in the South Asian community without prompting. Due to the memos and the data, the researcher added two probing questions to the interview guide after the sixth interview to consciously collect this data from the other interviewees: “In your opinion, what would be the best way to educate the South Asian community about cervical cancer?; and “How about for gynecological services?”

Generating a codebook for this data provided a basis for storing codes and their definitions within a Word document and within the QSR-NVIVO program. The codebook served to provide consistency within coding. The PI re-coded all interviews on two different occasions to ensure the reliability of the coding since this demonstrated that the PI was not randomly coding sections of the text (intra-coding agreement). The PI also hired two graduate students from the Rollins School of Public Health to serve as independent coders. These graduate students were CITI-certified and versed in qualitative research methods [Study Staff: Diamond Bruner and Linda Vo]. Codes (deductive and inductive) were identified by the three separate coders [The PI and study staff]. The coders met three times to develop and agree on a codebook based on agreement the research questions, specific interview questions, and responses from the first 5 interviews.

Thematic coding was also conducted in the analysis. Braun & Clarke (2006) state, "its advantages are many" (p. 78). Thematic analysis is flexible and it is intuitive.[140] Thematic analysis comprises the identification of the main/recurrent or most important (based on the specific question being answered or the theoretical position of the reviewer) issues or themes.[140] It is a common method for identifying, grouping and summarizing findings and grounded theory can be built from this process. It is inductive; i.e. without the complete set of a priori themes to guide data extraction and analysis from the outset (just as grounded theory is not driven by a priori themes). Study staff and the PI used thematic analysis on the first 2 interviews. They determined codes independently and then met to discuss the codes. The third transcript was coded collectively with all three staff to develop a common understanding of the coding system. The fourth and fifth transcripts were coded independently by all three coders. These codes were reviewed in a group setting and differences in use of codes were discussed. Once the team began coding in a consistent manner, the three coders coded each transcript individually.

Codes (initially determined from the thematic analysis) corresponded roughly to the topics covered in the interview guide, such as social stigma, taboo, perceptions of susceptibility to cervical cancer, etc. [see section on Measures, p.46 for more details]. More specific coding categories were developed as the first few transcripts are reviewed, and were modified as new themes emerge from the data. Once the codebook was developed, inter-coder agreement was assessed on a random sample of 8 transcripts (nearly half the size of the total number of interviews: n=20). The coders used QSR-NVIVO for storage, retrieval, and analysis of interview data. Transcripts and codes were entered into the software for analysis and reports were generated using this software. For instance, a report was generated to retrieve all text associated with linking stigma as a barrier to seeking gynecological exams. The PI and two independent coders identified the major themes associated with each research question and agreed on the major themes.

Generating and defining codes delineated inductive from deductive themes. Inductive themes are those that emerge from the data on their own compared to those that were found in previous literature or sought after by the researcher (deductive). In grounded theory, inductive codes can provide a basis for original theories that have not yet been explored by other researchers (Error Input1). For these interviews, constructs from constructivist theory ("dialogue;" "traditional beliefs;" "gender roles;" etc.) and the HBM ("perceived severity;" "perceived susceptibility;" "benefits;" "barriers;" etc.) served as pre-determined codes (deductive), but coders were urged to create other necessary codes as they saw fit. Thus, codes on some of the barriers to getting a gynecological exam were deductive, while women speaking about moving from city-to-city made them feel like that there was a "lack of stability" in their lives that contributed to interruptions in their healthcare were inductive, or unexpected. The "in-vivo" codes, such as "discomfort," "control," lack of stability," and "traditional beliefs," all came directly from an interview and were found throughout all other interviews.

For the close-ended survey questions, descriptive statistics for all study demographics were computed through Excel and presented in Table 3 in the results section. Other data from the surveys were included as additional findings [See Appendix D].

Following the coding of data, thick description of several codes and cross-comparisons of codes served to build up theories and ideas about the participant's knowledge or experience with cervical cancer and their subsequent cervical cancer screening seeking or non-seeking behavior. The results of the analysis can be found in the next chapter.

CHAPTER IV: RESULTS

DEMOGRAPHICS OF PARTICIPANTS

A total of 20 interviews were completed for this study. Below is a table that gives some background information on the 20 participants that completed an interview. For more information on the survey data, please see Appendix D.

Table 3: Data from the Short Surveys

DEMOGRAPHIC DATA ON PARTICIPANTS (N=20)		
Age In Years (Mean, SD) **24.5 Years (3.33)**		
	Description	**N, %**
Marital Status	Single	17 (85%)
	Engaged	3 (15%)
Ethnicity	Afghani	2 (10%)
	Bengali	3 (15%)
	Indian	10 (50%)
	Pakistani	5 (25%)
Religious Affiliation	Agnostic	1 (5%)
	Atheist	2 (10%)
	Christian (non-Catholic)	2 (10%)
	Hindu	4 (20%)
	Jain	2 (10%)
	Shiite Muslim	1 (5%)
	Sufi Muslim	1 (5%)
	Sunni Muslim	7(35%)

As seen in Table 3 above, the average age of participants for this study was about 24 years (3.33 SD). A majority of participants (85%) reported that they were single. In terms of ethnicity, half of the participants (50%) identified themselves as Indian while a quarter of the total participants (25%) identified themselves as Pakistani. The other two ethnicities that were captured by this study included Bengali (15%) and Afghani (10%). Religious affiliation was diverse: a majority (35%) stated they were Sunni Muslim, followed by those who identified themselves as Hindu (20%). There was a three-place tie between Christians (non-Catholic) (10%), Jain (10%), and Atheist (10%). Only one participant identified herself as being Agnostic (5%). If all Muslim sub-sects (Shiite, Sufi, and Sunni) were combined into a single Muslim category, they would make up 45% of this study's sample.

INTRODUCTION TO QUALITATIVE RESULTS

This section will discuss some of the themes that emerged from the interviews and how they construct a framework of factors that may influence a South Asian American women's likelihood of accessing cervical cancer screening in the United States.

INDIVIDUAL PERCEPTIONS:

PERCEIVED SUSCEPTIBILITY

Interviewed participants had strong views on sexual activity. All 20 participants stated sexual activity (either one partner or multiple) as being a major risk factor for cervical cancer. If participants stated they were virgins, they were even less likely to think of any other risk factors for cervical cancer. A 21-year old single Indian participant said,

> I think multiple partners and unsafe sex. I see someone who is promiscuous or "shame-shame." Or maybe even someone who even slept with one person. I mean STDs are really infectious, right? I mean, like, you know, if you haven't had your partner tested, then you can get HPV from that person, and then you could cervical cancer. I mean, obviously non-virgins are more at risk, I think, and since I'm not, you know, having sex, then I'm not at risk.-Participant #4

Many other participants mentioned that they did not feel at risk because they had not had sex yet; for instance, the engaged Afghani participant mentioned that she scheduled to get her Pap "right after her marriage;" when she was "allowed to have sex."[1] Another Afghani Muslim participant stated explicitly,

> "So, um, well I guess not necessarily Pap smear, but, like, I guess cervical cancer wouldn't... Um... but like, (pause) and, so I feel like if you're not sexually active yet then you DON'T have a need to get it done yet."-Participant #13

Other participants were quick to judge the sexual practices of "others" versus themselves. Those who stated that they were not engaging in sexual behavior saw others, notably non-South Asians, as being more at risk for cervical cancer due to their risky sexual behavior. When asked what kind of woman would have cervical cancer, a 23-year old Christian

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[1] Interview #1

Indian participant stated,

> A good girl is someone who, um, basically isn't like white or black American people, like, obviously like good at school and academics because Indians are so big on academics, and just more nice, quiet, and polite and other American girls, like white and black Americans, can be loud and rude. Like one thing I always got in trouble for was being outspoken, because I'm so loud. Um, and then, I think the big thing that we're talking about right now is a good Indian girl is someone who doesn't date a lot of boys or kiss a lot of boys, or hold their hand in public or have sex before they're married because that's like only a bad, American girl and that's not allowed for Indian girls, even if we're born American.-Participant #6

A 25-year old Jain Indian woman said,

> I think South Asian women associate it with being sexually um, sexually…not deviant, but sexually active. And that may kind of be like…Well people will be like "Oh my god! You are sexually active? What is going on with you?" They might view that as being like promiscuous, like even if you sleep with one guy and that guy is your boyfriend...if you are being promiscuous then you are not being like…you are not suppose to be doing that sort of thing. I know I'm not and my Indian, Muslim, Hindu, brown-friends aren't being sexually active. That's what white American girls do-sleep around. Or like others who can get away with pre-marital sex without their parents killing them, but not me, not us.-Participant #2

Even those who stated that they were sexually active still saw sex as a major risk factor to developing cervical cancer and for seeking gynecological exams. A 29-year old Bengali participant shared,

> Well, I became sexually active, and decided right away that it's probably a good idea at this point to – to go get a Pap smear done. But if I wasn't sexually active then, yeah, then I wouldn't have gone to get the Pap smear. It's only really needed if you have sex and can be exposed to sexual diseases.-Participant #18

The most surprising finding was a tentative interpretation of a young Afghani participants' statement:

> Breast cancer is kind of, like...random, you know, It's almost out of your control. But with cervical cancer, I guess, like...there's that weird stigma or taboo attached to it because it's—it's more, like, in your control, I guess to an extent...because it's associated with sex.-Participant #1

This may sum up the idea that cervical cancer is no one's fault but the women's, since she is the one who has control over initiating sex with a man.

Control was mentioned several times over several interviews. Control over sexual relations, when to get an exam/when to not get an exam, when to schedule an appointment all centered on it being “her” body. Even though “her” body was the focus, she had the control on how it could be perceived by the community; conversely, she felt controlled by culture-bound norms, gender roles, expectations, and viewpoints that were placed on her body.

PERCEIVED SEVERITY

In terms of severity, all 20 participants stated that cervical cancer was a severe disease, but not all of them described it as an immediate threat to their health. Most were surprised to hear how common it is for South Asian women to be diagnosed with cervical cancer. A young nineteen-year old Pakistani girl said,

> I’m surprised that cervical cancer could affect so many South Asian women. I’m so surprised it’s so high! I mean, I guess, I thought, you know, it’s such a serious disease so umm…why doesn’t anyone, like, any of the aunties know about it? I think I’m still too young, I guess, to worry about it, but it worries me that my mom could have it.-Participant #5

This mindset was echoed in all most of the other interviews as well. The general sense was that participants felt that because they felt they were “too young” or “still virgins;” that they were not at an immediate risk for cervical cancer or HPV. Another nineteen year-old Indian participant stated,

> Um... I guess I kind of have like, issues with like, my like... I guess, like... I really want to have kids but like, having, actually having a baby come out of me kind of freaks me out. Like anything with like, my area that…area…(whispers “vagina”) and stuff... kind of like... I guess that makes me a little nervous sometimes...because, you know, I haven’t been seen by a man, like ever.-Participant #8

Even an older participant (a twenty-five year old Bangladeshi) said,

> I mean it’s scary because my mom said, “Oh, you don’t really need to do that. If you’re having sex, that’s when the Pap smear might start becoming important for STD’s and all those things.” Um… actually she was like, “You don’t need to start going through that pain already.” You know, wait a couple of years type-of-thing. It was, “You’re too young to have to go through that” but I’m almost engaged and I still haven’t seen the gyno.-Participant #12

How participants view themselves and how others see them, especially their mothers, may put the issue of personal risk for disease not as an immediate concern for alarm and may diffuse the fear of having cervical cancer.

Nearly all participants stated that they were surprised that cervical cancer could be a major health threat to South Asian women. Many mentioned other diseases, such as TB and diabetes, as major concerns in their community and more severe issues than cancer.

> I would say diabetes. Like, I wouldn't necessarily think of something like cervical cancer. Or, like, I think more of chronic illness, like diabetes, heart problems…things like that.
> -Participant #19

> Um…I immediately think of…well I work in TB, so I think of TB as one of the major ones. But I think of chronic diseases…like diabetes, because I probably have a handful of relatives that *don't* have diabetes. So those things, high cholesterol, you know, heart disease…but also things like asthma, TB, HIV/AIDS…-Participant #7

However, few of the participants who reported being sexually active were more likely than those who were not sexually active to report concerns of the severity of the disease and the risk it posed to their health. This is further discussed in the section, *Cues to Action*.

MODIFYING FACTORS:

LIMITED/INCORRECT KNOWLEDGE ABOUT CERVICAL CANCER AND GYNECOLOGICAL EXAMS

Knowledge on the different risk factors for cervical cancer and the purpose of gynecological exams was extremely limited for this group. When asked about gynecological exams and screenings, most of the participants had second-hand knowledge on gynecological exams or other services, since only 7 of the 20 interviewees (35.0%) had ever received a Pap smear or been to a gynecologist for another feminine issue. Most participants learned about gynecological exams and cervical cancer in school or by friends or online and by media advertisements for the HPV vaccine. Many of them stated that they were unsure of the risk factors for cervical cancer or when to seek gynecological services. One typical participant explained,

> I think a lot of people are ignorant about what is going on in the South Asian community in terms of healthcare and so, they just don't feel like talking about it. It really is frustrating to realize that. I mean most of the time, most South Asian women, me included, don't know these facts. I am pretty ignorant about what is going on and I think most of us are. We don't know and we aren't told what causes cervical cancer and who or what the gynecologist does besides check your lady-parts before you get married.-Participant #7

A few interviewees were not really sure about other risk factors to cervical cancer-all participants were quick to jump to HPV and sexual behavior (risky, initiation, or just sex in general). Other risks were unknown to these women (i.e., smoking, birth control, immunosuppression issues (HIV), diet low in fruits and vegetables, DES exposure, etc.). Although knowledge about cervical cancer risk factors was varied among the 20 participants, all had a general understanding of the disease. Additionally, all 20 participants were aware of the importance of preventive care and screenings, but all had different reasons as to why they chose to get/not get a Pap smear and when they decided to get the Pap smear.

CULTURAL FACTORS

Even though all the participants were born and raised in the United States, all had a very strong sense of identifying themselves as South Asian first, even before any religious affiliation. Their parent's culture shaped their identity and separated them from "other" Americans.

> I think because our parent's culture is just so tightly woven with our identity, you know, like…when you go home, you speak the language, or your parents speak the language, and you have to go to these functions, and it just never really escapes you. I think it's like this for all of us-whether we are Hindu, Jain, Muslim, Buddhist, or Christian. Being South Asian is more important, or at least more linked to our identity, than other identifying markers and maybe it's even stronger for us than for other Americans who have been here longer.-Participant #15

For some participants, the South Asian identity defined any and all their actions and they compared themselves as being "different" or "cleaner" to other Americans.

> I wanted them to think I was like clean and things because they saw my American friends as kind of dirty or more loose, like, dating a lot of boys, kissing boys in public, and holding hands in public, And a lot of the girls I played basketball with ended up getting pregnant before we graduated high school so I wasn't good friends with them

> but it was kinda this culture, the American system is dirty and I wanted them to think that I was like cleaner, kinda.-Participant #10

Modesty or shyness was mentioned across several interviews, especially being seen naked by male doctors or male nurses. Most participants claimed that they would be uncomfortable having a male doctor and several mentioned that they only have female doctors; however, stigma and taboo seemed to be stronger cultural factors than modesty alone.

> Um, one of the issues would be male versus female gynecologist. And, you know, it's sort of universally there. The thought of having a male gynecologist is…has been too disturbing for most of my friends. My first gynecological exam was done by a male. But that was the only doctor that was available in my town to do the exam…It was still awkward.-Participant #14

It may even have been that modesty and shyness were linked to the stigma in seeking gynecological exams, especially for unmarried South Asian women. A 27-year old Pakistani participant laid out a very detailed explanation of how stigma, culture, taboo, dialogue, and shyness all relate to one another:

> I think stigma is a big issue. You know, my mother was concerned with the problems I had down there and she took me to the doctors right away, but we never *NEVER* talked about intercourse and we never talked about menstrual cycle, that "special place," and in other ways she was kind of private and shy and um…very…and not sure of what the word is, but she only brought it up because it was a health concern, but I think it wouldn't have come up otherwise at all-me going to the gynecologist probably would have never happened until I left home and went to college because my mother would never talk to me about something like that. I mean my mother is like all other South Asian mothers that attach stigma to gynecological health and they apply it to their daughters, and women, when they are growing up, are not talked to about their bodies and when it comes time to go see the gynecologist they may not ever go because they don't know or they feel ashamed or uncomfortable. Anything having to do with sex-you don't talk about it…it doesn't exist. Babies just appear and since gynecological health is related to it somehow, that is how the stigma would be attached to it. I mean my mother never ever has talked to me about intercourse even though I am close to 28 years old and engaged.-Participant #16

When asked if anyone ever talked to them about gynecological exams, all but one said that their mothers never spoke to them about gynecological exams, and very few spoke about it with friends.

> There doesn't seem to be that openness that a daughter can go to her mom and say she wants to go to the gynecologist ---there's no one to tell her what it's like; what it's for; when to go; who to go to…no one talks about, not even my friends. Maybe a doctor would? I mean mine hasn't talked to me about it, but she's Indian. I just go online to WebMD or I look for information myself.-Participant #20

The one participant whose mother spoke to her about the gynecological exam did so out of necessity. This participant was only twelve or thirteen when she had to seek a gynecologist's care since she started missing her period due to her extreme dieting. Her mother was concerned and took her to see the gynecologist, but she did not really go into too much detail about the exam or what the doctor would do.

> I was dragged there. Well, I was 12 or 13 years old, maybe a year to two years after my period. I started getting really irregular periods and missing periods and I was concerned and my mother was concerned, so she took me to the gynecologist. I knew I had to go to see the doctor, but the experience was traumatizing. After the appointment I thought it was so terrible that I thought no young woman should ever go through that! [laughs] I mean if I were older and I understood my body more, you know, like what I looked like "down there" and knew what was going on "down there." I'm sorry, I apologize. I can't say the other word. But, like using an exam like that made me really hate it. And so when my problem persisted and I had to go a couple more times, I REALLY hated it. Especially since my mother didn't really tell me anything. Before we went…well, my mother just told me that I should probably take a shower after the exam. Yeah, umm…that was the extent to which she prepared me and I was too young and too uncomfortable to ask her more questions and she looked uncomfortable so I didn't push it. I mean she told me the doctor would check me out and would find out what's wrong, but she didn't tell me the graphic details of what the exam would entail and what would happen. But the first time I went, the doctor herself explained to me what would be done and what the steps were, but it wasn't enough.-Participant #17

Even in this situation, the mother only revealed a little information about what the exam was for and what would be done during the exam. It seems as though the mothers, but also the daughters, are unwilling to talk about the exam. Notably, only two of the 20 participants could even mention the word "vagina" during the interviews without laughing or blushing. Most participants used euphemisms, such as "the area down there;" "down there," "special place," "below the waist," "lady-parts," "va-jay-jay," etc.

LIKELIHOOD OF ACTION:

PERCEIVED BENEFITS MINUS PERCEIVED BARRIERS

Barriers were linked to several reasons. In a majority of the interviews, it was suggested that culture, stigma, and taboo were primary barriers to getting a gynecological exam, while two interviews mentioned that "access" specifically was a major barrier (not culture, stigma, or taboo). However, the two interviewees who said access was the only barrier for them to seek cervical cancer screening also stated that taboo, stigma, and culture would be possible barriers for "traditional" women; just not for herself. One Indian participant whose parents are both doctors stated that,

> I mean I think that the main barrier is probably just access. Um… I personally don't have a problem I know that if I try to make an appointment at the clinic, or with who ever, um besides time…for getting an appointment, it wouldn't… I don't think it would be an issue. I think for those who might not have access to healthcare or access to a free clinic or I don't know if there are free clinics to Pap smears, but that would be a huge barrier. Because I feel like if you don't have access to health care or a place to go, you're only going to go in if it's urgent and not preventive. I feel that maybe a great barrier. I think. I guess… In the U.S., I dunno, I guess that if more traditionally, if there are still one, or someone who you know practices more traditional values, might be you know, gender, like if a spouse or a parent even doesn't want them to go because of traditional Indian values or because of traditional values from their culture back home.-Participant #3

Another interviewee who identified herself as an atheist said,

> I mean I'm a scientific rational person. So culture and tradition, not really my beef-especially since my whole family is pretty 'Americanized.' I guess for traditional South Asians, whatever that means since I rarely hang out with any other Indians, may be turned off from going to the doctors because of taboo and stigma. I could care less what people say. I just don't have access to the time-the time to schedule, the time to sit and wait, the time. Hell, I don't even have the patience to wait five minutes for a friend.
> -Participant #9

However, when the researcher re-examined all the transcripts, all interviews proposed access as a barrier. The main difference between the interviews was that the issue of access was subtly mentioned in several of the interviews (i.e., issues around time, scheduling, health insurance, culturally appropriate same-sex doctors, and money) as opposed to overtly. For instance,

> Um…yeah, I mean I've always, you know, thought about it and…they say that once you're over 18 that, you know, you should start getting them regularly, but, being from a South Asian family, if I ever mentioned it to my mom, she was like, "No, no. You don't need that right now." And so, you know, I never did. I was under my parents' insurance, too, so all this kind of factored in and I didn't think it was important, but when…finally when I became sexually active I figured, you know, at this point…this is my health, so… But I didn't feel I could go without talking to them first…I was under my parent's insurance.-Participant #13

When asked about other barriers to seeking gynecological services, all of the participants talked again about how gynecological exams were only appropriate for sexually active women and if anyone "found out" that they had gone to see a gynecologist when they were single, that would be shameful and harmful to their reputation and family's reputation. The fear of shame, or losing face, was widely spoken about in the interviews. Other fears dealt with monetary cost of the exam (especially for those without insurance), fear of the results being positive, and fear of pain or extreme physical and mental discomfort.

All participants mentioned that their physicians or online medical sources, such as WebMD or Medline, seemed to be useful methods or ways in which knowledge/information about gynecological services could be transmitted. However, even though these sources of knowledge and information were easily accessible and private, participants were unsatisfied with the information they received from their doctor. Two different participants told the PI that,

> No one talks-no one does. Well I mean I've never had it and none of my family or friends. But my doctor talked to me about the HPV vaccine and we talked about reasons on why I should or shouldn't get the vaccine. Even when the doctor brought up Pap smears, it's just known that I should get it but it's never been explained to me like why, but I mean I know why, but they never sit you down and tell you in detail and, it's odd because they shouldn't assume that you should know anything about it. It should be talked about more, especially since our families and communities won't talk about it. -Participant #19

> Well, I think, yeah, it's just that we don't talk about, you know, sex, or your sex organs, or…anything like that, pretty much below the waist. You don't…you just don't discuss those things openly, and so I feel like that would be one major barrier that we face, and

> um…tied to that maybe the assumption that if you're getting a pap smear, that, like, implies that you're sexually active. I mean, it should have nothing to do with that, it's more about your own health. So…I just look online and don't ask my family, my friends…I might ask my doctors but they sometimes look at me like I'm crazy…like, "You're so old, why don't you know this?," You know? –Participant #17

For facilitators, it seems as though a participant has to believe that Pap smear tests are "necessary" and "routine." This seemed to be linked to knowledge about Pap smear tests. The few participants who received a Pap smear or had been to a gynecologist said that the screenings made them feel safe. However, all participants mentioned that they thought that cervical cancer screening "was important" and should be "done more often to feel safe" Perhaps more questions or interviews may have to be conducted to fully flesh out findings on facilitators or other benefits and pros to cervical cancer screenings. An Afghani participant shared,

> The reason why I would go is pretty much I would like to make sure that I am okay, you know, like make sure I am doing the right things. Just to make sure everything is um…fine and everything. And, as uncomfortable as it seems, physically uncomfortable, it is an uncomfortable feeling, but it is a better feeling than not getting it done because you want to make sure that you are safe.-Participant #13

CUES TO ACTION

A remarkable finding was that perceived susceptibility was linked to personal experience or experiences of family/friends and also knowledge about risk factors to cervical cancer. For instance, one interviewee mentioned that she had a friend who had a strain of HPV. This experience spurred her to get a gynecological exam, especially since she herself had become sexually active:

> …one of my friends, um…when she went in for her pap smear a few months before that, found out she has one of the strains of HPV, so I mentioned that to my mom, and that vaccine was just starting to come out, and so we started having that discussion and I said I need to, you know, go do it, and it was fine.-Participant #2

Others, like this Indian participant, had a personal experience of a drunken one-night stand that caused her to "take control and get an exam." She said that:

> (long pause) Umm…okay. Well, I definitely don't doubt that it's a serious disease. I think that…um…I actually had a cervical cancer scare a few years ago…where, um, they had found abnormal cells or whatever and it scared me a lot. I did follow up with the um…what is it called? gyno, gynocoloscopy? Colposcopy? Yeah, yeah I got that done. Everything turned out fine, so…but for the most part I am not surprised that, that is the case. I think it sad that people do not want to be more informed about their health, like overall when it comes to that issue. I think that women can, you know, may have to go get themselves checked out and that sort of thing. So…yeah. Especially because it is so serious and because its cancer and it can affect your body.-Participant #14

For one Indian participant, the concern about cancer was greater because her mother had recently passed away last year from colon cancer:

> …you know how I told you my mom died…she died of colon cancer. I mean it was so weird, she's a vegetarian and I mean she didn't smoke or anything, but because she thought she just had "gas" she never ever went to the doctor about her stomach issues. I always wonder about what could have happened if she's just gone to get screened? Like it scares me and now I think I should be paying more attention to my health. :looks down at table: …I think my mom's death was just a wake-up call. That preventive care is really important and could potentially save lives.-Participant #3

It was also noted that age may be an important factor to getting a Pap test (getting tested based on the age proposed by health guidelines). All interviewees mentioned that they knew there was a recommended age to get a Pap test; however, **all** were completely unclear as to what age the recommended guidelines suggested. For instance, interviewees kept vacillating between ages 18-22, while others just said that they were unsure of the age.

> Um…and so by, and I think Pap smears are supposed to be used for women who are sexually active or over the age of 21, 22? I'm not sure of what the age is…-Participant #1

Tied to age was being sexually active, in that sexual activity is necessary to seeking a Pap smear test and sexual activity was reserved for married women. In addition, sexual behavior was repeatedly mentioned as a major risk factor for cervical cancer. All interviewees mentioned that they did not think seeking cervical cancer screening was applicable to them until they had become/or would become sexually active. This was interesting, because the mothers and community were also reported as viewing Pap smears as a necessary health exam only for women who were having sex (for women who were married, not single or even just engaged):

> I think taboo plays a role, for unmarried especially because you're not supposed to…unmarried women are not supposed to unless they've been sexually active. Traditionally they're not supposed to be sexually active...So if they get one, it could imply that they've been sexually active and would be taboo in that community-which could be stigmatized. And also because I think men are supposed to be the first ones to :laugh: break it :laugh: And this is regardless of whether they've been sexually active or not. I mean that, if they get one regardless of whether they're sexually active or not, it's taboo to have something stuck up there before marriage.-Participant #8

> Because, you know, I haven't been sexually active yet, and so, like, it would guard against cervical cancer, and I was like, I don't need that, because I haven't had sex!...My friends mostly feel the same way about this too.-Participant #11

> She[mom]…I mean, I'm sure the unspoken reason was, you know, "Oh, you don't really need to do that." If you're having sex, that's when the Pap smear might start becoming important. STD's and all these things.-Participant #14

> I guess the parents also may be against it. Because I guess it's just not in the culture, to go… only when there's a problem should you go. If there's not a problem, they don't want their women to go… like there won't be a problem because they're still virgins. So I guess they don't think there's a need for an exam? I guess they're afraid that that – what is that word? Hume, hymen? I mean that is like really important to be a virgin and to have a hymen. Always. That's why my mom got mad…I don't tell her I go anymore since she'll say something and I don't want to be grilled and judged about my, you know…my status.-Participant #5

For some, the need for more information (a barrier to seeking cervical cancer) stemmed from the fact that they still had not found, or chosen, a permanent physician. All twenty of the participants mentioned that their families moved around several times while growing up. A lot of this instability influenced participants' general health seeking behavior. For example, since all the participants were above 18 years of age, and all had attended, or were attending an undergraduate institution, they felt that they did not have a constant "credible source"[2] for health information, which all 20 participants stated was "the doctor." One of the youngest participants (aged 19) said,

> Participant #5: Usually when she [Doctor] tells me what I can get, I just say yes, because I don't want to get those diseases. So usually I trust her opinions. But my mom always gets mad when I come back and I'm like, "Well, I got this because the doctor said it would be good…" I usually just trust the doctor's opinion.

---

[2] Interview #12

> *Interviewer: And why do you trust the doctor's opinion over your mother's opinion?*
>
> Participant #5: I guess because the doctor has studied in the field? And I mean, maybe she does profit off of distributing medication and services, but I feel like, as a doctor, her primary responsibility is my health. And my mother, I feel, her primary responsibility is also my health, but she hasn't had all the education in medicine, and she might not be as informed about what vaccinations or screenings are good for me. I just trust the doctor more to know what she is talking about.

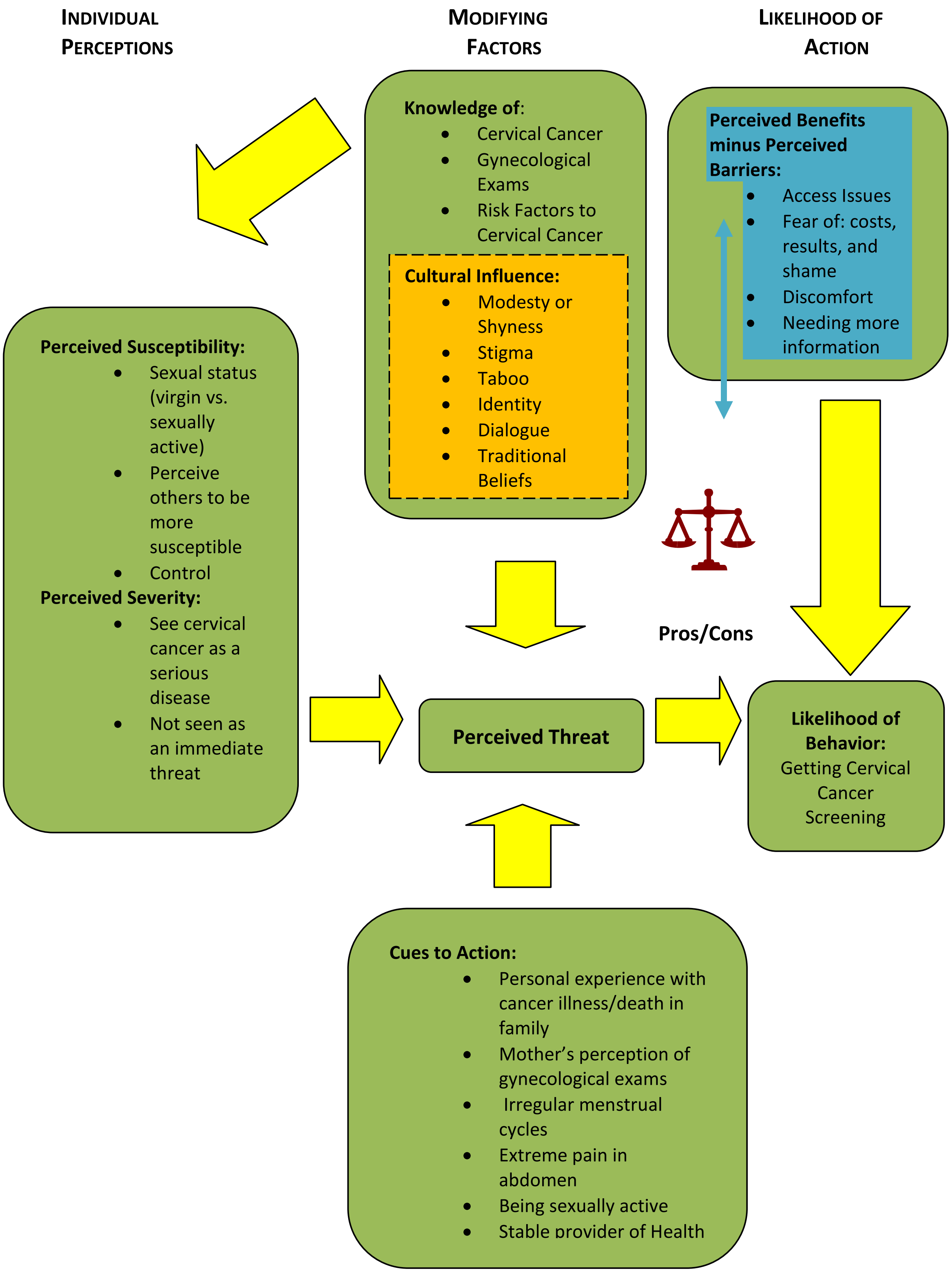
Chronic pain and irregular menstrual cycles were also mentioned as main reasons to seek gynecological care or even cervical cancer screenings. Three of the seven participants who admitted to seeking gynecological care mentioned that they had only sought out the healthcare to relieve other feminine issues, such as irregular menstrual cycles or extreme abdominal pain. Of the other four participants who sought out gynecological services due to their status as being sexually active, all but one were concerned about HIV and other STIs, but not about HPV or cervical cancer. Only one participant mentioned that she had gone to see the gynecologist specifically about HPV and cervical cancer---but this was mostly due to her friend getting HPV.

CONCLUSION:

This qualitative study using in-depth interviews (n=20) was conducted using 11 questions derived from the HBM, social construction, and the TTM. Interviews revealed that there was misinformation and some lack of knowledge about cervical cancer. The women associated gynecological care for married women and women who were sexually active only. The findings showed that major structural barriers were economic and time factors. A few of the main psychosocial barriers included fear of results and shame. Participants stated that medical advice and education would influence them to undergo a Pap test.

CONCEPTUAL FRAMEWORK: HBM+

Figure 3: Participant interviews Analyzed with the HBM, TTM, and Social Construction Theory



Explanation of the Conceptual Framework: HBM+ (Figure 3)

In this conceptual framework, just as with the regular HBM, a person's health behavior would be influenced by person's perception of a threat posed by the health problem and the value associated with actions aimed at reducing the threat. The three different categories (Individual Perception, Modifying Factors, and Likelihood to Action) identify different constructs that would affect the participants' likelihood of seeking care. Each construct has a list of examples from the 20 interviews that were unique to this study population. The HBM assumes that each construct is critical to reaching the desired health behavior outcome (i.e., cervical cancer screening), and that a person must perceive the benefits of the cervical cancer screening to outweigh the perceived barriers.[72] The Social Construction theory, as explained in Chapter 2, includes culture and language as major influencers on how individuals perceive their reality and beliefs.[71] The construct of decisional balance from the TTM has been likened to a scale, which refers to an individual reviewing both the positive and negative aspects of a behavior and identifying expected gains and losses that would result from a behavior change. These positive and negative aspects are referred to as 'pros' and 'cons', which are similar to the Health Belief Model's concepts of perceived benefits and barriers. In this study, the weighing out of pros and cons would influence the perceived barriers and benefits to getting cervical cancer screening. Likewise, perceived barriers and benefits could influence the weighing of pros and cons to getting cervical cancer screening.

The major findings of this research fit into the visual conceptual framework on the previous page. The framework was based mostly on the Health Belief Model, but also contained a box that incorporated the Social Construction theory and incorporated the construct of decisional balance from the TTM [See Figure 3, orange highlighted box for Social Construction and the blue highlighted box/arrow coming from the image of scales for the decisional balance construct of TTM]. This study found that results were almost consistent with the HBM and the Social Construction theory, making them useful modalities for understanding the participants' perceptions and resulting behavior. As stated earlier in the literature review, the Health Belief Model is made up of three categories: Individual Perceptions, Modifying Factors, and Likelihood of Action (see Figure 2 on p. 21 for an image of the HBM). These categories are used to describe the constructs that affect a person's likelihood of seeking care.

For instance, looking at the conceptual framework, "Individual Factors" was a major code that was further broken down into two sub-codes, called "Perceived Susceptibility" and "Perceived Severity." Under these sub-codes, there are examples of sub-sub codes, such as "Sexual Status," "Control," and "Not seen as an Immediate Threat." Therefore, it was found that unmarried South Asian women participants were less likely to feel susceptible to feeling the threat of developing cervical cancer, so they were less likely to seek gynecological care. On the flip side, those who identified themselves as sexually active were more likely to perceive cervical cancer as a threat to them, and may have sought gynecological care.

When looking at the major code, "Modifying Factors," there are two sub-code underneath titled, "Knowledge" and "Cultural Influence." Under "Knowledge" there are several sub-sub code examples, such as "Cervical Cancer." Most of the participants had limited knowledge on cervical cancer or unclear knowledge about gynecological exams. Therefore, they were less likely to understand the threat of the disease and less likely to then seek cervical cancer screening. The sub-code of "Cultural Influence" was a construct of the social conctructivist theory. Thus, for women who felt that there would be a negative view of them if they sought a gynecological exam, it would be because their community saw them as "unclean" or "unchaste", which would automatically stigmatize the woman and her family, because only married women are allowed to get the exam in their culture.

For “Cues to Action,” having a friend or other personal experience, such as a family member, with diagnoses of any type of cancer, was more likely to influence these women in seeking cervical cancer screening. This was uncommon among this population, so a major cue to action was underlying health causes, such as irregular menstrual cycle or extreme pain in the abdomen as a way to seek the gynecologists care.

The barriers to getting a cervical cancer screening were many and far outweighed the benefits. One barrier that was also listed as a “Cue to Action” was the mother’s perception of gynecological exams. Since most of the participants stated that their mothers told them that the gynecological exam is only for married women, many felt they did not need to go (85% of participants were single and not engaged). Another major barrier was access issues, in which a number of barriers were listed, such as: lack of time, lack of money, and lack of health insurance.

Chapter V: Discussion

MAIN FINDINGS

The completion of 20 interviews provided an in depth understanding the worldview of young unmarried South Asian American women on Pap smears and cervical cancer. This qualitative study uncovered several main findings. Evidence on how stigma and taboo can serve as barriers in talking about Pap smear tests and cervical cancer were noted across all 20 transcripts. Pap smears and cervical cancer center on a body part that is "awkward" to talk about; especially since talking about a Pap smear test may imply sexual activity. As one participant noted, "It could imply that you're sexually active, that might be more of a stigma of, you know, being unmarried." This was noted in past studies on South Asian populations. For example, Chaudry et al. reported that South Asian women in the United States had greater odds of having had a Pap smear if they were married.[122] It may also be awkward to talk about cervical cancer screenings because of shame or because of parental ideas on when to receive a Pap smear test. All 20 interviews revealed that talking about Pap smears and cervical cancer were linked to talking about sexual behavior.

These are important findings because sex before marriage is a taboo subject in South Asian culture. If people in the South Asian community knew that these young unmarried women received a Pap smear test could lead to stigmatization of these women. Gender roles of women, as dictated by culture, make it so that young unmarried women in the South Asian culture are not "touched" before marriage. Culture seemed to really play a role in how and when these women would seek out Pap smear tests; in that, sexual activity was the only reason to seek gynecological care. Only two interviewees sought a Pap smear before sexual experience. However, culture may not be as strong of a barrier to receiving Pap smears since several of the interviewees were sexually active and unmarried, while only three participants were unmarried virgins who would explicitly only seek a Pap smear test after marriage.

In terms of education and knowledge, all participants admitted that they knew very little about cervical cancer, the Pap smear test, or the services provided by the gynecologist. Many did not speak to friends or family members about the Pap smear. All 20 participants mentioned online websites, such as WebMD, as important sources of information for them, especially since it was accessible and private. Most participants said whatever they learned about health was in school, by friends (usually other non-South Asians), television, other media, and their physicians.

In terms of a usual source of care on health seeking behavior, many interviewees mentioned that they would be open to hearing about Pap smears and cervical cancer from their physicians. However, due to the instability in their lives (from constant moving due to parent's employment opportunities, attending colleges away from home, and between careers), few had a constant connection to a primary care provider, let alone any specialists.

Due to parental views/pressures, many participants were aware that sex before marriage was a violation of "being South Asian." Most, if not all, participants mentioned that their mothers would view gynecologists' visits or Pap smears for those who were having sex. Women who were having sex were only married women, and not their unmarried daughters. Several participants tried to engage their mothers in explaining Pap smears, but most cited embarrassment or discomfort in raising this "taboo" subject with their mothers or other female family members.

COMPARISON WITH RESEARCH ON OTHER ETHNIC AND RACIAL GROUPS:

As stated in the literature review, few studies, if any, have examined South Asian women's perceptions, beliefs, and attitudes towards cervical cancer and cervical cancer screenings. Literature that does exist on barriers to seeking cervical cancer screening for South Asian Americans included lack of knowledge about the cancer and the screening, as well as cultural beliefs in modesty and stigma in seeking gynecological care.[84,85,107,111,112,122] Overall, while some barriers and facilitators raised in the study were similar to those found in other groups, others were different. For instance, one of the major barriers noted for the South Asian participants in this study was that going to a gynecologist was primarily associated with women who were married and actively sexual, and not for prevention of cervical cancer.

Like other racial and ethnic groups studied in the literature, this group of 20 participants mentioned access to healthcare as a barrier due to time constraints, fears about costs, lack of usual source of care, lack of health insurance, to name a few.[124-129] However, unlike their parents or other racial or ethnic groups who have immigrated to the United States, language was not mentioned as a barrier to seeking care for the women in this study.[74,75,79,81-85] Notably, the strength of cultural beliefs in shaping the identity of the South Asian women in this study was something that stood out compared to the barriers that were associated with African Americans and non-Hispanic Whites.[123-125] This cultural identity played a role on the types and access of knowledge on cervical cancer and Pap smears. Due to cultural influences, the women in this study were limited in the modes and methods to seeking information about cervical cancer and Pap smears. That is, they could not talk to their mothers and other family members openly about seeking cervical cancer screenings. While lack of education and knowledge on cervical cancer and screenings was mentioned broadly in the literature, it did not go into as much detail for other racial and ethnic groups. Other important findings included low perceived risk of developing cervical cancer and less perceived severity of the disease, which could be due to the participants' age (mean age about 24 years) and status of being single and never married (85%).

STRENGTHS:

This study had a strong methods-based approach and was grounded in theory. All the in-depth interviews were conducted in English and transcribed verbatim to ensure the validity and reliability of the data.

VALIDITY

Validity in qualitative research deals with credibility. Threats against validity are determined by exploring how the researcher might have erred. In addition, there are three goals to qualitative research when determining validity: 1) to develop descriptions of context, behaviors, acts, settings, etc.; 2) to develop an understanding of the participants' perspectives; and 3) to develop an understanding of the processes through which X phenomenon leads to Y phenomenon (explanation). To deal with threats to these three goals there were a series of steps taken throughout the study process to minimize the effects on the results.

For descriptive validity, threats included misremembering, omitting, mishearing, and mis-transcribing data. For this study, all 20 interviews were digitally recorded and field notes were taken. Transcripts were written verbatim and were checked twice for accuracy (by listening to the recordings over again and going through a draft of transcription). Field notes were used to capture body-language and non-verbal cues.

For interpretive validity, threats include an imposition of the researcher's perspective in the study. The researcher, as a young unmarried South Asian woman, has her own ideas of why Pap smear test rates are low in her community. Personally, the researcher has an Aunt who was recently diagnosed with cervical cancer. This Aunt had never received a Pap smear test or gynecological exam since she is still unmarried. However, knowing this, she wrote mini-memos on every process of her study. Issues of biases were presented in an ongoing dialogue through the journalistic memos. For instance, the researcher wrote:

> "I also felt that maybe I had asked leading questions at times in my interviews. It is so difficult to engage a conversation and follow a script and not revert to free-style talking...I still worry that maybe I am reading too much into the interviews I could be pushing codes onto the data to make "it fit" with my research question. It is all so subjective and it is difficult not to remove my own interpretations of the data. I wonder if it would have been better to just look at the interview and code and then go back to the memos and interview guide to see if they matched rather than start at re-reading

> the memos and the guide to see what themes I was initially looking for?..." (Memo 13, February 13th, 2011)

In response to this reflection, the researcher felt that since this was her first major qualitative study and since she was aware of her identity, she knew that her identity would shape and inform the interpretations of her data.

The researcher also shared tentative findings with 13 of the interviewees as "member checks" to her data. These 13 interviewees had requested the PI send them a preliminary report of the findings via email. All 13 were surprised, but supportive, of all the findings. Thus, the researcher was cognizant of her own personal and social background and how it could have played a role in shaping the interpretations of the data, as well as the interactions with the participants. All these concerns were solicited for feedback from non-member checks (5 non-interviewees) and member checks.

In terms of theoretical validity, the main threat is accuracy of the concepts developed and their postulated relationships. There is an ongoing process to minimize this threat which was discussed in the findings. Discordant data and alternative explanations were posed when deemed necessary. However, the crux of validity issues stem from the researcher's engagement in harsh reflexivity.

LIMITATIONS:

As in the case of any type of qualitative study, findings from in-depth interviews cannot be generalized to the greater population. However, this is not a main purpose of qualitative studies, including for this researcher. The rich data that emerged from the 20 in-depth interviews contributes towards fully comprehending and understanding a complex issue that exists for unmarried young South Asian American women.

A main limitation was perhaps the amount of probing that was NOT done during an interview. For instance, from examining the transcripts, it was noted that mothers had a role in perhaps influencing their daughter's decisions to getting a Pap smear test. It was noted that mothers and daughters both believed that sexual behavior was linked to cervical cancer and that Pap smear tests were reserved for women who were sexually active. It would have been interesting and may have added to the interpretations of the data to find more information on this relationship. Taking it a step further, it would add a lot to the research if the mothers of these daughters were also interviewed. Commonality and differences in how these two groups of women view cervical cancer and Pap smear tests may provide information on how to educate and inform mothers to talk about Pap smear tests with their unmarried daughters.

Other issues could be related to issues of bias. Effect of social desirability in interviews is possible, especially if topics are politicized, stigmatized, taboo, or embarrassing. In this situation, participants may have answered in a manner that was pleasing to the interviewer, potentially altering or fitting their responses to fulfill the perceived expectations of the interviewer. If the participants distrusted the researcher, they may not have fully disclosed information or chose to frame responses in a guarded manner. However, a strength of interviewing is that it allows the researcher to observe non-verbal cues and social dynamics (between the interviewee and interviewer) that may reveal valuable information that would be difficult to capture with quantitative methods. If discrepancies between "words and actions" were present, they were noted in the researcher's field notes.

In-depth interviews are time-consuming and require a lot of attention (interviewing, transcribing, coding, analyzing, etc.). The process includes recruiting participants, which may be difficult given that the topic of gynecological exams has been associated with "sexual activity" which is taboo in South Asian culture; especially for young unmarried women. Eligible participants may not have participated for this reason. Participants who chose to interview may differ from participants who chose not to. The young unmarried women who chose to participate may be more outspoken, have less "traditional" families, may be more "modernized/Americanized," and may have different views than those who choose not to participate, leading due potentially different findings. It could have been that if more "Americanized" participants were recruited, that culture, taboo, and stigma would not have been listed as barriers to getting a Pap smear test.

Lastly, interviewing is a technical skill. The interviewer must make participants comfortable and look interested in what they have to say. Questions, such as yes/no or leading ones, must be avoided. Personal opinions of the interviewer must also be kept in check and reflected upon throughout the process. This would influence the write-up of the results and make. It may be helpful to have another researcher check the interview scripts afterwards to see if there could be any changes to the questions or more/less probing.

IMPLICATIONS:

If additional research confirms the majority of these findings, then one implication of these findings is that it may just be a matter of having conversations/dialogue with these communities and educating them on the risks to cervical cancer and the benefits of Pap smear test screening. There seems to be a lot of misperception on risk factors to cervical cancer and an unnecessary strain on getting a Pap smear test for these young unmarried South Asian women. There may also need to be a conversation on HPV vaccine and just a more open forum around sex (which may be very difficult to do with this population, but not impossible).

Many participants suggested that conversations about women's health issues should occur at their doctors' offices, especially since doctors are "respected" in the South Asian community and since women's health issues are rarely discussed within the family.[107] Other mechanisms for communication could be in school or through faith-based and cultural center leaders. As one of the participant's shared,

> Yeah, I think the faith community is an untapped resource and I think that you should have women who are in the faith community that could put together an event at a mosque or a temple because that is where people go to meet regularly and that is where community is based on. And women at this event could spread the word. And place flyers at the area of worship? Just get people talking about it. There's no dearth of physicians! I mean, my god! So many doctors…but like they don't talk about it…I wonder why…-Participant #20

Specific to health care providers, although recent studies have revealed an increasing recognition of the need to understand cultural influences on the construction of health meanings and health practices, this information may not be available to health professionals. Thus, providing continuing education on these topics is vitally critical.[141] Critical self-awareness of a health professional's own culture and recognition his/her biases is a skill that can be and fostered to counter stereotyping.[142]

Offering information on Pap testing and follow-up in a variety of formats (radio, TV ad, website, etc.) would also be beneficial for this group. To get at stigma, taboo, and cultural issues, it may be beneficial to do linguistically appropriate outreach to the mothers of these girls. This could be done through faith-based or cultural centers, or even in women-centered clinics that are common in areas of South Asia.[70]

Community education initiatives could also address misconceptions about cervical cancer and Pap smear screening to encourage regular screening. Some of the findings from this study suggest that such initiatives should focus on issues such as risk of cervical cancer in a woman's lifetime, the need for screening to be regular if it is to be effective, and the importance of having a health checkup regardless of symptoms. At a broader level, this study has shown that health care providers still need to consider accessibility and acceptability as a means of adherence to cervical cancer screening. A good proportion of women in this study cited cost y of Pap smear screening (usually tied to lack of insurance) as barriers to routine screening; in addition, fear that if the individual does have cervical cancer, the potential cost of treatment ties into fear of getting the exam. Furthermore, providing an acceptable service, such as having a female doctor perform the Pap smear, should also be taken into consideration.

FOR PUBLIC HEALTH

The current state of affairs in the United States has been slow to respond to the booming Asian American (AA) population and their many service needs. Despite the growth in AA population, current cancer prevention and cessation infrastructure is rare and has largely failed to serve entire communities. For example, Georgia's cancer database reports failed to report any data or information on AA's. Furthermore, there are no educational programs that have targeted the diverse AA populations in Atlanta. Very few services are available that are linguistically and culturally accessible by recent immigrants and refugees.

While it is common knowledge for many people that Pap tests are efficacious in early detection of cervical cancer, this knowledge may not be relayed to the diverse AA communities where cultural beliefs and linguistic isolation are common barriers. The lack of prevention education and knowledge for this population of AAs may have serious consequences. The latest cancer incidence and mortality patterns among specific AA groups indicate that cancer is the leading cause of death for Asian American women; cervical cancer is the most common cause of death for Southeast Asian and Vietnamese women.[25,26] As it happens, these are two of the largest AA groups in Georgia. Other educators outside of the family may need to be tapped to educate Asian women about preventive screening (e.g., doctors, schools, etc.).

Through understanding *why* and *how* (reveled through the pros and cons), we have discovered how some South Asian American women in Atlanta would be open to receiving interventions. This study also uncovered information on the current services and messages that are available to this population. Sources that are distrusted, trusted, noticed, or ignored in relationship to cervical cancer and Pap smear were also revealed through the interviews.

Overall, the findings from this study may provide a base of knowledge that has been previously unknown about this specific population. The data collected will aid in creating informed and grounded socio-cultural messages and programs that will increase Pap smear tests reception in South Asian American women, which may lead to a decrease in the rate of cervical cancer in this population.

For instance, this study may have clear implications for designing a social marketing campaign or messages for Pap smear tests that is both culturally appropriate and relevant to South Asian women in the United States. This study provided information on how South Asian American women view Pap smears and whether cervical cancer is a major problem in their communities (which none of the participants noted). It identified elements that young unmarried South Asian women believe are key to increasing receipt of Pap smear tests in their population (such as religious-related activities, normalizing dialogue on cervical cancer and gynecological exams inside and outside of their communities, etc).

It was noted before (in Limitations) that mothers have a role in influencing their daughter’s decisions to getting a Pap smear test. Both mothers and daughters believed that sexual behavior was linked to cervical cancer and that Pap smear tests were reserved for women who were sexually active. It would add a lot to the research if the mothers of these daughters were also interviewed. Commonality and differences in how these two groups of women view cervical cancer and Pap smear tests may provide information on how to educate and inform mothers to talk about Pap smear tests with their unmarried daughters. Overall, research focused on understanding South Asian women’s perceived barriers to care is necessary to stemming the alarming rates of cervical cancer in the population.

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APPENDICES

APPENDIX A: INFORMED CONSENT

Emory University Rollins School of Public Health
Verbal Consent and Study Information Sheet to be a Research Subject

TITLE:
Voices of a Silent Group: An exploration of cervical cancer screening attitudes and behavior among South Asian Women.

PRINCIPAL INVESTIGATOR(S):
Zunera Mirza (Principal Investigator); Dr. Michelle Kegler (Faculty Adviser, Co-Investigator)

INTRODUCTION AND PURPOSE:
You are invited to take part in an interview about cervical cancer and related health behaviors of young unmarried US-born South Asian women. You are being invited to volunteer in this study because you have self-identified as an unmarried South-Asian woman, born in the United States, and between the ages of 18-30 years old. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.

PROCEDURES:
If you choose to participate in the study, you will be interviewed on your experiences and beliefs on cervical cancer. Some questions may include health behaviors, such as gynecological exams. The interview will take about 45-60 minutes. I will digitally record the interview so I can make sure that I capture everything that you are saying. There will also be a short survey at the end of the interview that will ask you information about your age, place of birth, ethnicity, and a few questions on cervical cancer.

RISKS, DISCOMFORTS, AND INCONVENIENCES:
There are no foreseeable risks or discomforts associated with this study. However, some of the topics that we will discuss in the interview may be sensitive and private. The interview may cause you to feel uncomfortable or upset. You may experience a small amount of shame if others find out your responses. If you feel uncomfortable, you may stop participating at any time. If we do touch upon a topic that is upsetting for you, we can stop the interview, take a break, or skip to another question.

BENEFITS:
Taking part in this research study may not benefit you personally; however, this is a great opportunity to voice your opinions. The results of this interview may help me to develop a strong study of young South Asian women who are born in the United States and their experiences, specifically on cervical cancer.

COMPENSATION
You will not be offered payment for being in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

Participation in this study is completely voluntary. You have the right to refuse participation in the study. You may stop your participation in the study at any time.

CONFIDENTIALITY:

To minimize the risk of having others find out your responses, all of the papers pertaining to the study will be kept in a locked desk-cabinet, and all electronic data will be stored in password-protected computer files in a secure and locked office that only I have access to. I will encrypt the digital audio file on a secure laptop when I have completed this interview, and destroy the file once I have finished taking notes on it. The results of this interview and survey will include responses with a numeric ID instead of your name. The surveys do not ask for any of your personal contact or identifying information, so findings will be reported without any individual identification. Within six months of this interview, I will destroy ALL my notes and other materials from the interview and survey.

People other than those doing the study may look at study records. Agencies and Emory departments and committees that make rules and policy about how research is done have the right to review these records. The government agencies and units within Emory responsible for making sure that studies are conducted and handled correctly that may look at your study records in order to do this job include the Office for Human Research Protections, the Emory University Institutional Review Board, and the Emory Office of Research Compliance. In addition, records can be opened by court order or produced in response to a subpoena or a request for production of documents. We will keep any records that we produce private to the extent we are required to do so by law. Again, we will use a study number rather than your name on study records where we can. Your name and other facts that might point to you will not appear when we present this study or publish its results.

CONTACT PERSONS:

If there are any problems, questions, complaints or concerns, please feel free to contact:
Zunera Mirza. (610)945.8556. e-mail: zmirza@emory.edu
Dr. Michelle Kegler. e-mail: mkegler@emory.edu

If you have questions about your rights as a research subject or of you have questions, concerns, or complaints about this research, you may contact the Emory University Institutional Review Board at (404)712.0720 or at IRB's toll-free number:1.877.503.9797, or via e-mail: IRB@emory.edu.

CONSENT:

Nothing in this form or study can make you give up any legal rights. By verbally agreeing to be part of this study, you will not give up any legal rights. We will give you a copy of this consent form to keep. You are free to take home another copy of this form and talk it over with family or friends. Do not sign or write your name anywhere on this consent form. Do not give verbal consent unless you have had a chance to ask questions and get answers that make sense to you.

By you answering the survey/interview questions that I will ask, this means you consent to participate in this research project. Do you have any questions? If you do not have any other questions or concerns, do you consent to being part of this study?

APPENDIX B: INTERVIEW GUIDE

RESEARCH QUESTIONS:

- What is the *worldview* of South Asian women regarding cervical cancer?
    - How do young unmarried US-Born South Asian women perceive their vulnerability and susceptibility to cervical cancer?
- What do young, unmarried, US-born South Asian women see as the *pros and cons* of getting gynecological exams?
- What barriers and facilitators exist for young unmarried South Asian women to getting gynaecological exams?

OPENING SCRIPT:

Hello (participant). My name is Zunera Mirza and I am conducting this study as part of my Master's thesis work. I really appreciate your taking the time to talk to me about your health and cervical cancer. Before we begin, I want to emphasize that the reason we are here today is to better understand what you have to say about cervical cancer and health behaviors among US born South Asian women. There are no right or wrong answers to the questions I am about to ask.

Our discussion is being digitally-recorded so that I will be able to remember what we hear. All your comments and response to questions will be kept confidential—I won't be associating your name with what you say here. Your name and other identifiers will be removed from any written records and any materials that come out of this discussion will be analyzed by me alone. All comments will remain confidential.

In front of you, you will find a consent form. The consent form is to help you understand your rights and roles in this discussion. I will review the form and ask me any questions you have about the study. If you accept the invitation to be in this study, then please tell me now. Let me know if you have any questions.

[Allow participant to read and choose to sign the consent form.]

Our discussion today will last about 45-60 minutes. We will not be taking a break. If you'd like to use a restroom before we start, they are located [INSERT LOCATION]. After the interview, there will be a short 10-minute survey asking basic information about you and what you know about cervical cancer.

***

1. First, I'd like to hear about your family.
   Probes:
    i. Where is your family from?
    ii. Who is in your family? (immediate or extended)
        a. Who lives in your home?
    iii. How long have they lived in the US?

<u>*Thank you for sharing. I now want to ask you some questions about your opinions on health behaviors, specifically about women's health behaviors.*</u>

2. Have you ever had a health exam? (a health-exam can include a physical assessment done by a doctor, eye exam, etc)

Probes:

  - i. [If participant has mentioned that she's had any health exam]- How often do you go to the doctor in a typical year?
    - a. Do you go for prevention services (ex. Vaccines, screenings) or only when you are sick?
  - ii. What kind of exams do you usually have?

3. What has been your experience with gynecological exams, such as a Pap smear, pelvic exam, or HPV test?

   Probes:

  - i. [If participant has mentioned that she's had an exam]-How was your first gynecological exam?
    - a. How did you decide to get an exam?
    - b. Did anyone try and dissuade you from getting the exam?
      - i. If so, what happened?
        - 1. What did they say?
        - 2. What did they do?
    - c. Did anyone support you in getting the exam?
      - i. If so, what happened?
        - 1. What did they say?
        - 2. What did they do?
  - ii. [If participant has stated that she has not ever had an exam] Have you ever considered going to get a gynecological exam?
    - a. How do you feel about going to get an exam?
    - b. What is your overall opinion towards gynecological exams, such as Pap smears? (e.g., are they useful? Are they necessary?—why/why not?]
    - c. Why haven't you gone to get an exam?
    - d. Have you talked to anyone about getting the exam?
      - i. What have they said?
  - iii. What barriers are there in getting a gynecological exams (such as Pap smear, pelvic exams, HPV test), for you?
    - a. IF YES, (there are barriers) Why are there barriers to getting these exams?
      - i. Are any of these barriers specific to being a S. Asian woman in the US?
    - b. If NO, (there are no barriers) Why aren't there barriers in getting these exams?
  - iv. What barriers are there in getting a gynecological exam (such as Pap smear, pelvic exams, HPV test) for other young women?
    - a. IF YES, (there are barriers) Why are there barriers to getting these exams?
      - i. Are any of these barriers specific to being a S. Asian woman in the US?
    - b. If NO, (there are no barriers) Why aren't there barriers in getting these exams?

   - v. In your opinion, how much of a role does taboo play a role in preventing unmarried women in the South Asian American community to getting gynecological exams?
   - vi. How much of a role does stigma play?
   - vii. How do you feel about unmarried women having gynecological exams, such as Pap smear tests?

4. Have any women in your family ever talked to you about gynecological exams, such as Pap smears?
   Probes:
   - i. What did they say? ….What didn't they say?
   - ii. Have your friends ever talked to you about gynecological exams, such as Pap smears? What did they say?
     - a. Community members (such as "aunties," "uncles," religious elder/advisor, Sunday school teachers, South Asian language teacher or dance teacher , etc.)
     - b. Coworkers…
   - iii. If no one you know has ever talked to you about gynecological exams, where else have you looked elsewhere for information?
     - a. Where did you look? (e.g., internet, magazine, etc.)
     - b. Where do you look for general women's health information?

5. What comes to your mind when you think of the word "cervix"?
   Probes:
   - i. How would you define it?
   - ii. Is it a comfortable thing to talk about?
     - a. Why or why not?

     [Positive/Negative associations-getting at stigma and taboo]

I'm going to read you a statement and then ask for your opinion
"Cervical cancer is the second most common malignancy (disease) in South Asian women." (WHO Report)

6. What comes to your mind when you hear this statement? [Do you think this is true?]
   Probe:
   - i. Why/why not? What diseases are prevalent for women in your community?
7. What comes to your mind when you think of cervical cancer?
   Probes:
   - i. What specific behaviors lead to cervical cancer?
     [Risk factors-pathogenicity, virulence, health behavior]
       - a. What do you think causes cervical cancer? A biological organism or through social behavior? (e.g., smoking, sleeping around, etc.)
   - ii. What kind of person do you picture having cervical cancer?
     [Positive/Negative associations-getting at perceptions]
   - iii. How serious of a disease is it?
     - a. Why/Why not?

8. What has been your experience with cervical cancer?
   Probes:
   - i. Do you know anyone who has cervical cancer (friend or family etc.)?
   - ii. Has your doctor talked to you about it?
   - iii. How about your friends? Or Family?

9. Have you heard of the HPV vaccine?
   Probes:
   - i. What do you think of the HPV vaccine?
   - ii. Where have you heard about it?
   - iii. Who told you about it?
   - iv. Do you know what it is for?
   - v. What are the risks of the vaccine? What are the benefits for this vaccine?
   - vi. (if they haven't heard of it)-Why do you think you haven't heard about this before?

10. Have you gotten the HPV vaccine?
    If YES-
    Probes: [If participant has mentioned that she's gotten the vaccine]-Did you get the whole series of 3 shots?
    - i. How did you come to decide to get the vaccine?
    - ii. Did anyone try and dissuade you from getting the vaccine?
      - a. If so, what happened?
        - i. What did they say?
        - ii. What did they do?
    - iii. Did anyone support you in getting the vaccine?
      - b. If so, what happened?
        - i. What did they say?
        - ii. What did they do?

[If the participant has NOT gotten all three shots, but only 1 or 2]-Will you complete the series?

<u>Probe: If the participant says NO</u>

- a. What are the reasons why you will not get all 3 shots?

If NO-

Probes: [If participant has stated that she has not gotten the HPV vaccine]-Have you ever considered getting the vaccine?

- i. How do you feel about going to get the HPV vaccine?
- ii. What are your reasons for not getting the vaccine?
- iii. Have you talked to anyone about getting the vaccine?
  - a. What have they said?
- iv. What barriers are there in getting this vaccine (if any)?
  - a. Why are there barriers to getting this vaccine?
    - a. Are any of these barriers specific to being a S. Asian woman in the US?
  - b. Why aren't there barriers in getting this vaccine?

11. Lastly, if you had to choose between getting a gynecological exam, -OR- getting the HPV vaccine series as a method to prevent cervical cancer, which would you choose? [Getting at

understanding if there is more acceptability towards receiving a vaccine versus an 'invasive' exam/test even though both are recommended for preventing the same disease.)
Probes:

i. (if they choose gynecological exams)- Why not the vaccine?
ii. (if they choose HPV vaccine)- Why not the exam?
iii. (if they choose neither)- Why?
iv. (if they choose both)-Why?
v. Which method do you think is easier to talk about with women like you?
    a. Why?

We are at the end of our talk. I want to thank you very much for taking the time for being here and sharing your thoughts with me about this topic. Is there anything else you would like to add/say to this discussion? Do you have any questions for me?

APPENDIX C: SHORT SURVEY INSTRUMENT

DEMOGRAPHIC AND HEALTH SURVEY

These 6 questions will ask you some basic information about yourself so that the researcher can have a better understanding of your age and ethnicity. Your name, home address, contact information will not be collected. Only answer the questions asked. Please do not write your full name or other contact information anywhere on this survey.

1. Age (in Years):

____

2. Place of Birth:

_________________ , _________________

City **State**

3. Marital Status: (Please circle ONE answer)

1. Single, never married
2. Single, divorced
3. Engaged
4. Married
5. Separated
6. Divorced
7. In a committed relationship
8. Widow

4. Ethnicity: (Please circle ALL that apply)

1. Afghani
2. Bengali
3. Bhutanese
4. Burmese
5. Indian
6. Nepali
7. Pakistani
8. Sri Lankan
9. Maldivian
10. Tibetan
11. Other Ethnicity:

____

4. Parent's Country of Origin: (Please circle ALL that apply)

1. Afghanistan
2. Bangladesh
3. Bhutan
4. Burma
5. India
6. Nepal
7. Pakistan
8. Sri Lanka
9. Maldives
10. Tibet
11. Other:

____

5. Religious Affiliation: (Please choose ONE answer)

1. Ahmedi
2. Baha'i
3. Buddhist
4. Catholic
5. Other Christian (non-Catholic)
6. Hindu
7. Jain
8. Judaism
9. Mirzai
10. Parsi
11. Shiite Muslim
12. Sikh
13. Sufi
14. Sunni Muslim
15. Zoroastrianism
16. Atheist
17. Agnostic
18. Spiritual
19. Other:

____

KNOWLEDGE QUESTIONS

These 5 questions will ask you about general knowledge about cervical cancer. Please answer **all** the **questions IN THE ORDER THEY ARE PRESENTED** to the best of your ability. <u>Even if you are not sure of the answer, please take a guess</u>.

1. **How common is cervical cancer among gynecological cancers?** (Fill in **ONE** answer)

Least Common	Moderately Common	Most Common
0	0	0

2. **What is <u>the</u> major cause of cervical cancer?** (Fill in **ONE** answer)

0 Genetics
0 Infections
0 Environmental
0 Behavioral
0 Other: ________________
0 Don't know

3. **What organism do you think can cause cervical cancer?** (Fill in **ONE** answer)

0 Bacteria
0 Virus
0 Fungus
0 Don't know
0 Parasite
0 Other: _________________

4. **If a virus can cause cervical cancer, which one is it?** (Fill in **ONE** answer)

0 HIV
0 Rotavirus
0 Human papillomavirus virus (HPV)
0 Other: _________________
0 Don't know

5. **What are risk factors for cervical cancer?** (Please check **ALL** that apply)

Having an STD	↑
General infection	↑
Lead exposure	↑
Family History	↑
Old Age	↑
Use of contraception (e.g., condom, pills)	↑
Multiple Partners	↑
Poor Hygiene	↑
Smoking	↑
Genetics	↑
Early age at first coitus	↑
Being sexually active	↑
Other:_____________________________	↑
Don't know	↑

OPERATIONALIZATION OF THE HEALTH BELIEF MODEL TO ASSESS PERCEPTIONS OF CERVICAL CANCER AND HPV SOUTH ASIAN AMERICAN WOMEN (18-30 YEARS OLD)

These 5 questions will ask you about your perceptions on cervical cancer and HPV. Please fill in **ONE** circle answer on the scale. Choose the answer that BEST describes what you think or feel. There is no right or wrong answer, so please be as honest and complete **all** questions.

1. **How likely do you think it is that you will get cervical cancer?**

Extremely Likely	Very Likely	Moderately Likely	A little likely	Not at all likely	Don’t Know
0	0	0	0	0	0

2. **How bad do you think it would be to have cervical cancer?**

Extremely Bad	Very Bad	Moderately Bad	A little Bad	Not Bad at all	Don’t Know
0	0	0	0	0	0

3. **How likely do you think it is that minimizing your number of partner(s) will help you reduce your chances of being diagnosed with cervical cancer?**

Extremely Likely	Very Likely	Moderately Likely	A little likely	Not at all likely	Don’t Know
0	0	0	0	0	0

4. **How difficult would it be to reduce your number of sexual partner(s) for the sake of preventing cervical cancer?**

Not difficult at all	A little Difficult	Moderately Difficult	Very Difficult	Extremely Difficult	Don’t Know
0	0	0	0	0	0

5. **How confident are you in your ability to use a condom for protection the next time you have sex to prevent the possible development of cervical cancer?**

Not confident at all	A little confident	Moderately Confident	Very Confident	Extremely Confident	Don’t Know
0	0	0	0	0	0

DETERMINING SCREENING RATE

The following 2 questions are about gynecological exams. Choose answers that BEST describes what you think or feel. There is no right or wrong answer, so please be as honest as possible. If you feel uncomfortable answering, please remember that this survey is completely confidential and anonymous. Your answers will NEVER be identified and/or released with your name/address/other contact information.

1. **Have you ever received a gynecological exam, such as a Pap smear?* (**Fill in **ONE** answer**)**

Yes *(**<u>Continue</u>** to <u>question 2</u>*)	No (End of Survey)	Don't know (End of Survey)
0	0	0

2. **How old were you when you FIRST received a gynecological exam?* (**Fill in **ONE** answer**)**

0 Less than 18 years old
0 19-24 years old
0 25-30 years old
0 Don't remember
0 Have never received an exam

3. **What was the year of your last Pap smear?**

____
Year

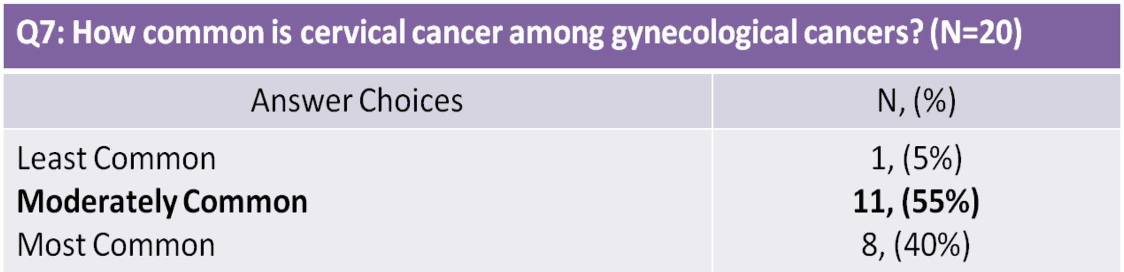
This concludes the study. Thank you for your time!

APPENDIX D: DATA FROM THE SHORT SURVEYS IN TABLES

Detailed Characteristics of Interviewed Participants

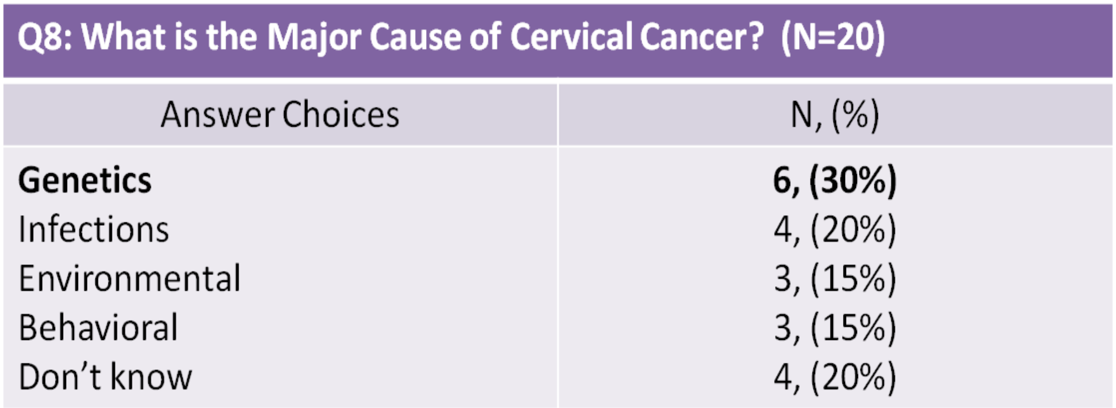
Interview **Label**	**Age (in Years)**	**Place of Birth**	**Marital Status**	**Ethnicity**	**Parent's Country of Origin**	**Religious Affiliation**
#1	22	Boston, MA	Engaged	Afghani	Afghanistan	Sunni Muslim
#2	25	Chicago, IL	Single, never Married	Indian	India	Jain
#3	28	Marietta, GA	Single, never married	Indian	India/Pakistan	Hindu
#4	21	Baton Rouge, LA	Single, never married	Indian	India	Hindu
#5	19	Radnor, PA	Single, never married	Pakistani	Pakistan	Sunni Muslim
#6	23	Nashville, TN	Single, never married	Indian	India	Christian (non-Catholic)
#7	25	Bronx, NY	Single, never married	Pakistani	Pakistan/United States	Sufi Muslim
#8	19	Providence, RI	Single, never married	Indian	India	Hindu
#9	26	New Hyde Park, NY	Single, never married	Bengali	Bangladesh	Atheist
#10	20	Atlanta, GA	Single, never married	Indian	India	Jain
#11	22	Passaic, NJ	Single, never married	Indian	India	Hindu
#12	25	Dallas, TX	Single, never married	Bengali	Bangladesh	Sunni Muslim
#13	26	Cape Cod, MA	Single, never married	Afghani	Pakistan	Sunni Muslim
#14	28	Mexico, ME	Single, never married	Indian	India	Sunni Muslim
#15	29	New Orleans, LA	Single, never married	Pakistani	Pakistan	Shiite Muslim
#16	27	Richmond, VA	Single, never married	Pakistani	Pakistan	Sunni Muslim
#17	28	Houston, TX	Engaged	Indian	India	Sunni Muslim
#18	29	Bronx, NY	Engaged	Bengali	Bangladesh	Agnostic
#19	26	Chicago, IL	Single, never married	Pakistani	Pakistan	Atheist
#20	21	Ann Arbor, MI	Single, never married	Indian	India	Christian (non-Catholic)

Knowledge Questions from the Short Survey



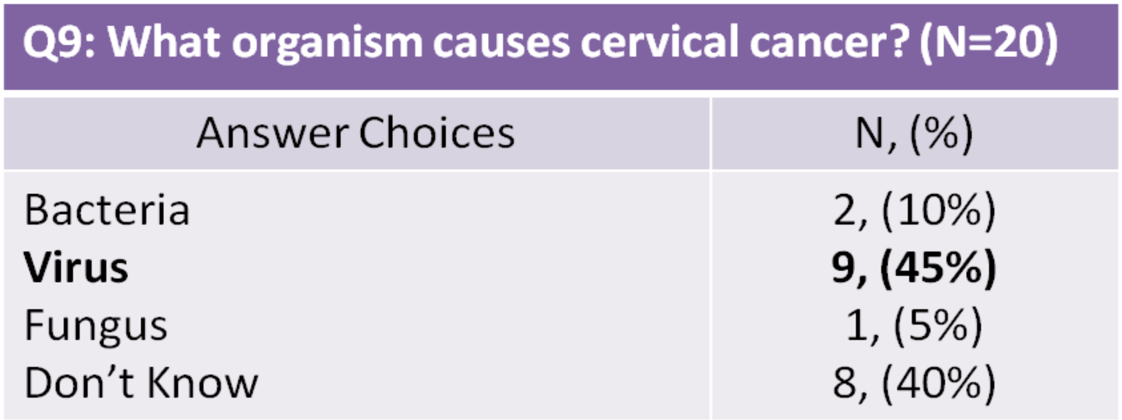
Q7: How common is cervical cancer among gynecological cancers? (N=20)

Answer Choices	N, (%)
Least Common	1, (5%)
Moderately Common	**11, (55%)**
Most Common	8, (40%)



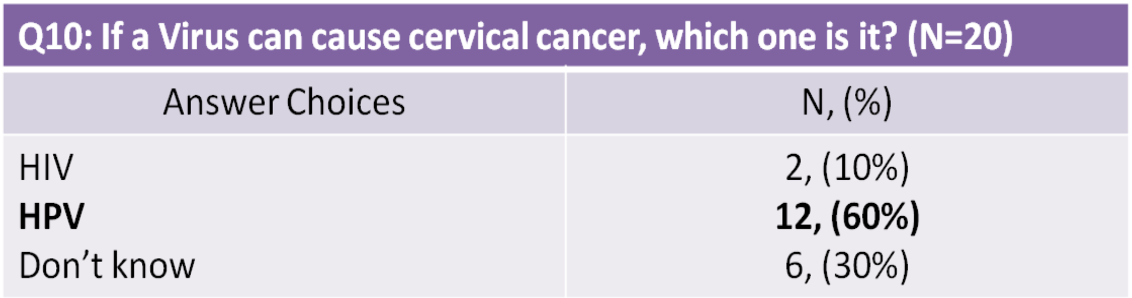
Q8: What is the Major Cause of Cervical Cancer? (N=20)

Answer Choices	N, (%)
Genetics	**6, (30%)**
Infections	4, (20%)
Environmental	3, (15%)
Behavioral	3, (15%)
Don't know	4, (20%)



Q9: What organism causes cervical cancer? (N=20)

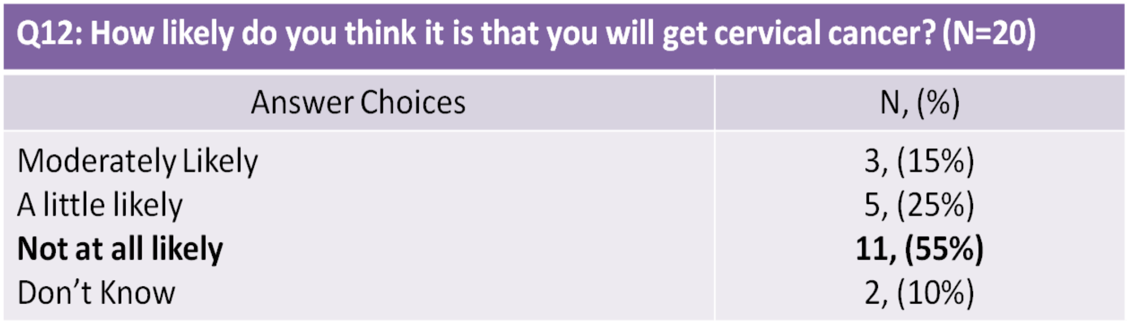
Answer Choices	N, (%)
Bacteria	2, (10%)
Virus	**9, (45%)**
Fungus	1, (5%)
Don't Know	8, (40%)



Q10: If a Virus can cause cervical cancer, which one is it? (N=20)

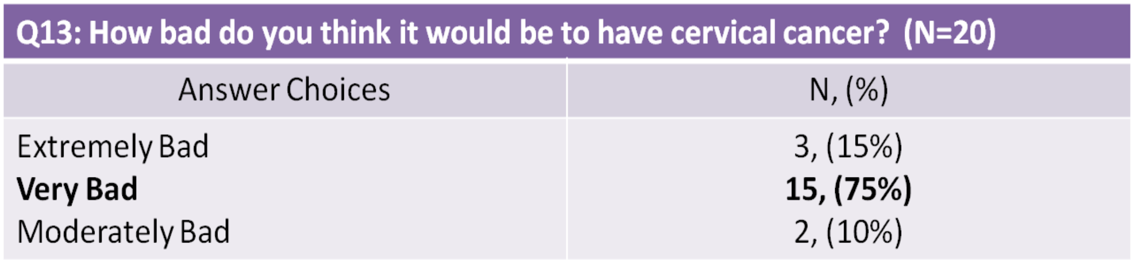
Answer Choices	N, (%)
HIV	2, (10%)
HPV	**12, (60%)**
Don't know	6, (30%)

Perceived Susceptibility and Severity of Cervical Cancer Questions from the Short Survey



Q12: How likely do you think it is that you will get cervical cancer? (N=20)

Answer Choices	N, (%)
Moderately Likely	3, (15%)
A little likely	5, (25%)
Not at all likely	**11, (55%)**
Don't Know	2, (10%)



Q13: How bad do you think it would be to have cervical cancer? (N=20)

Answer Choices	N, (%)
Extremely Bad	3, (15%)
Very Bad	**15, (75%)**
Moderately Bad	2, (10%)

Screening Rate Question from the Short Survey

Q17: Have you ever received a gynecological exam, such as a Pap smear? (N=20)	
Answer Choices	N, (%)
Yes	7, (30%)
No	13, (65%)