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Assessing Cervical Cancer Knowledge Among High-Risk Women Living In The Us-Mexico Border Region In El Paso, Tx

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ASSESSING CERVICAL CANCER KNOWLEDGE AMONG HIGH-RISK WOMEN LIVING
IN THE US-MEXICO BORDER REGION IN EL PASO, TX

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IN THE US-MEXICO BORDER REGION IN EL PASO, TX

by

CRYSTAL COSTA, B.A.

THESIS

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ABSTRACT

Despite major decreases in cervical cancer incidence rates in the U.S. over the past several decades, certain populations of women continue to be disproportionately affected by it. One of these groups includes US Latina/Hispanic women who have the highest cervical cancer incidence rates as compared to their racial/ethnic counterparts. To improve detection and prevention in US Latina/Hispanic women, it is important to first understand their current knowledge and health literacy with regard to cervical cancer.

This cross-sectional study examined perceived self-knowledge of cervical cancer and cervical cancer functional health literacy in high-risk Hispanic women living in the El Paso, Texas border region. Women were recruited via health clinic flyers and word-of-mouth from downtown El Paso neighborhoods and surrounding neighborhoods in the border region. Data were collected through phone interviews using a questionnaire that queried demographic and self-reported anthropometric measures, perceived self-knowledge of cervical cancer, vaccine history, and family history of disease. In addition, a previously standardized health literacy assessment instrument, Cervical Cancer Literacy Assessment Tool (C-CLAT), was administered. IRB approval was obtained from the University of Texas at El Paso. Descriptive and inferential data analyses were conducted with data from 85 women Latina/Hispanic women, ages 18-65, currently living in the El Paso border region.

Descriptive analyses revealed that over 50% of women had never received printed information regarding cervical cancer. Moreover, of those that said they knew what cervical cancer was (75.3%), only about half were able to demonstrate basic knowledge of the disease. As compared to women who did not know what cervical cancer was,

cervical cancer health literacy scores were significantly higher among women that were able to demonstrate cervical cancer knowledge. Surprisingly, functional health literacy was not predicted by whether women had previously received any health information regarding the disease, or whether women had previously received printed health information regarding the disease.

We concluded that current education regarding cervical cancer among Latina/Hispanic women in the El Paso border region may be both seriously lacking and inadequate when provided. The practice of educating women about cervical cancer must be instituted in our medical and public health communities; approaches for education must be expanded to include media and content that are both culturally sensitive and easy to understand. Perhaps most importantly, women must be educated on minimum prevention behaviors to ensure early disease detection.

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1. INTRODUCTION

For over 15 years, ischemic heart disease and stroke were the leading causes of global mortality (Ritchie & Roser, 2018). Findings from new research however have shown that in some high-income and upper-middle class income countries, cancer is surpassing heart disease as the leading global cause of death among adults aged 35-75 years (Dagenais, 2019), and cancer is now becoming the leading cause of death in countries worldwide (Mahase, 2019). In the U.S., this trend of decreasing heart disease with increases in cancer is inconsistent across communities, but has been found specifically among US Hispanic/Latinx¹ populations (Heron, 2017).

Cancer is currently the leading cause of death among US Hispanics. Although this population tends to have lower cancer incidence and mortality rates as compared to non-Hispanic whites for some of the most common cancers, US Hispanics tend to have higher incidence and mortality rates for cancers associated with infectious agents (Miller, 2018). One of these cancers is cervical cancer, it is also one of the most preventable ones. For several decades now, cervical cancer incidence rates have declined in the United States due to the introduction and use of the Pap exam. However, from 2011-2016, cervical cancer incidence rates were nearly 40% higher among US Hispanic women as compared to non-Hispanic white women (American Cancer Society [ACS], 2018). From 2012-2016, cervical cancer mortality rates were 26% higher as compared to non-Hispanic whites.

These increased rates suggest gaps in screening and a need for education that leads to individual behavior change. In doing so, it is essential to consider internal factors such as an individual's health knowledge and health literacy level that may be influencing screening

¹ Having Hispanic or Latinx ethnicity refers to “a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race” (US Census Bureau, 2018). For simplicity purposes, the term Hispanic will be used hereafter to refer to both Hispanic or Latinx/o/a.

practices.-Researchers continues to investigate lack of cancer awareness and low levels of knowledge in conjunction to health literacy as important barriers to access and health care which may lead to inadequate screening rates (Chaka, 2018; Reynolds, 2004; Lindau et al., 2002).

Before comprehensive interventions can be developed, we need to understand gaps in knowledge and the factors that may influence cervical cancer screening in higher risk female populations such as those living along the US-Mexico border. Women living in that particular geographic location experience greater cervical cancer screening disparities as compared to women living in other US regions (Fernandez, 2009). Furthermore, women living along the US-Mexico border face different health risks and challenges and barriers to care compared to women in the US general population (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2009).

1.1 Cancer Health Disparities Among US Hispanics

Health disparities afflict minority racial/ethnic and low-income groups such as US Hispanics. Hundreds of studies conducted over the past 40 years have shown that people of Hispanic descent have specific health disparities (Velasco-Mondragon, 2016) which encompass chronic diseases such as diabetes mellitus, stomach cancer, liver cancer, and namely cervical cancer (Vega, 2009). They play a pronounced role in the increasing disproportional rates of cervical cancer among US Hispanic women.

In the US, Hispanic health and health disparities are a focus of many modern initiatives in medicine. There are many reasons for this responsiveness. First, Hispanic populations are currently the largest ethnic minority residing in the US (Lopez, 2013). According to data from the United States Census Bureau in 2017, approximately 18.3% of the total population and its territories self-identified as Hispanic. There is a high concentration of Hispanics in the Western

and Southern parts of the US with more than half residing in three states including California (27%); Texas (19%); and Florida (9%) (ACS, 2018). Additionally, Hispanic populations are one of the top three fastest growing sub-populations in the United States. By 2060, the total US population and its territories are expected to have approximately 29% Hispanic peoples (Colby, 2015).

A second reason for responsiveness to increasing rates of cancer among Hispanic populations is their age. Hispanic populations are the youngest racial/ethnic group living in the US. In 2015, Hispanics had a median age of 27 years while the US general population had a median age of 37 years and non-Hispanic whites had a median age of 42 years (Velasco-Mondragon, 2016). As this population transitions to older age in the coming years, the demographic of Hispanics aged 65 and older will increase 134% between 2012 and 2050 in comparison to only 58.4% among non-Hispanic whites (Ortman, 2014). Since cancer is a chronic disease and more often occurs in older adults, this will have important implications for the increased economic and cancer burden of this population as well as the entire nation as a whole (Erikson, 2007). Increases in cancer diagnosis will also have an impact on cancer care, especially for certain minorities that experience higher cancer incidence rates and lower cancer survival rates as compared to non-Hispanic whites (Smith, 2009). Cancer care treatment regimens will also need to be inclusive of older adults and minorities such as Hispanics who have been particularly vulnerable to suboptimal cancer care due to the under-representation they have in cancer clinical trials, and the disparities in cancer treatment they experience (Smith, 2009; Gross, 2008).

Third, Hispanics, especially women, rank among the highest in prevalence for certain cancer risk factors including obesity and type 2 diabetes (Sauer, 2017). A prior study conducted

among US adults aged 50 and older approximated 20% of cancer deaths due to obesity in women and 14% of obesity-related deaths occur in men (Calle, 2003). Over the last 25 years, more research has accumulated showing how physiological characteristics of obesity including increased IGF-1 (Weroha, 2012), chronic low-level inflammation (Schacter, 2002), and increased estrogen production (Clemons, 2001), contribute to increased cancer risk. Current studies continue to add to the evidence of links between obesity and 13 different types of cancers that include gastrointestinal and reproductive system cancers.

According to the American Cancer Society, in 2015-2016, obesity prevalence was 51% among Hispanic adult females and 43% among Hispanic adult males as compared to 38% among non-Hispanic whites of either sex. Although the association of type 2 diabetes and cancer risk is not yet fully understood, there is growing evidence that type 2 diabetes also increases cancer risk for several types of cancers which may include liver, pancreas, uterine, breast, colon, bladder, and perhaps ovarian cancer (Wang, 2017).

Lastly, Hispanics are particularly vulnerable to an array of health disparities. These often result from the broad range of factors attributed to the social determinants of health (SDOH) that may include educational level, socioeconomic status, access to health care, employment, and the built-environment (Askim-Lovseth, 2010). For instance, as compared to non-Hispanic whites, US Hispanics are four times more likely to not have finished high school, are twice as likely to live below the poverty line, and are 20 times less likely to speak English (Velasco-Mondragon, 2016). Moreover, when compared to other ethnic groups, US Hispanics have lower rates of health insurance, have less access to health services, and are less likely to use preventive services (Velasco-Mondragon, 2016; Vega, 2009). Of key importance is insurance coverage because it is a determinant of access to health care services. Prior population-based studies have determined

that cancer patients without private insurance are more likely to be diagnosed at more advanced stages of the disease, are less likely to receive treatment, and have worse survivorship experiences (Colby, 2018; Pan, 2017). Moreover, not having health insurance and having limited access to health care can also lead to under recognition of disease, and underestimates of self-reported disease prevalence (Dominguez, 2015). Of special interest are Hispanic women because as a group, they endure adverse social and health conditions and often times lack access to health care services (Paz, 2016). This is especially true among Hispanic women living along the US-Mexico border in El Paso, TX.

1.2 Cancer Risk Among Females Living in the U.S. – Mexico Border Region

El Paso, TX, is a border city that is geographically located on the western most tip of Texas. It occupies over 1,000 square miles and borders both New Mexico and Ciudad Juarez, Chihuahua, Mexico. According to demographic data provided by Healthy Paso del Norte, El Paso TX currently has a population size of approximately 850,000 including 49.2% males and 50.8% females. The majority (88%) of the population is of Hispanic/Latinx ethnicity and the population is relatively young. Eighty-eight percent of the Hispanic population is under the age of 65 years. The median household income varies by race/ethnicity with Hispanics averaging \$41,737, ranking lower than the rest of Texas (U.S. Census Bureau, 2018). The educational attainment of the population for adults 25 years and older is varied, for example only 76.9% have a high school degree or higher; and only 22.2% have bachelor's degree or higher. Approximately 21.7% of families currently live below the poverty level. In addition, there are marked disparities concerning health and access to health care services in El Paso. Approximately 32.5% of adults do not have health insurance and 22.8% of adults are unable to afford to see a doctor (Healthy

Paso Del Norte Far West Texas, Southern New Mexico, Ciudad Juarez, 2019). Perhaps of greatest concern is the increasing incidence of cervical cancer in El Paso, TX.

1.3 Cervical Cancer Incidence and Mortality Rates

From 2011-2015, US Hispanic women had the highest cervical cancer incidence rates, 9.6%, as compared to their racial/ethnic counterparts which included non-Hispanic White, non-Hispanic Black, Asian and Pacific Islander, and American Indian and Alaskan Native; rates were 7.1%, 9.2%, 6.0%, and 9.2% respectively (ACS, 2018). Additionally, regionally specific cervical cancer incidence rates show that pockets of U.S. women are at significantly higher risk as compared to women in other regions (Horner, 2011). Hispanic women living in the Midwest (Mississippi Valley and southern Appalachia) and the Texas-Mexico border had among the highest cervical cancer incidence rates in the nation (15.3 per 100,000) and similar mortality rates (American Cancer Society [ACS], 2015; Horner, 2011). Yet data from another study revealed that for women living along border communities the cervical cancer incidence rate is actually higher (16.6 per 100,000) (Molokwu, 2014).

It is important to note that cervical cancer incidence and mortality rates declined by 3.9% and 2.3%, respectively, between 2003 and 2012 among US Hispanic women and are currently estimated to be 9.6% and 2.6% but are still considered unacceptably high (ACS, 2015).

However, In El Paso, Texas, incidence rates are currently on the rise. Reported data from the National Cancer Institute (NCI) during 2011-2015 showed that the cervical cancer incidence rate was 10.3 per 100,000 females. Presently, according to the most recent NCI available data (2012 to 2016) cervical cancer incidence rates are at 10.8 cases per 100,000 Hispanic females and 8.8 cases per 100,000 non-Hispanic white females. When the El Paso overall cervical cancer incidence rate, (10.5/100,000) is compared to the Texas state value (9.2/100,000), and the US

national value (7.6/100,000 females), it is higher in El Paso amplifying the cervical cancer disparity among minority women (Healthy Paso Del Norte Far West Texas, Southern New Mexico, Ciudad Juarez, 2019).

1.4 Cancer Fundamentals in US Hispanic Populations

Cancer is a term used to describe a disease in which abnormal cells divide uncontrollably and invade nearby tissues, which can lead to the growth of polyps; there are over 100 different types of cancers (NCI, 2015). These cancers are normally named for the organs or tissues where the cancer forms, or described by the type of cell that formed them (NCI, 2017). Infection-related cancers are a special class of cancer and result from infectious agents that can cause cancers of the liver, stomach, and uterine cervix (ACS, 2018).

In the United States general population, the four most common cancers include lung, colorectal, breast and prostate (ACS, 2015). Interestingly, incidence rates of the four most common cancers are lower in US Hispanics in comparison to higher incidence rates among non-Hispanic whites (NHWs), but for some acculturated Hispanics the rates approach or surpass those of NHWs (ACS, 2018). Conversely, incidence and rates of infection-related cancers (stomach, liver, cervix) and gallbladder are higher among Hispanics than in NHWs, similar to the cancer burden in economically developing countries such as Latin America (Torre, 2015). Mortality rates of infection-related cancers are also higher among US Hispanics relative to NHWs, especially for first generation immigrants for stomach and cervical cancers.

Cancer of the uterine cervix, also known as cervical cancer, begins in the cervix. The cervix is conical shape and is located in between the vagina (birth canal) and the upper part of the uterus (womb where baby grows) (Centers for Disease Control and Prevention [CDC], 2019). In non-pregnant fertile women, the cervix measures approximately 3cm in length and 2.5cm in

diameter (National Center for Biotechnology Information [NCBI], 2014). The lower one third of the cervix is known as the ectocervix and is covered with flat, thin cells called squamous cells. The upper two thirds of the cervix is known as the endocervix and is made up of columnar cells. The area where the ectocervix and the endocervix join is known as the “transformation zone” (T-Zone) and is where most precancerous or abnormal cells develop (NCBI, 2014). The majority of cervical cancers (80-90%) are squamous cell cancers while the remaining cases are adenocarcinomas (CDC, 2019). One prevalent source of these cervical cell abnormalities is long lasting infection with the human papillomavirus (HPV).

1.5 Cancer Risk and HPV

HPV is the most common sexually transmitted infection (STI) in the US. Seventy-nine million Americans are currently infected with the HPV virus (CDC, 2018). It is acquired after initiating sexual activity and does not usually present symptoms, making it difficult to detect and easy to transmit. Adding to the complexity is the fact that there are more than 200 related HPV types and more than 40 that can be spread through direct sexual contact (NIH, 2019). As a result, HPV types are categorized into two groups, low-risk HPVs and high-risk HPVs (CDC, 2018). Low-risk HPVs include types that can cause warts. The most common ones include HPV6 and HPV11 which account for about 90% of genital warts (CDC, 2015). While low-risk HPVs cause almost no disease, high-risk HPVs (oncogenic) can cause up to at least 6 different types of cancers. These include cancers of the vulva, vagina, penis, anus, oropharynx and notably, cervix (CDC, 2018). Two of the most common high-risk types, HPV16 and HPV18, are responsible for 70% of cervical cancers and pre-cancerous cervical lesions (World Health Organization [WHO], 2019). In most cases, however, HPV infection (regardless of type) is short lived since the body’s

immune system is able to spontaneously eliminate the infection in less than two years (NCBI, 2014). As a result of this phenomenon, very few HPV infections lead to cervical cancer.

When persistent infection by high-risk HPV types occurs, changes in cells of the cervix can lead to pre-cancer cells. These cells are not cancerous, and they do not cause symptoms. In most cases, pre-cancer cells change back to normal on their own and if they do not, they can be treated. If the pre-cancer cells are left untreated they can turn into cancer (ACS, 2016).

Moreover, if pre-cancer cells are not identified at all over the course of time, it too can lead to cervical cancer. In these cases, symptoms may manifest because the cancer will be at a more advanced stage. These symptoms can include abnormal vaginal bleeding or discharge, pelvic pain or pressure, frequent urination and/or constipation, abdominal or back pain, itching, burning, pain or tenderness of the vulva, and changes in the vulva color or skin, such as rash, sores, or warts (CDC, 2016).

Though HPV research is still ongoing, the association between HPV infection and the development of cervical cancer was demonstrated as early as the 1980s by German virologist Harald Zur Hausen (Bosch, 2002). In the years that followed, largely from observational studies, more evidence accumulated between the link of several HPV types and the development of other gynecological cancers. In fact, it is now widely recognized that almost all cervical cancers are caused by HPV (CDC, 2019).

1.6 Other Cancer Risk Factors Among Women

In addition to long term infection with HPV, there are other risk factors that can put a woman at an increased risk for developing cervical cancer. These include having multiple sex partners, early age at first intercourse, being a tobacco smoker, having an autoimmune disease such as HIV/AIDS, using birth control pills for five or more years, and having given birth to

three or more children (CDC, 2019; Reynolds, 2004). Those at highest risk for cervical cancer include women between the ages of 40 to 59 and women who have not been screened at all or who have been inadequately screened (Flores, 2013).

1.7 Preventing Cervical Cancer

While some risk factors such as age are not modifiable, there are certain behavioral practices that can be initiated and/or modified in order to reduce the risk of developing cervical cancer, a disease that is highly preventable. Perhaps most importantly, for women with access to knowledge and healthcare, specific behavioral practices including vaccinating against HPV and regular screening for abnormal cell changes in the cervix, can almost completely prevent cervical cancer, and/or improve survivorship if detected, through effective treatment.

Recognizing the critical importance of supporting changes in behavioral practices, the World Health Organization (WHO) recommends a comprehensive multidisciplinary approach. The comprehensive approach focuses on interventions across a person's life span that involve primary, secondary and tertiary levels of prevention and intervention (WHO, 2014). The approach also centers on integrating health education at every level of prevention to improve awareness and build knowledge of cervical cancer and screening for improved cervical cancer outcomes. Past literature has shown that appropriate health education interventions among diverse populations can increase screening uptake and thus reduce fatalities from cervical cancer (Abiodun et al, 2014).

1.8 Primary Prevention of Cervical Cancer: HPV Vaccination

The first level of prevention begins with primary prevention. This entails receiving an HPV vaccination against infection from certain types or strains of HPV. Presently, there are three HPV vaccines marketed throughout the world. These include a bivalent, a quadrivalent, and a

nonvalent vaccine (WHO, 2017). As the names suggest, the vaccines vary in the types and number of strains they protect against. All three types of vaccines have proven to be efficacious in preventing HPV infection with high-risk types and in some cases, low-risk types (Petrosky, 2015); importantly, these are available in several countries.

The quadrivalent HPV vaccine was first introduced in the US in June of 2006. It was licensed by Merck & Co. under the name of Gardasil and approved for use by the US Food and Drug Administration (FDA). It protects against four types of HPV-6, 11, 16, and 18 (KFF, 2018). In December 2009, the FDA approved the bivalent vaccine known as Cervarix and licensed by GlaxoSmithKline which only protects against the two common HPV high-risk types (Petrosky, 2015). In 2014, the nonvalent vaccine (next generation Gardasil) was approved by the FDA and is currently the only vaccine available in the US (NCI, 2019). This vaccine known as Gardasil 9, protects against 9 types of HPV; the four from the first-generation Gardasil vaccine in addition to five other HPV types: 31, 33, 45, 52, and 58 (Chesson, 2016). Together, these types are responsible for about 90% of cervical cancer cases (ACS, 2018).

The current HPV vaccines guard against viral infections and contain virus-like particles (VLPs) that are comprised of surface components from the real HPV virus. The VLPs do not contain the virus's DNA and therefore do not lead to infection of the real HPV virus upon vaccination. Since virus-like particles closely resemble the real virus, the body stimulates production of antibodies and these bind to the protein to prevent it from infecting healthy cells. Later, if the natural HPV virus enters the body, antibodies will recognize it, bind to the virus at a much faster response rate, and thus prevent infection (NCI, 2019). The strong immunogenic properties that the VLPs produce make the vaccines highly effective.

A highly significant component in determining the effectiveness of a vaccine is the component's uptake characteristics. Understanding dosage requirements and following the appropriate recommendations are critical. For example, according to the most up to date recommendations provided by the CDC's Advisory Committee on Immunization Practices (ACIP), 9-14 year old adolescent males and females should receive a 2-dose series before their 15th birthdays with the second dose administered 6-12 months after the first dose. For both males and females between the ages of 15-26, a 3-dose series is recommended for those who receive their dose on or after their 15th birthday and for people with immunocompromising conditions. Following a 3-dose series schedule means that the second dose should be given 1-2 months after the first dose and the final dose should be given 6 months after the first dose. Effective primary prevention depends upon knowledgeable providers and knowledgeable patients.

1.9 Secondary Prevention of Cervical Cancer: Medical Screening

The secondary level of cancer prevention includes the regular use of cancer screening tests. As stated by the National Cancer Institute, cancer screening refers to the detection of pre-cancerous or early cancer signs, when no apparent symptoms are present, with the overall goal of decreasing cancer related morbidity and mortality. For cervical cancer screening, the most widely used screening test is the Papanicolaou (Pap) exam and more recently the HPV exam (CDC,2019). These two screening tools allow for early detection of cervical cancer or early identification of precancerous lesions. The Pap exam is used to identify changes in cells of the cervix or abnormal cells. During the test, cells of the cervix are lightly brushed or scraped off and then sent for laboratory analysis (ACS, 2017). Pap exams are effective in finding precancerous cells and cancer cells. The HPV exam checks for the human papilloma virus that

causes the cell changes or abnormal cells; the HPV and Pap tests can be conducted simultaneously.

Major professional groups such as the American Cancer Society (ACS), the American College of Obstetricians and Gynecologists and the US Preventive Services Task Force (USPSTF) have set forth recommendations and guidelines for screening exams in order to detect and/or reduce cancer-related mortality among individuals who may not be experiencing cancer-related symptoms (CDC, 2019). While individuals are free to select which recommendations to follow, the USPSTF recommendations are considered hereon after and are outlined in table 1.

Table 1. US Preventive Services Task Force (USPSTF) Cervical Cancer Recommendation Summary

Table 1. Recommendation Summary		
Population	Recommendation	Grade
Women aged 21 to 65 years	The USPSTF recommends screening for cervical cancer every 3 years with cervical cytology alone in women aged 21 to 29 years. For women aged 30 to 65 years, the USPSTF recommends screening every 3 years with cervical cytology alone, every 5 years with high-risk human papillomavirus (hrHPV) testing alone, or every 5 years with hrHPV testing in combination with cytology (cotesting). See the Clinical Considerations section for the relative benefits and harms of alternative screening strategies for women 21 years or older.	A
Women older than 65 years	The USPSTF recommends against screening for cervical cancer in women older than 65 years who have had adequate prior screening and are not otherwise at high risk for cervical cancer. See the Clinical Considerations section for discussion of adequate prior screening and risk factors that support screening after age 65 years.	D
Women younger than 21 years	The USPSTF recommends against screening for cervical cancer in women younger than 21 years.	D

Table 1. Recommendation Summary		
Population	Recommendation	Grade
Women who have had a hysterectomy	The USPSTF recommends against screening for cervical cancer in women who have had a hysterectomy with removal of the cervix and do not have a history of a high-grade precancerous lesion (cervical intraepithelial neoplasia [CIN] grade 2 or 3) or cervical cancer.	<u>D</u>

The U.S. Preventive Services Task Force (USPSTF) assigns one of five letter grades (A, B, C, D, or I). Grade A: The USPSTF recommends the service. There is high certainty that the net benefit is substantial. Grade D: The USPSTF recommends against the service. There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits. Source: <https://www.cdc.gov/Cancer/cervical/pdf/guidelines.pdf>

Sauer et al., reviewed cancer screening use among US adults in 2017. Concerning cervical cancer screening, for over three decades Pap exams have reduced incidence and mortality rates by 50%. However, even though Pap test screening prevalence in the US has exceeded 80% in the overall population of women since 1987, it remained lower in certain racial/ethnic populations of women. In 2015, Pap test use was similar among black and white women (84.7%, 83.1% respectively) but was lower among women of the following origins; 77.4% Hispanic, 73.3% Asian, and 70.9% American Indian/Alaskan Native. Further analysis that evaluated recent Pap test use (within 3 years) revealed it was lowest among specific subgroups of women which included uninsured and immigrant women (60.8%, 68.2% respectively). This is consistent with other literature findings that have additionally found the lowest rates of Pap screening among women with less than high school education, women with the lowest incomes, and women living in certain regions such as the US-Mexico border (ACS, 2018; Fernandez, 2009).

Of significant concern, are Hispanic women who have lower cervical cancer screening rates than non-Hispanic white women (Flores, 2013). A cervical cancer screening analysis

conducted across all Hispanic subgroups revealed that Mexican women had one of the lowest cervical cancer screening rates, lower than women of Cuban origin (ACS, 2018). However, findings from another study revealed that Mexican women had the lowest Pap screening rates when compared to other subgroups of Hispanic women (Cokkinides, Bandi, 2012).

1.10 Tertiary Intervention Approaches: Managing Cancer

Tertiary cancer treatment entails interventions that focus on the management of a cervical cancer diagnosis and includes treatment and palliative care. This type of intervention is for individuals who have been diagnosed with cancer with the intent of inducing and maintaining cancer remission for as long as possible. Due to great strides in research and medical advancements, treatment of cervical cancer has improved greatly. Included in each of these three levels of prevention/intervention is increasing disease education for the promotion of behavioral change, including increased adoption of preventative vaccines and screening (Davis, 2002).

1.11 Barriers to Cervical Cancer Screening

Past literature has identified personal, cultural, socioeconomic and institutional barriers to cervical cancer screening among US Hispanic women (Watts, 2009). Other very important barriers that have been less explored include cervical cancer disease health knowledge and health literacy. However, it is critical to consider these in order to reduce the cervical cancer burden and improve cervical cancer outcomes among high-risk Hispanic women.

When considering health knowledge, health literacy may also be linked but it is important to understand that they are two different concepts. For example, one definition provided by Chin et al., on “health knowledge” refers to facts, information, and skills acquired through experience or education, and theoretical or practical understanding of a subject related to health and health-care (Chin et al, 2015).

Health literacy on the other hand, is ever evolving; it is conceptualized into numerous theories that may integrate hierarchical levels such as functional, interactive, and critical health literacy (Nutbeam, 2008) and /or additional components such as attitudes, beliefs, and societal norms and expectations that can impact how a person makes use of health/disease knowledge specifically for disease prevention. Adding to the complexity of health literacy is the role “health knowledge” plays within “health literacy” as it is still largely debated across models and definitions in the literature. For instance, Gellert & Tille, provide an overview of three separate health literacy theories that conceptualize the role of health knowledge as either an antecedent, a domain of health literacy, or as a consequence of health literacy (Gellert, Tille, 2015).

1.12 Cervical Cancer Knowledge and Health literacy

In addition to primary, secondary and tertiary level interventions, prevention through health education is key in implementing the comprehensive approach. Past studies have shown that having cervical cancer knowledge is not a sole predictor for cervical cancer screening (Watts, 2009); attitudes and beliefs (components of “health literacy”) are other significant predictors that have been shown to influence behavior for Pap smear uptake (Suarez, 1997; Chavez, 1995). Despite this, knowledge but not attitudes regarding cervical cancer and screening, were shown to influence behavior change with regard to increasing cervical cancer screening and decreasing the burden of cervical cancer (Ramirez, 2000).

In a qualitative study conducted by Torres et al., 45 US Latina women were followed up after having participated in a community-based educational program to understand influential factors related to decision-making for breast or cervical cancer screening. After participating in the cancer education program, they reported increased knowledge about screening guidelines, HPV, the importance of early screening and information on free and low-cost cancer screening

resources. More importantly, feelings of “empowerment” were stated which led to an increased sense of confidence and motivation to take better care of their health (Torres, 2013).

Furthermore, the women mentioned that the tailored educational program along with the resource- related information that was in a language they could understand was an important benefit of the program that influenced their overall health-seeking behavior and screening utilization.

In another recent study, a systematic and meta-analysis review examined evidence on 1) the effect of cervical cancer education to improve cervical cancer screening rates and 2) the effectiveness of provider recommendations for cervical cancer screening on screening rates in diverse high-risk women (Musa, 2017). Pertaining to the first, findings from five studies examined revealed that the implementation of theory-based educational interventions that were culturally and linguistically-sensitive and integrated a community-participatory model, had a positive effect on screening rates. Importantly, these types of interventions increased cervical cancer awareness, knowledge, emphasized the importance of screening and offered barrier counseling and guidance with scheduling for cervical cancer screening appointments (Calderon-Mora et al., 2020; Shokar et al., 2019; Musa, 2017; Nuno, 2011; Hou, 2002; Byrd, 2013; Mishra, 2009; Taylor, 2002).

Other research has shown that timely screening can be associated with both health literacy and knowledge regarding a target disease (Flores, 2019). A systematic review found a trend suggesting that limited health literacy and knowledge of a target disease could predict screening rates (Oldach & Katz, 2014). Determining gaps in knowledge and health literacy among high-risk women regarding cervical cancer may prove to be critical for improving screening rates and early detection.

1.13 Family History of Disease

Other research, though inconsistent, has explored the influence of an individual's family history of a particular disease(s) on screening practices and/or knowledge about the disease. In a study conducted by Williams et al., it was found that among African American women and non-Hispanic white women who had a family history of any cancer in an immediate family member, higher cervical cancer screening rates were completed as compared to women who did not report a family history of disease for any cancer (Williams et al., 2009). However, Bird et al., who assessed the level of knowledge, attitudes and screening behaviors among Mexican women residing along a US-Mexico border city with and without a family history of breast cancer revealed opposite findings. In that particular study, there were no statistically significant differences in breast cancer screening practices between women with and without a positive family history of breast cancer (Bird, 2011). Furthermore, knowledge of breast cancer and screening did not differ significantly among women with a family history of disease and those with no family history of disease.

1.14 Gaps in Knowledge

Gaps in cervical cancer knowledge and screening still exist globally, especially in middle and low-income countries such as Ethiopia, Tanzania, and Cambodia (Chaka, 2018; Mabelele, 2018; Touch, 2018). These gaps also exist in high-income countries such as in the United States but are more commonly found among underserved populations such as US Hispanic women. In a study conducted by Document et al., it was revealed that among low-income and minority populations, those of which included African American, Amish, Appalachian, and Latina women, awareness of cancer risk and screening was low. Most of the participants had inaccurate

information about cancer risks, screening guidelines respective to their age, frequency of screening, and the types of screening needed (Document et al., 2008).

Another study by Byrd et al., conducted among 84 women living along the US-Mexico border revealed that although most participants had knowledge about cervical cancer and the Pap exam, they too were unsure about screening guidelines and the recommended frequency of the exam. Furthermore, women also had misconceptions regarding the causes of cervical cancer and none mentioned HPV as a cause (Byrd, 2007). However, women identified that better education on cervical cancer and on the Pap exam would serve as an important facilitator for the uptake of cervical cancer screening.

1.15 Lack of Standardized Instruments on Cervical Cancer Knowledge and Health

Literacy for US Hispanic Women

As aforementioned, several studies in relation to cervical cancer have been conducted in different parts of the world on women to assess major theoretical constructs employed in health behavior research. These studies have included examining barriers, attitudes, beliefs, perceived vulnerability, self-efficacy and knowledge. Consequently, several varied instruments have been created to quantitatively measure these constructs. Despite these efforts, there currently exists a lack of standardized instruments and more specifically knowledge scales that can effectively measure cervical cancer knowledge among underserved populations. Furthermore, the few that do exist have been conducted on non-Hispanic women and/or have measured different constructs that do not necessarily measure specific health disease knowledge.

In a study conducted by Simon et al. in 2012, two instruments were developed and standardized by a panel of experts to measure ovarian and cervical cancer awareness of symptoms and risk factors among female postgraduate students (Simon, 2011). These

instruments were created to assess population levels of awareness, to track changes in awareness over time, and to evaluate awareness-raising interventions. A separate cross-sectional study conducted in Ethiopia also developed and validated a questionnaire to describe the knowledge and attitudes of cervical and breast cancer among women aged 18 and older living in specific regions of Ethiopia (Chaka, 2018). However, both studies were conducted in different geographical regions and were made up of different demographic profiles, meaning they were tailored for non-Hispanic women.

One of a very few cervical cancer standardized instruments created for US Hispanic women, more specifically for Mexican American women, includes a cervical cancer screening self-efficacy scale (Fernandez, 2009). However, this scale focuses on one component of health literacy- self efficacy, and does not explicitly state the role of health knowledge. While the scale was developed for low-income status women, it was created for women fifty years of age and older and did not consider younger participants. A separate study that did include young US Hispanic women (18-25 years) was conducted by Byrd et al. and it evaluated beliefs and attitudes about cervical cancer screening and prior screening history. However, it did not use a standardized scale to assess cervical cancer knowledge (Byrd, 2004).

At present, there is one scale, the Cervical Cancer Literacy Assessment Tool (C-CLAT) that is used for the assessment of functional cervical cancer health literacy (Williams, 2013). Functional cervical cancer health literacy is defined as “a woman’s functional understanding of her personal and familial risk of the disease, including how to minimize her risk and the risk to her family through preventive early detection screenings and life style changes and how to access the health care system and engage providers to minimize her risk and the risk of to her family” (Williams 2013; Williams, Mullan & Fletcher, 2007). It focuses on three specific cervical cancer

content domains- Awareness, Knowledge, and Prevention/Control. Equally important is the fact that this scale has been validated for use among Black, Arab, and Latina women and can be administered by a lay person for use in community-based health promotion interventions. For these reasons, the C-CLAT scale was chosen for the present study.

1.16 Research Aims

While several initiatives have been implemented in an effort to address the cervical cancer disparity, gaps in knowledge and health literacy still persist and cervical cancer incidence rates continue to increase among certain US Hispanic women living along the US-Mexico border. Therefore, it is imperative to effectively assess these gaps so that targeted interventions can address them while simultaneously promoting cervical cancer health education.

The aims of this study involved two 1) to determine unqueued knowledge of cervical cancer in high-risk Hispanic women living in the Texas, El Paso border region 2) to determine functional cervical cancer health literacy in high-risk Hispanic women living in the Texas, El Paso border region. Data from this study also explored the debate on whether cervical cancer health knowledge is likely to precede, be a part of, or follow cervical cancer health literacy.

There are specific justifications why this needed to be done. The first is that even though prior studies conducted over the last two decades have examined attitudes, perceptions, and other factors such as disease/health knowledge surrounding cervical cancer and its relation to screening behaviors among US Hispanic women, most have not used standardized scales to measure such constructs. Moreover, the most common approach for data collection has mostly been quantitative (i.e. close ended questions) while much less have focused on qualitative data (i.e. open-ended questions). However, qualitative data can be beneficial in capturing raw and valuable data that may be able to identify gaps in knowledge that quantitative data may not be

able to do. Secondly, similar to cervical cancer health knowledge, there are not many studies that have assessed health literacy specifically for cervical cancer using standardized instruments among underserved populations. This may be partially explained by the unclear definition of health literacy and the various theories that measure different constructs. Thirdly, while more research has been conducted among US Hispanic women, it has not always been inclusive of underserved high- risk young women that are 18 years of age and older (Byrd, 2004; Kim, 2015). Examining cervical cancer knowledge among younger women may also have surprising findings with the relatively recent wide spread availability of the HPV vaccine among younger demographic groups in the US. Moreover, having a diverse sample in age is important when implementing a comprehensive multidisciplinary approach that spans across a person's life span. Especially because cervical cancer can be prevented if cervical changes are discovered early on and treated.

2. METHODS²

One proposed strategy to reduce the racial/ethnic health disparity surrounding cervical cancer among US Hispanic women is to assess the current knowledge base of cervical cancer and other potential factors such as health literacy that may be influencing cervical cancer screening of the high-risk population. Results from such data can lead to the development or improvement of interventions that can increase the uptake and timely screening of cervical cancer among underserved populations. The methods described are approved by the UTEP Institutional Review Board (Study # 13532261-1, C. Costa, PI).

2.1 Hypotheses

H1: As compared to participants without cervical cancer knowledge (as determined using the CCQ), participants with cervical cancer knowledge will have higher cervical cancer functional health literacy (significant higher scores on the C-CLAT).

H2: Participants with a family history of cancer will have higher C-CLAT (cervical cancer functional health literacy) percentage scores than participants with no family history of cancer.

Other exploratory hypotheses

- 1) As compared to women who have not received cervical cancer information in the past, women who have received cervical cancer information from one, or 2 or more sources will have higher C-CLAT percentage scores.
- 2) As compared to women who have not received printed cervical cancer information in the past, women who have received printed cervical cancer information will have higher C-CLAT percentage scores.

² Study methods were adapted and amended due to the COVID-19 state order restrictions and social distancing requirements.

- 3) As compared to women who did not receive cervical cancer information in the past, women who have received cervical cancer information from one, or 2 or more sources will have cervical cancer knowledge.
- 4) As compared to women who did not receive cervical cancer printed information in the past, women who did receive cervical cancer printed information will have cervical cancer knowledge.
- 5) As compared to women who did not have recent pap exams (within the last 3 years), women who did have recent pap exams (within the last 3 years) will have higher C-CLAT percentage scores.

2.2 Study Participants

Study participants included Hispanic women between the ages of 18-65 years living in the border region of El Paso, TX. Recruitment of participants took place from May to June 2020 via health clinic flyers and word of mouth from downtown El Paso neighborhoods. Women who chose to participate called the PI at the number provided on the flyer. Women were read a consent form in the language of their choice (English or Spanish) and once the participants had no more questions, they were asked to provide verbal consent as approval of their voluntary participation. They were then asked to answer questions from the two questionnaires. The study sample size included 85 women.

2.3 Study Design

A cross sectional, mixed methods study design was used to assess unqueued cervical cancer knowledge and functional cervical cancer health literacy. This study design allowed for the examination of other individual factors (income level, education, family history of disease)

that may have predicted higher and lower levels of knowledge and health literacy pertaining to cervical cancer among high-risk Hispanic women living in a US-Mexico border region.

2.4 Measures

For the purpose of this study, the “Cervical Cancer Questionnaire” (CCQ) was developed to gain a more profound assessment of cervical cancer “perceived self-knowledge” and “knowledge” among a specific subgroup of US Hispanic women living in a US-Mexico border region. Questions for the CCQ were adapted from other questionnaires that sought to assess cervical cancer knowledge, awareness, and knowledge of risk factors and cervical cancer screening practices.

The CCQ is a questionnaire that captured both quantitative and qualitative/descriptive data. It provided a total of twenty-five structured questions from determining the following information: basic demographics (age, marital status, heritage, education level, income level, and household number); self-reported anthropometric measures (height, weight, and a yes/no/don't know question about overweight and obese); three open- and closed-ended questions- perceived-self-knowledge of cancer (whether the woman says she knows what cancer is (yes/no); knowledge of cancer (whether the woman can correctly state what cancer is); perceived-self-knowledge of cervical cancer (whether the woman says she knows what cervical cancer is (yes/no); knowledge of cervical cancer (whether the woman can correctly state what cervical cancer is); perceived self-knowledge of what causes cervical cancer (yes/no); and knowledge of what causes cervical cancer (whether the woman can correctly state at least one cause of cervical cancer).

One question had a combination of both a close-ended and open-ended response and participants were allowed to select more than one option. This question was for the receipt of

cervical cancer information (type and source). The question queried participants to select an option(s) of where they had received cervical cancer information and also a brief explanation on who or where the source may have been obtained from. The next question queried receipt of cervical cancer printed information (yes/no). If participants responded “yes” to having previously received cervical cancer printed information, they were then asked an additional four close-ended questions (yes/no) that asked about language understanding of the printed information, questions asked about the printed information, trust of printed information, and whether or not participants believed the information that was provided to them.

The next questions captured self-reported cervical cancer screening (yes/no and year), self-reported vaccine history table (influenza, human papillomavirus (HPV), pneumonia, Hepatitis A, Hepatitis B); and self-reported family history of disease (for first-degree, second-degree, and third-degree relatives) regarding for health problems related to cancer, metabolism, heart, respiration, organ function, mental health, and sexually transmitted infections (STIs).

All close-ended items on the CCQ were scored qualitatively (yes/no). With regard to the open-ended items, responses were carefully peer evaluated and qualitatively rated as “correct” or “incorrect.” Only two of the open-ended and closed-ended questions were used for analysis in this paper. These included perceived-self-knowledge of cervical cancer (whether the woman says she knows what cervical cancer is (yes/no); knowledge of cervical cancer (whether the woman can correctly state what cervical cancer is); perceived self-knowledge of what causes cervical cancer (yes/no); and knowledge of what causes cervical cancer (whether the woman can correctly state at least one cause of cervical cancer). To determine a rating for the open-ended items, a list of key words/phrases was first devised and compared to the list of the women’s responses; one list for knowledge of cervical cancer and one for knowledge of what causes

cervical cancer see appendix page 80. These key words/phrases were established based on the current literature that provided definitions for cervical cancer and previously identified risk factors for cervical cancer.

The ratings were then used in different combinations to examine whether women's perceptions of knowledge accurately reflected stated knowledge. From this, a final (yes/no) rating for basic cervical cancer "knowledge" was assigned for each woman, based on the following criteria: correct/incorrect rated response for question Q10b: Please explain what cervical cancer is; correct/incorrect rated response for question Q13b: Please explain what contributes to cervical cancer. If both cervical cancer knowledge (Q10b) and what contributes to cervical cancer knowledge (Q13b) were rated as "correct" (based on the list of key words/phrases) women were assigned a rating of "knowledgeable." If one or both questions were rated as incorrect, then the woman was assigned a rating of "not knowledgeable."

To assess health literacy and more specifically functional cervical cancer health literacy, a standardized instrument known as the Cervical Cancer Literacy Assessment Tool (C-CLAT) was administered (Williams, 2009). The C-CLAT includes 21 items that measured functional cervical cancer health literacy through true/false and multiple-choice questions. Three content domains for cervical cancer were queried- Awareness, Knowledge, and Prevention/Control. All items but one (Q15) were summed for a final score that determined whether participants had "passing" or "non-passing" levels of functional cervical cancer health literacy based on the established passing value of ≥ 0.75 . Question 15 was a "neutral" item that asked about belief of whether cervical cancer resources were available in the community or not and therefore omitted in the calculation. Each participant completed both a CCQ and C-CLAT questionnaire.

2.5 Data Collection Procedures

Women were recruited via health clinic flyers and word-of-mouth from downtown El Paso neighborhoods and surrounding neighborhoods in the border region. A simple cell phone was purchased just for the study and contact slips with study eligibility information and phone number were distributed to the health clinics. Enrollment in the study was sequential, according to participant phone calls. When participants called they were read the consent form in the language of their choice (Spanish or English) and once they provide their verbal approval, the two questionnaires were administered. The PI documented all the response provided by the participants. Upon completion, the PI offered an optional review of the C-CLAT assessment and provided a basic overview of the educational/informational material to the participant and answered questions. Participants received an incentive card number with a redemption code over the phone upon completion.

To avoid queueing certain concepts, the CCQ was administered first in an attempt to capture true cervical cancer perceptions and ultimately knowledge among the participants; total time was approximately 20-30 minutes. Afterwards, the C-CLAT was administered and lasted approximately 5 minutes. The PI administered both questionnaires orally. After completion of both questionnaires, participants received two resources: 1) a printed fact sheet with basic cervical cancer information and 2) a directory of services for HPV vaccination. Participants had the option of receiving a 5-10-minute educational briefing of the resource information if they requested to do so. All materials and vocal interactions were provided in the language preference of the participant, English or Spanish.

While no personally identifying data was collected from the women, measures were put in place throughout the study to protect the data collected and to ensure the highest quality

results. All data was entered as the data was being collected and checked for accuracy using a triple-check method. As data were being collected, the descriptive characteristics of the data were checked to ensure that there were no issues with the collection or integrity of the data. When all data was collected, descriptive analyses were conducted to determine the proportions of answers obtained, examine trends in the data, and to characterize the sample.

2.6 Statistical Analysis

Data was entered into an Excel database. Data analysis was conducted for a total of 85 participants using SPSS for descriptive and inferential statistics. Descriptive statistics showed the characteristics of the sample population. Inferential statistics were used to examine the association for the variables of interest from the CCQ (cervical cancer knowledge, received cervical cancer information, received cervical cancer printed information, cervical cancer screening, family history of disease) and from the C-CLAT the C-CLAT percentage score variable (functional cervical cancer health literacy). Analysis of variance, chi-square models, and one t-test were used to test the planned hypotheses and exploratory questions.

Inferential analyses were conducted to statistically test the differences observed. The first analysis examined whether there was an association between “knowledge” as rated by the CCQ and C-CLAT percentage scores. Whether “knowledge” is required for “literacy” is debated in the literature, thus the goal of this analysis was to test the relationship between these constructs. The model compared the C-CLAT percentage scores of participants with and without “cervical cancer knowledge” and included family history of cancer in self or first-degree relatives, because it was reasoned that experiencing cancer was likely to yield higher knowledge (and perhaps literacy). There were certain variables that were not analyzed in this study, however they may be analyzed in the near future.

3. RESULTS

A total of 85 women completed the Cervical Cancer Questionnaire and the Cervical Cancer Literacy Assessment Tool (C-CLAT). Women were recruited via health clinic flyers and word-of-mouth from downtown El Paso neighborhoods and surrounding neighborhoods in the border region. Approximately eight hundred flyers were distributed. Given stay-at-home order and requirements for social distancing, all women were interviewed by phone (described in detail in Methods, page xx above).

3.1 Descriptive Statistics

The mean age of the sample was 42.79 (SD 13.23) see table 2. All of the participants self-identified as Hispanic/Latina and when asked about their heritage, three quarters, 75.3%, reported being of Mexican ancestry while 18.8% reported being of Mexican-American ancestry and 5.95% reported being of two or more backgrounds. Nearly half of the participants, 47.1%, had an annual income of \$10,000 to less than \$25,000 while 18.8% reported no annual income and 16.5% reported making less than \$10,000 per year. Additionally, nearly half of the participants, 47.1%, reported being currently married and one quarter, 25.9%, reported never being married. Pertaining to educational attainment, approximately one quarter (24.7%) reported being high school graduates; slightly fewer reported having less than a high school education (21.2%); and (17.6%) had undergraduate degrees. Half of the participants, 50.6%, chose Spanish as their language of preference when conducting the questionnaires while the other half, 49.4%, chose English as their primary language.

In addition to basic demographic information, the Cervical Cancer Questionnaire (CCQ) queried cervical cancer knowledge as shown in Table 3.

Responses to the Cervical Cancer Questionnaire knowledge questions (“perceived self-knowledge” and “knowledge”) were first examined followed by a final “knowledge” rating. When first asked (Do you know what cervical cancer is?) a majority of participants (76.3%) believed they knew what cervical cancer was (yes/no), and all but one participant, (75.3%) offered a knowledge explanation. However, only about half (56.5%) could in fact accurately explain cervical cancer. With regard to perceived self-knowledge of what contributes to cervical cancer, less than half of the participants (43.5%) believed they knew and all but one participant (42.4%), offered a knowledge explanation. Of those who did, only about one third (31.8%), could accurately state one or more causes such as persistent HPV infection, multiple sex partners, and/or smoking. With regard to final “knowledge” ratings, approximately one quarter of participants (27.1%) were “knowledgeable” (approximately three quarters (72.9%) did not know what cervical cancer was and/or could not state one or more causes). The CCQ also queried women about the number of sources of where they had previously received cervical cancer information and whether or not (yes/no) they had received printed information. Nearly half (48.2%), reported having previously received cervical cancer information from at least one source and approximately one third (31.8%) reported having previously received cervical cancer printed information. The majority of participants (81.2%) reported having recent pap exams (within the last 3 years).

Among the women participants, family history for any cancer type was reported for self, first-degree, second-degree, and third-degree relatives. Those who reported a positive family history of cancer included 69.4%; of those with a positive family history of cancer, 34.1% had a personal experience of cancer or cancer had occurred in a first-degree relative. In the tested hypotheses below, family history of cancer (in self or in a first-degree relative, yes/no) was used

as a control variable because it was reasoned that having a personal experience with cancer would be likely to increase knowledge.

The Cervical Cancer Literacy Assessment Tool (C-CLAT) was administered to measure cervical cancer “functional health literacy” (see Methods, page 26 above) and was used as the outcome variable for the primary hypotheses. Table 4 shows the means (SDs) and percentages of women meeting criteria for “cervical cancer functional health literacy.” The mean C-CLAT percentage score was 0.73 (SD 0.12) which was below the established C-CLAT “passing” score of (0.75). Similarly, there were approximately equal proportions of passing vs non-passing scores pertaining to cervical cancer functional health literacy; 54.1% and 45.9% respectively.

Table 2: Demographics and Characteristics of Study Population Results N=85

Variable		
Age (<i>mean, SD</i>)	42.79	13.23
	N	%
Language		
Spanish	43/85	50.6
English	42/85	49.4
Ethnicity		
Mexican	64/85	75.3
Mexican American	16/85	18.8
2 or more ethnicities	5/85	5.9
Annual Income		
No income	16/85	18.8
Less than \$10,000 per year	14/85	16.5
\$10,000 to less than \$25,000	40/85	47.1
\$25,000 to less than \$50,000	12/85	14.1
\$50,000 or more	3/85	3.5
Family Composition		
Married	40/85	47.1
Divorced/Separated	12/85	14.1
Widowed	3/85	3.5
Never Married	22/85	25.9
Unmarried Couple/Living with a partner	8/85	9.4
Education		
Less than High School	18/85	21.2
GED	9/85	10.6
High School Graduate	21/85	24.7

Technical School Graduate	5/85	5.9
Associates Degree	7/85	8.2
Undergraduate Degree	15/85	17.6
Graduate Degree	10/85	11.8

Table 3: Knowledge-Base of Cervical Cancer Results from Cervical Cancer Questionnaire (CCQ)

Variable	N	%
Perceived self-knowledge of cervical cancer (Q10a: Do you know what cervical cancer is?)		
Yes	65/85	76.5
No	20/85	23.5
Knowledge of cervical cancer (Q10b: Please explain what cervical cancer is.)		
Yes (offered an explanation on what it is)	64/85	75.3
No (Did not offer an explanation on what it is)	21/85	24.7
Rating for knowledge		
Correct	48/85	56.5
Incorrect	37/85	43.5
Perceived self-knowledge of what contributes to cervical cancer (Q13a: Do you believe you understand what contributes to a person getting cervical cancer?)		
Yes	37/85	43.5
No	48/85	56.5
Knowledge of what contributes to cervical cancer (Q13b: Please explain what contributes...)		
Yes (offered an explanation on what it is)	36/85	42.4
No (Did not offer an explanation on what it is)	49/85	57.6
Rating for Knowledge of what contributes to cervical cancer		
Correct	27/85	31.8
Incorrect	58/85	68.2
Overall cervical cancer basic knowledge rating (Knowledge of cervical cancer + Knowledge of what contributes to cervical cancer)		
Knowledgeable (both answers correct)	23/85	27.1
Not Knowledgeable (one or both answers incorrect)	62/85	72.9
Sources of Cervical Cancer Information		
No information received	13/85	15.3
1 source	41/85	48.2
2 or more sources	31/85	36.5
Cervical Cancer Printed Information		
Yes	27/85	31.8

No	58/85	68.2
Recent pap exam (within last 3 years)		
Yes	69/85	81.2
No	16/85	18.8
Family hx of any cancer (self, 1 st , 2 nd and/or 3 rd degree relatives)		
Yes	59/85	69.4
No	25/85	29.4
Missing	1/85	1.2
Family hx of any cancer (self & first-degree relatives)		
Yes	29/85	34.1
No	55/85	64.7
Missing	1/85	1.2

Table 4: Cervical Cancer Literacy Assessment Tool (C-CLAT) Results N=85

Variable		
C-CLAT % score (<i>mean, SD</i>)	.7318	.1236
	N	%
Functional Health Literacy		
Yes	46/85	54.1
No	39/85	45.9

3.2 Inferential Statistics

Prior to conducting the planned analyses, the distribution of the main outcome variable, the C-CLAT score distribution was tested for normality. The histogram of values is shown in Figure 1. A Shapiro-Wilk's test was performed and the results are presented in Table 5. Based on both test results, C-CLAT percentage score was treated as normally distributed.

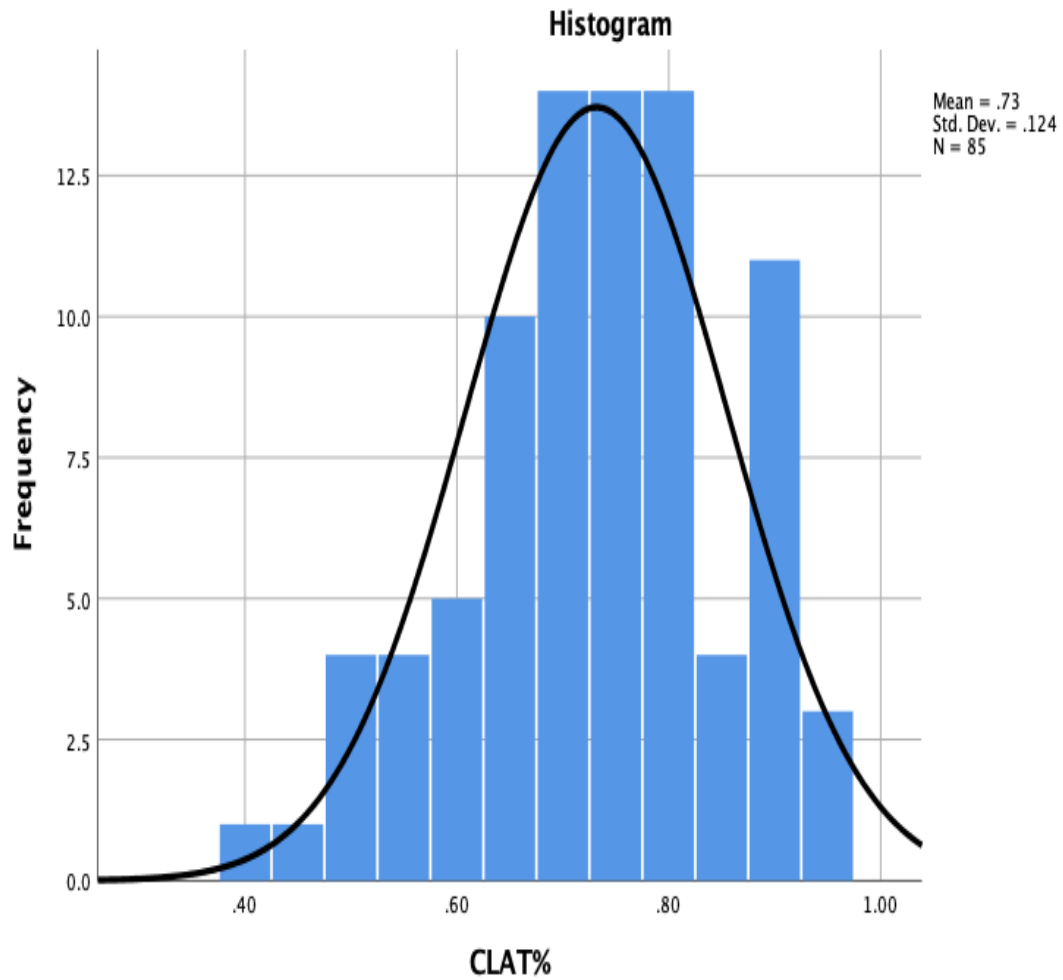


Figure 1

Table 5: Test of Normality for C-CLAT %

Tests of Normality			
	Shapiro-Wilk		
	Statistic	df	Sig.
CLAT%	.966	85	.024
a. Lilliefors Significance Correction			

Analysis of variance and chi-square models were used to test the planned hypotheses and exploratory questions. For the primary hypotheses, one ANOVA model was used to test both hypotheses. The model tested whether two predictive factors, “cervical cancer knowledge” (main effect, CCQ) and “family history of cancer” (main effect, CCQ) predicted C-CLAT percentage scores. The interaction of knowledge and family history of cancer was also tested. Table 6 shows the results. The model was significant ($F = 2.87$, $df = 3$, $p = 0.42$). There was a main effect for “cervical cancer knowledge.” “Family history of cancer” was not associated with C-CLAT percentage score. Thus, women with basic knowledge of cervical cancer (could state what cervical cancer was, and at least one cause) scored higher on the measure of cervical cancer literacy.

Table 6: ANOVA, Tests of Between-Subject Effects for Variables “Cervical Cancer Knowledge” and “Family History of Cancer”

Dependent Variable: CLAT%					
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	.120 ^a	3	.040	2.868	.042
Intercept	32.533	1	32.533	2332.065	.000
CQccknow	.076	1	.076	5.440	.022
CQfamhx	.048	1	.048	3.467	.066
CQccknow * CQfamhx	.004	1	.004	.298	.587
Error	1.116	80	.014		
Total	45.898	84			
Corrected Total	1.236	83			

a. R Squared = .097 (Adjusted R Squared = .063)

Two additional hypotheses were tested to explore the possible sources of the effect observed in the first model. Two additional models were calculated to determine whether having received prior information on cervical cancer would predict C-CLAT percentage scores. In both

ANOVA models, two predictive factors were used including “cervical cancer information received” (yes/no), and “family history of cancer” (yes/no). The main effects and interaction were tested. The results are shown in Table 7. Receiving any type of prior information on cervical cancer did not predict C-CLAT scores, and family history of cancer did not influence C-CLAT scores.

Table 7: ANOVA, Test of Between-Subjects Effects for Variables “Cervical Cancer Information Received” and “Family History of Cancer”

Dependent Variable: CLAT%					
Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	.121 ^a	5	.024	1.696	.145
Intercept	31.365	1	31.365	2194.514	.000
CQfamhx	.051	1	.051	3.598	.062
CQinfo	.017	2	.009	.606	.548
CQfamhx *CQinfo	.044	2	.022	1.546	.220
Error	1.115	78	.014		
Total	45.898	84			
Corrected Total	1.236	83			

a. R Squared = .098 (Adjusted R Squared = .040)

The second exploratory analysis tested whether having received prior printed information might influence C-CLAT scores. The ANOVA model again included family history of cervical cancer as a control factor and two main effects and the interaction were tested. As shown in Table 8, neither prior receipt of “printed information on cervical cancer”, nor “family history,” were significantly associated with C-CLAT scores.

Table 8: ANOVA, Test of Between-Subjects Effects for Variables “Cervical Cancer Printed Information Received” and “Family History of Cancer”

Dependent Variable: CLAT%					
Source	Type III Sum of Squares	Df	Mean Square	F	Sig.

Corrected Model	.085 ^a	3	.028	1.973	.125
Intercept	36.470	1	36.470	2535.057	.000
CQfamhx	.039	1	.039	2.723	.103
CQprint	.038	1	.038	2.661	.107
CQfamhx * CQprint	2.166E-5	1	2.166E-5	.002	.969
Error	1.151	80	.014		
Total	45.898	84			
Corrected Total	1.236	83			
a. R Squared = .069 (Adjusted R Squared = .034)					

In a further attempt to understand what past experiences regarding cervical cancer might predict cervical cancer knowledge (as determined by the CCQ), two chi-square analyses were also planned to determine whether “cervical cancer knowledge” (yes/no) was associated with having received prior cervical cancer information, or with having received (specifically) printed cervical cancer information. Given that family history of cancer was not a significant predictor in prior models, this variable was not included in these tests.

The variables in the first chi-square test did not allow for further analysis due to low cell count (one cell size was < 5); data criteria was also not met for a Fischer’s exact analysis. However, the second Chi-square test was conducted and it showed that having received prior “cervical cancer printed information” was not associated with “cervical cancer knowledge.” (X^2 (df=1, N=85) =3.753, p=.053) (table 9).

Table 9: Chi-Square Test for Variables “Cervical Cancer Printed Information Received” and “Cervical Cancer Knowledge”

Chi-Square Tests					
	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	3.753 ^a	1	.053		
Continuity Correction ^b	2.806	1	.094		
Likelihood Ratio	3.616	1	.057		

Fisher's Exact Test				.068	.049
Linear-by-Linear Association	3.709	1	.054		
N of Valid Cases	85				
a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 7.31.					
b. Computed only for a 2x2 table					

The final test examined whether women who had recent pap exams (within the last 3 years) would have higher C-CLAT percentage scores as compared to women with no recent pap exams (within the last 3 years). The analysis showed that among 85 participants, there was no significant difference in the average C-CLAT percentage scores for women who did have recent pap exams (within the last 3 years) (M= .7370; SD= .11871) compared to those who did not have a recent pap exam (within the last 3 years) (M=.7094; SD= .14517) ($p \geq 0.001$) (table 10).

Table 10: T-Test for Variables “recent pap exam” and “C-CLAT percentage scores”

Independent Samples Test										
	Levene's Test for Equality of Variances		t-test for Equality of Means							
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference		
								Lower	Upper	
CLAT%	Equal variances assumed	.913	.342	.802	83	.425	.02758	.03438	-.04080	.09597
	Equal variances not assumed			.707	19.907	.488	.02758	.03900	-.05380	.10897

4. DISCUSSION

In order to alleviate the marked racial/ethnic health disparity surrounding the high rates of cervical cancer in Hispanic/Latina women, comprehensive multidisciplinary approaches that also integrate health education, are needed to improve cervical cancer knowledge and health literacy and perhaps in turn, increase screening uptake, early detection and ultimately, cervical cancer fatalities. However, before more appropriate/effective interventions that encompass health education can be established for such groups, finding gaps in cervical cancer knowledge and health literacy is essential.

Though research on cervical cancer among US Hispanic women has increased over the last several years, relatively few studies have examined cervical cancer knowledge in Hispanic/Latina women, and even fewer have examined cervical cancer health literacy using standardized instruments.

The goal of this study was to assess uncued cervical cancer knowledge and functional health literacy among Hispanic women between the ages of 18-65 living in one US-Mexico border region in El Paso, TX. Upon completion of the questionnaire and C-CLAT assessment, women were provided with the correct responses for the assessment and had a cervical cancer educational briefing that included education on what cervical cancer is, who is at risk, risk factors for cervical cancer, screening guideline recommendations by the CDC, preventive measures, and information on where to get screened for cervical cancer and HPV immunization venues.

4.1 Summary of Findings

Descriptive and inferential analyses were conducted. Descriptive analyses revealed that while a majority of women (75.3%) expressed the belief that they knew what cervical cancer

was, only about half of those women (56.5%) could actually provide accurate information regarding the disease. With regard to knowledge of cervical cancer risk factors, fewer than half (42.4%) expressed the belief that they knew possible risk factors, and only one third of those women (31.8%) could accurately state one or more risk factors. The number of women rated by study-specific criteria for “cervical cancer knowledge” yes/no (see Methods page 33 above) was surprisingly low. Only about one quarter of women queried (27.1%) had basic cervical cancer “knowledge.”

The descriptive analyses also revealed that only about one half of the women (48.2%) had previously received cervical cancer information from at least one source; and only about one third (31.8%) recalled previously receiving cervical cancer information in printed form. Over three quarters of the participants (81.2%) were current with cervical cancer screening (reported having had a pap exam with the last 3 years).

With regard to family history of cancer, over half of the women (69.4%) reported a positive history of cancer among themselves, first-degree, second-degree, and/or third-degree relative(s). Of those, about half (34.1%) reported having had cancer themselves, or knew of a cancer occurrence in one or more first-degree relatives.

All participants completed the Cervical Cancer Assessment Tool (C-CLAT), a previously standardized measure of functional cervical cancer literacy. The mean percentage score was 0.73 (SD 0.12) and fell slightly below the established C-CLAT “passing score” of (0.75). In this population, 45.9% of women did not achieve a “passing” C-CLAT percentage score.

The analysis revealed that participants with cervical cancer knowledge (CCQ) had significantly higher C-CLAT percentage scores (higher cervical cancer functional health literacy) as compared to participants without cervical cancer knowledge. Contrary to expectations, this

analysis also revealed that having a “family history of cancer” was unrelated to C-CLAT percentage score.

Given the descriptive findings suggesting the relatively low rates of knowledge and literacy among participants, the next analyses attempted to understand reasons for the lack of knowledge and literacy, and to understand whether cervical cancer information remembered by Hispanic/Latinx women in this sample made any difference, that is, resulted in higher literacy scores. First, analyses tested whether having previously “received cervical cancer information” (yes/no) would predict C-CLAT percentage scores (higher cervical cancer functional health literacy). The analysis revealed that there was no effect of having previously “received cervical cancer printed information.” The C-CLAT percentage scores of women who had and had not received prior cervical cancer information did not differ.

Presuming that printed information might have more impact, another model was calculated to determine whether perhaps having received specifically printed information on cervical cancer might predict higher C-CLAT scores. Similar to the previous analysis, the C-CLAT scores of women who had and had not received prior printed information did not differ. In other words, having received prior printed information on cervical cancer seemed to have no relationship to C-CLAT scores. Finally, a chi-square analysis examined whether knowledge (yes/no) and having received printed information (yes/no) were associated. There was no association. (The model testing the association between knowledge and “any information” could not be interpreted due to one or more low count (< 5) cell size which invalidated the model; the Fischer’s exact model could not be done either due to data not meeting minimum criteria for that specific model).

4.2 Cervical Cancer “Knowledge”

Few studies have explored cervical cancer knowledge among US Hispanic women. Assessing “knowledge” poses many challenges (Watts, 2009; Ramirez, 2000). It is a complex construct that cannot always be easily measured, and if so, it is not always done using standardized instruments. In fact, there are few studies that have explored the concept of knowledge pertaining to cervical cancer among US Hispanic women. One such study conducted by Byrd et al. did so, and participants were from the same US-Mexico border region as participants in the study here described. The Byrd et al. study also explored attitudes and perceptions about cervical cancer and cervical cancer risk. In that study, participants were interviewed in focus groups, and it was reported that there was a mix of accurate and inaccurate knowledge, as well as misconceptions of cervical cancer (though specific results were not stated). This is consistent with findings from this study. Moreover, findings from the Byrd et al. study revealed that none of the participants in the focus groups were able to identify HPV, or even a virus, as a cause of cervical cancer. Participants did however mention multiple sexual partners as a risk factor.

Interestingly, in contrast to the Byrd et al. study, conducted in 2007, participants in the present study were able to accurately cite one or both of the aforementioned causes in their responses, in addition to other risk factors. This may suggest some small progress in this region over the intervening 13 years. This could also be due however to the demographic profile of the sample in this study, as there were more participants with higher educational attainment in the present study, as compared to the participants in the Byrd et al. study.

4.3 Cervical Cancer Health Information

Findings revealed that nearly half (48.2%) of the participants had previously received cervical cancer information from at least one source. The most commonly remembered sources of cervical cancer information included verbal information provided by an OBGYN and the media (ex. tv, internet, radio). The least commonly reported sources of information were from a family member/relative and or friends/peers. The women were clearly receptive to receiving cervical cancer information from their physicians in healthcare settings. However, in order for that to happen, it means that women must first have access to physicians and screening services. Ensuring this access is foundational for achieving disease reduction.

The findings also suggested that media were another valuable means for communicating important health education information pertaining to cervical cancer. Further exploration on how to best incorporate cervical cancer health messages into various media platforms (ex: t v, internet, radio) may also prove to be effective for cervical cancer knowledge and health literacy learning. Moreover, it was notable to find that over half of the women participants stated they had never received printed information regarding cervical cancer. This was surprising given the vast amount of educational printed material widely available (although not always in the Spanish language).

4.4. Cervical Cancer Screening

The American Cancer Society reported in 2015, lower up-to-date cervical cancer screening rates among US Hispanic women as compared to non-Hispanic white women (79% vs 89% respectively). In comparison to the US general population of Hispanic women with up-to-date screening (79%), the rate was similar in the present study; over three quarters (81.2%) of the study participants were current with cervical cancer screening. This finding suggests that the

women in the present study had some type of access for screening services for cervical cancer. Given the high rate of cervical cancer screening, this may also suggest that the women who participated in the current study may have already had a heightened awareness of cervical cancer and therefore were more adept to cervical cancer screening.

4.5 Family History of Cancer

Women were very willing to share their family history of cancer. There were a few instances where women knew that a relative in the family had been diagnosed with cancer but they either could not recall which type of cancer it was or they simply were unsure because it had happened a long time ago, or it had occurred in a relative with whom they did not have close family ties. It was also observed that for some women, having to recall family history disease made them realize that they could be more susceptible to certain diseases. Reviewing family history could perhaps be developed as a valuable tool for better sensitizing women to risk of disease.

4.6 Cervical Cancer Literacy Assessment Tool (C-CLAT)

With regard to the Cervical Cancer Assessment Tool (C-CLAT), the sample mean percentage score fell below the established C-CLAT “passing score.” Moreover, among those women who had a passing C-CLAT score, several of the women during the assessment admitted to not knowing the answers to one or more of the question items and therefore made educated guesses that turned out to be correct. Thus, the average passing score may be an over-estimate of what women actually knew.

4.7 Qualitative Observations of Participant’s Responses to C-CLAT Items

The C-CLAT is one of very few cervical cancer literacy rating tools standardized specifically for Arab, Black, and Latina women. While the tool is a valuable addition to the

literature, it is important to consider feedback from respondents about the items. For example, some of the women simply did not understand specific question items even though they were completing the questionnaire in the language of their choice (either Spanish or English). This in turn could have led to participants' inability to know how to answer certain items. These observations raised important questions about the extent to which the initial standardization study needs to be replicated with different subpopulations of Hispanic women.

It is also important to highlight that this specific sample of women included residents living along the US-Mexico border region and therefore, some of the participants answered questions regarding optimal screening frequency according to screening guidelines established in Mexico, and not in the U.S. For future studies conducted on the border, it will be important to capture this variability quantitatively. In other words, one or more additional questions should be added to indicate on which guidelines the participant is basing their answer.

Upon completing the assessment, women were given the option to review items they did not answer correctly, and 100% of the participants chose to go over the responses they had missed with the PI. This was another opportunity to obtain rich qualitative information about women's knowledge and C-CLAT scores. For example, several of the participants did not agree that the correct response for "Getting a Pap test is very painful" should be "false." When queried further about their views, participants explained that "women have different pain thresholds;" "doctors may not always be gentle;" and "women can be different down there" (referring to depth and size of cervix). During the educational briefing, some women also expressed concern/disagreement over the screening guidelines established by the CDC, and stated that screening every three years was too long of a time period, and that annual checkups would be "safer" in order to prevent and/or detect cervical cancer earlier. In fact, guidelines for Pap

screenings have shifted around over the past 10 years leaving women confused. They were all very good points, again raising important questions regarding whether the current C-CLAT standardization scale is adequate to use in any subpopulation of Latina women.

4.8 Association of Cervical Cancer Knowledge and Higher Health Literacy

Findings from this study revealed that participants that demonstrated “knowledge” had higher cervical cancer functional health literacy scores. Importantly, this was a simple validation of the CCQ “knowledge” ratings (yes/no). This finding was also very interesting because prior research on health literacy has debated the role of health knowledge within health literacy theories. Research is still exploring whether health knowledge functions as an antecedent of health literacy, is part of health literacy itself, or is a consequence of health literacy (Gellert & Tille, 2015). While the primacy of cervical cancer knowledge in health literacy could not be fully tested in this study, the fact that women with “knowledge” had significantly higher C-CLAT scores logically suggested that knowledge could be either antecedent or concomitant with literacy, and, indirectly, did not support the view that knowledge followed literacy. In other words, this finding was not consistent with the existing literature that suggests health knowledge happens as a consequence of functional health literacy theories (Berman et al., 2011). More research is needed to explore this.

4.9 Association of Family History of Cancer and Higher Health Literacy Scores

It was interesting to find that there was no meaningful difference in C-CLAT percentage scores between women with and without a family history of cancer. It was presumed that women who reported a positive family history of cancer (for any cancer type) among themselves or a among a first-degree relative(s), higher cervical cancer functional health literacy scores would be observed. The analysis showed in fact that experiencing cancer did not confirm any additional

health literacy among this sample of women. This may suggest that even while women are undergoing cancer treatment themselves or among a first degree relative, cancer education may not be happening. If education is happening, it may also suggest that the individuals may not be processing it at the time or were not seeking it. Other possibilities may include individuals actively avoiding the education as a coping strategy. Future studies are needed to explore this phenomenon.

4.10 Association of Cervical Cancer Screening and Higher Health Literacy

One of the major goals of the present study was to assess cervical cancer health literacy because it was assumed that this would be associated with cervical cancer screening.

Surprisingly, there was no association between cervical cancer health literacy and screening behavior. This means that health literacy scores (as determined by C-CLAT) were not higher among women who did have recent pap exams (within the last 3 years) as compared to women who did not have recent pap exams (within the last 3 years). This suggests that despite being screened, cervical cancer health literacy is not being enhanced.

4.11 Understanding the Sources of Acquired Health Literacy

Another key goal of this study was to examine knowledge and literacy in this sample and to explore possible factors that might or might not contribute to literacy. Once it was determined that the mean literacy score for women in this sample was below the C-CLAT “passing” criteria, it became important to understand how having received prior information might or might not have influenced literacy. These analyses helped to understand the possible impact of receiving information on literacy. The analyses showed that cervical cancer functional health literacy score was not predicted by whether women had previously received any health information regarding the disease (from one or various sources reported), or whether women had received

specifically printed information on cervical cancer. Further, analyses showed that knowledge was not impacted by having received printed information.

These findings supported the notion that health literacy is multidimensional and highly complex. Consistent with broader health literacy theories, the findings suggested that much more may be required to build health literacy and knowledge than simply providing someone with health information, from one or more sources, and printed or not. Most importantly, taken together, these findings suggested that the current cervical cancer health information is wholly inadequate when provided to Hispanic women residing in the El Paso border region and ineffective in building knowledge or literacy.

4.12 Implications of Study Findings for Public Health Practice

This study offered valuable insight on the importance of examining “knowledge” and functional health literacy pertaining to cervical cancer among US Hispanic women living in the US-Mexico border region. The finding that only about one quarter of the women were “knowledgeable” about cervical cancer (that is, could describe what it was and could mention at least one risk factor) revealed that there is a huge gap in cervical cancer knowledge among high-risk women. This is very concerning. A lack of cervical cancer knowledge has been cited in the literature as a barrier for cervical cancer screening (Flores, 2013). If cervical cancer screening rates are to improve and continue, it is imperative to increase cervical cancer knowledge.

Additionally, the finding that only approximately half of the women had “passing” scores for cervical cancer functional health literacy is also very concerning. Though perhaps more challenging, increasing cervical cancer health literacy is equally, if not, more important to increase preventive screening. The literature continues to accumulate evidence for the negative impact of limited health literacy and health outcomes. Among adults with poor health literacy, it

has been shown that they have less knowledge of disease management, less knowledge of health promoting behaviors, report poorer health status, and are less likely to use preventive services (Wang, 2010).

Approaches for increasing both knowledge and health literacy pertaining to cervical cancer should be comprehensive and multidisciplinary. According to findings from this study, receiving health information on cervical cancer did not have an impact on women's knowledge or health literacy. However, that does not mean that health information should not be provided. Rather, it means that the practice of educating women about cervical cancer in medical and public health communities needs to improve. New models for educating women are needed that go well beyond the current health information provided. For example, women may need to be engaged in discussion groups that include role-playing exercises on how to ask questions in medical settings; they may need video content provided by cancer survivors, and they may need basic skills training to learn how to find credible health information. Research studies are needed to pilot and test the efficacy of these and other approaches for changing women's preventive health behaviors.

Women in this study reported receiving cervical cancer information most commonly from their obstetricians/gynecologists, and through media (ex. tv, internet, radio), two valuable sources that with some modification can facilitate cervical cancer knowledge and build on health literacy. Perhaps obstetricians/gynecologists could be taught how to use simpler language when they provide information about cervical cancer to their patients. More importantly, instead of solely providing information, they need to engage their patient's during basic educational briefings about cervical cancer by asking questions, and "testing" their patients in a collaborative and engaging way. Through this type of activity, patients have more opportunities to

communicate and ask open-ended questions. If the obstetricians/gynecologists cannot do this themselves, perhaps assistants can be trained to do it, and do so in the language of choice of the patient. Cervical cancer health information shared through media should also be available in both the Spanish and English languages, include simple and relatable language, and should be culturally sensitive to the target population. The focus of both health messages should include minimum prevention behaviors to ensure early disease detection.

To build cervical cancer health literacy, approaches need to go beyond individual's knowledge about the disease. This means that cervical cancer health education should also be reinforced by various materials and not just by handing out pamphlets or other written materials and assuming it will be read and easily understood. A comprehensive approach needs to happen over the course of time and not only as a one-time intervention. Integrating health education interventions across a woman's life span is essential to build not only knowledge but also health literacy for improved cervical cancer outcomes.

4.13 Limitations

This study had limitations that are worthy to note. First, the original goal to recruit 150 participants could not be achieved because of stay-at-home orders and requirements for social distancing. Therefore, a convenience sample was drawn upon which could have led to a biased sample. This means that the study could have attracted women with an already heightened awareness of cervical cancer. Additionally, if the sample size had been larger, it may have been more representative of the population and more analyses could have been conducted to explore other questions.

The CCQ is not a standardized instrument. Data collected through the questionnaire queried self-reported data for anthropometric measures, cervical cancer screening, vaccine

history, and family history of disease. While the questions were carefully designed to be easily answerable, self-reported data may not have been completely accurate and could not be validated. Furthermore, self-reported data could have led to recall bias and social desirability bias. Another limitation may have been introduced by the approach to assigning “knowledge” ratings. Measuring a construct like knowledge based on information from open-ended questions is challenging and ultimately subjective. The open-ended items on the CCQ could be improved to prompt for more structured responses that perhaps would be easier to rate. For example, when asked “do you know what contributes to cervical cancer?” some participants mentioned barriers to detecting cervical cancer, instead of cervical cancer risk factors. Additionally, the phrase “cervical cancer screening” in the English version of the questionnaire was not always clearly understood to mean utilization of a pap/hpv exam. Adding a question on insurance coverage would also be helpful for better examination of cervical cancer screening barriers and facilitators.

In reference to the C-CLAT assessment, the Spanish version had some challenges. There were specific question items that were not easily understood by the participants because certain words were not common to the vocabulary used by the women participants residing in the US-Mexico border area. Therefore, modification of certain terms would be beneficial for clearer understanding and replication of the standardization study in the Spanish language version of the instrument is needed.

4.14 Conclusions

Despite major decreases in cervical cancer incidence rates in the U.S. over the past several decades, certain subpopulations of women continue to be disproportionately affected by it. One of these groups includes US Latina/Hispanic women who have the highest cervical cancer incidence rates as compared to women from other racial/ethnic minorities. To improve

detection and prevention in US Latina/Hispanic women, it is critical to understand their current knowledge and health literacy with regard to cervical cancer. This study was among the first to explore the association of cervical cancer functional health literacy (using a standardized instrument [C-CLAT]) and basic cervical cancer knowledge (as determined by the CCQ) among both Spanish-speaking and English-speaking participants of mostly Mexican origin. In doing so, it revealed that only about one quarter of participants were able to demonstrate basic knowledge of cervical cancer, and approximately half had “passing” scores for cervical cancer functional health literacy. Furthermore, it revealed that current education regarding cervical cancer among Latina/Hispanic women in the El Paso border region is may be both seriously lacking and inadequate when provided. The practice of educating women about cervical cancer must be greatly enhanced in order to improve cervical cancer outcomes for high-risk Hispanic women living in the US-Mexico border region. Standardization of the C-CLAT instrument should also be re-evaluated for use among subgroups of Latina women living in the US.

5. MPH PROGRAM FOUNDATIONAL COMPETENCIES

There were five MPH program foundational competencies that applied to my thesis. The first one included: Evidence-based Approaches to Public Health. Under this area I was able to apply the following components; 1) Select quantitative and qualitative data collection methods appropriate for a given public health context, 2) Analyze quantitative and qualitative data using biostatistics, informatics, computer-based programming and software, as appropriate and 3) Interpret results of data analysis for public health research, policy or practice. The second foundational competency included Public Health & Health Care Systems. Under this area I was able to discuss the means by which structural bias, social inequities and racism undermine health and create challenges to achieving health equity at organizational, community and societal levels. The third foundational competency included Planning & Management to Promote Health. Under this area I was able to assess population needs, assets and capacities that affect communities' health. The fourth foundational competency I applied was Leadership which allowed me to apply principles of leadership, governance and management, which include creating a vision, empowering others, fostering collaboration and guiding decision making. The last foundational competency, included communication. Under this area I was able to communicate audience-appropriate public health content, both in writing and through oral presentation. Furthermore, I was able to apply one of the MPH program Hispanic and Border Health Concentration competencies which included stating the principles of prevention and control of disease, and discuss how these can be modified to accommodate cultural values and practices in Hispanic border communities.

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7. APPENDIX

Cervical Cancer Questionnaire (CCQ)

Date: _____

Date of Birth: _____	Subject ID: _____
Zip Code: _____	Verbal Consent: _____

Start Time: _____

End Time: _____

This is an anonymous survey; all information collected is for research purposes only.

Section 1: Demographics and Anthropometric

1. What is your marital status?
 Divorced/Separated Married Widowed
 Living with a Partner Never Married

2. What is your heritage?
 Alaska Native Mexican South American
 African American Mexican American Spaniard
 American Indian Central American Native Hawaiian
 Asian Cuban Pacific Islander
 Black Dominican Other: _____
 White Puerto Rican

3. What is your highest level of education?
 Less than high school Associates Degree
 GED Undergraduate Degree
 High School Graduate Graduate Degree
 Technical School Graduate Masters
 PhD

4. What is your estimated weekly income? _____ monthly? _____ No. household family members: _____

5. What is your height? _____

6. What is your weight? _____

7. Do you consider yourself overweight? Circle one. Yes No Don't Know

8. Do you consider yourself obese? Circle one. Yes No Don't Know

Section 2: Knowledge-base

9. Do you know what cancer is? Please explain.

10. Do you know what cervical cancer is? Please explain.

11. How did you learn about cervical cancer? Were you provided any of the following:
 Printed information, where: _____ Family member/relative
 Verbal explanation, who: _____ Friends/peers
 Media, please specify: _____ Other: _____
 College Course: _____ No information

12. When you learned about cervical cancer, were you given printed information?
- Yes
 - No
 - Not applicable
- a. When you learned about cervical cancer, was it in a language you could understand?
- Yes
 - No
 - Not applicable
- b. Did you ask any questions about the information that was given to you?
- Yes
 - No
 - Not applicable
- c. Did you trust the person/organization that gave you the information?
- Yes
 - No
 - Not applicable
- d. Did you believe the information that was given to you?
- Yes
 - No
 - Not applicable
13. Do you believe you understand what contributes to a person getting cervical cancer?
- Yes
 - No
- a. If yes, what do you think contributes to a person getting cervical cancer?

14. Have you ever been screened for cervical cancer?

- Yes
 - No
- Why not? _____

a. When was the last year you got screened for cervical cancer? _____

Section 3: Vaccine History

Please mark all the vaccines you have received and provide dates when applicable.

Vaccine Type:	Yes	No	Don't know	Last Year Given:
Influenza (Flu)				
Human papillomavirus (HPV)				
Pneumonia				
Hepatitis A				
Hepatitis B				

Section 4: Family History of Disease- Please indicate which medical conditions have been medically diagnosed.

	Maybe	No One		Self	Mother	Father	Sister	Brother	Grandmother (mom's mom)	Grandfather (mom's dad)	Grandmother (dad's mom)	Grandfather (dad's dad)	Child 1	Child 2	Child 3	Uncle 1 (mom's brother)	Aunt 1 (mom's sister)	Uncle 2 (dad's brother)	Aunt 2 (dad's sister)	Other Relatives		
			Cancer																			
			Breast Cancer																			
			Cervical Cancer																			
			Prostate Cancer																			
			Cancer, Other																			
			Metabolic																			
			Diabetes Type I																			
			Diabetes Type II																			
			Obesity																			
			Osteoporosis																			
			Heart																			
			Heart Disease																			
			Heart Arrhythmia																			
			Congestive heart failure																			
			Heart attack																			
			High Blood Pressure																			
			High Cholesterol																			
			Stroke																			
			Respiratory																			
			Asthma																			
			Emphysema																			
			Tuberculosis																			
			Organ																			
			Kidney Disease																			
			Thyroid Disease																			
			Mental Health																			
			Mental Illness (Diagnosed)																			
			Depression																			
			Autism																			
			Schizophrenia																			
			Post Traumatic Stress Disorder (PTSD)																			
			Alcoholism or Drug Use																			
			Seizures																			
			STIs																			
			Chlamydia																			
			Herpes																			
			Gonorrhea																			
			Hepatitis B																			
			HIV																			
			Syphilis																			
			Human papillomavirus																			
			Other, indicate type here:																			

Cuestionario de Cáncer Cervical

Fecha: _____

Fecha de Nacimiento: _____	ID del Sujeto: _____
Codigo Postal: _____	Consentimiento verbal: _____

Hora de Inicio: _____

Hora de Finalización: _____

Lo siguiente es una encuesta anónima; toda información obtenida será solo para uso de estudio.

Sección 1: Demografía y Antropométrico

15. ¿Cuál es su estado civil?
- | | | |
|--|---------------------------------------|--------------------------------|
| <input type="checkbox"/> Divorciado/Separado | <input type="checkbox"/> Casado | <input type="checkbox"/> Viudo |
| <input type="checkbox"/> Viviendo con un Compañero | <input type="checkbox"/> Nunca Casado | |
16. ¿Cuál es su patrimonio?
- | | | |
|---|---|--|
| <input type="checkbox"/> Nativo de Alaska | <input type="checkbox"/> Mejicano | <input type="checkbox"/> Sudamericano |
| <input type="checkbox"/> Afroamericano | <input type="checkbox"/> Mejicano Americano | <input type="checkbox"/> Español |
| <input type="checkbox"/> Indio Americano | <input type="checkbox"/> Americano Central | <input type="checkbox"/> Nativo Hawaiano |
| <input type="checkbox"/> Asiático | <input type="checkbox"/> Cubano | <input type="checkbox"/> Isleño del Pacifico |
| <input type="checkbox"/> Etnicidad Negra | <input type="checkbox"/> Dominicano | <input type="checkbox"/> Otro: _____ |
| <input type="checkbox"/> Etnicidad Blanca | <input type="checkbox"/> Puertorriqueño | |
17. ¿Cuál es su nivel más alto de educación?
- | | |
|---|--|
| <input type="checkbox"/> Menos que la preparatoria | <input type="checkbox"/> Licenciatura en un Asociado |
| <input type="checkbox"/> Diploma de educación general | <input type="checkbox"/> Licenciatura |
| <input type="checkbox"/> Graduado de Preparatoria | <input type="checkbox"/> Diploma de Posgrado |
| <input type="checkbox"/> Graduado de escuela técnica | <input type="checkbox"/> Maestría |
| | <input type="checkbox"/> Doctorado |
18. ¿Cuál es su ingreso semanal? _____ mensual? _____ Número de miembros en el hogar: _____
19. ¿Cuál es su estatura? _____
20. ¿Cuál es su peso? _____
21. ¿Se considera ser una persona de sobrepeso? Circule Uno. Sí No No Se
22. ¿Se considera ser una persona obesa? Circule uno. Sí No No Se

Sección 2: Base de Conocimiento

23. ¿Sabe que es el cáncer? Explique en detalle.
24. ¿Sabe que es el cáncer cervical? Explique en detalle.
25. ¿Cómo llego a saber del cáncer cervical? Le proporcionaron uno de los siguientes:
- | | |
|--|--|
| <input type="checkbox"/> Información impresa, donde: _____ | <input type="checkbox"/> Familiar/Pariente |
| <input type="checkbox"/> Explicación Verbal, quien: _____ | <input type="checkbox"/> Amigos/Compañeros |

- Redes Sociales, por favor especifique: _____
- Curso Universitario: _____
- Otra forma: _____

26. ¿Cuándo se enteró del cáncer cervical, le entregaron información impresa?

- Si
 No

e. ¿Cuándo se enteró del cáncer cervical, fue en un lenguaje fácil de entender?

- Si
 No
 No aplica

f. ¿Alguna pregunta que tuvo después que le otorgaron la información?

- Si
 No
 No aplica

g. ¿Le tuvo confianza a la organización que le otorgo la información?

- Si
 No
 No aplica

h. ¿Cree que la información que se le otorgo es auténtica?

- Si
 No
 No aplica

27. ¿Usted cree entender que es lo que contribuye a el cáncer cervical?

- Si
 No

b. ¿Qué es lo que usted cree, contribuye a el cáncer cervical?

28. ¿Se ha hecho estudios para el cáncer cervical?

- Si
 No
 ¿Porque
 no? _____

b. ¿Cuál fue el ultimo ano en que se izó estudios para el cáncer cervical? _____

Sección 3: Historial de Vacunas

Marque todas las vacunas que recibió y proporcione las fechas adecuadas.

Tipo De Vacuna:	Si	No	No Se	Ultimo Ano recibido
Influenza (Gripa)				
Virus del papiloma humano				
Neumonía				
Hepatitis A				
Hepatitis B				

Sección 4: Antecedentes familiares de enfermedad - Indique qué afecciones médicas se han diagnosticado médicamente en su familia.

Tal vez	Nadie		Yo	Mama	Papa	Hermana	Hermano	Abuela (mama de mama)	Abuelo (papa de mama)	Abuela (mama de papa)	Abuelo (papa de papa)	Hijo/a 1	Hijo/a 2	Hijo/a 3	Tío 1 (hermano de mama)	Tía (hermana de mama)	Tío (hermano de papa)	Tía (hermana de papa)	Otros parientes:
		Cáncer																	
		Cáncer de mama																	
		Cáncer cervical																	
		Cáncer de próstata																	
		Otro Cáncer																	
		Metabólica																	
		Diabetes Tipo I																	
		Diabetes Tipo II																	
		Obesidad																	
		Osteoporosis																	
		Corazón																	
		Enfermedad del corazón																	
		Arritmia cardíaca																	
		Insuficiencia cardíaca congestiva																	
		Ataque al corazón																	
		Alta presión sanguínea																	
		Colesterol alto																	
		Derrame cerebral																	
		Respiratorio																	
		Asma																	
		Enfisema																	
		Tuberculosis																	
		Órgano																	
		Enfermedad del riñón																	
		Enfermedad de tiroides																	
		Salud Mental																	
		Enfermedad mental Diagnosticada																	
		Depresión																	
		Autismo																	
		Esquizofrenia																	
		Trastorno de estrés postraumático																	
		Alcoholismo o uso de drogas																	
		Convulsiones																	
		Enfermedad de transmisión sexual																	
		Clamidia																	
		Herpes																	
		Gonorrea																	
		Hepatitis B																	
		El VIH																	
		Sífilis																	
		Virus del papiloma humano																	
		Otro tipo de enfermedad:																	

Cervical Cancer Literacy Assessment Tool^c

Awareness

1. Although there are many different names for types of cancers you can get them the same way.
_____ (1) True _____ (0) False
2. Cervical Cancer is preventable.
_____ (1) True _____ (0) False
3. Cervical Cancer is a slow growing cancer.
_____ (1) True _____ (0) False
4. Cervical Cancer does not have symptoms you can feel.
_____ (1) True _____ (0) False

Knowledge and Screening

5. A woman should begin to have a Pap test after she becomes sexually active or when she turns 21, which ever comes first.
_____ (1) True _____ (0) False
6. A woman should get a Pap test every three years if her previous results were normal.
_____ (1) True _____ (0) False
7. If a woman had a Pap test in the past with results that were abnormal, she does not need to continue getting regular Pap tests
_____ (1) True _____ (0) False
8. A pelvic exam is just another word for a Pap test?
_____ (1) True _____ (2) False
9. A woman is at risk for getting cervical cancer if she has unprotected sexual intercourse.
_____ (1) True _____ (0) False
10. I should request a Pap test from my healthcare provider if I have:
 1. Bleeding after intercourse
 2. Bleeding between periods
 3. Bleeding after menopause

- 4. All of the above
- 5. None of the above

11. I should request a Pap test if:

- 1. I have a discharge with an odor.
- 2. I have pain in my pelvic area.
- 3. I have painful sexual intercourse.
- 4. I have discomfort, back-pain or poor health.
- 5. All of the above.
- 6. None of the above.

Prevention and Control

12. Using condoms decreases a woman chance for getting HPV infection that is the main risk factor for cervical cancer.

_____ (1) True _____ (0) False

13. Precancerous changes and early cancers of the cervix generally do not cause pain.

_____ (1) True _____ (0) False

14. When detected early, cervical cancer can be cured.

_____ (1) True _____ (0) False

15. There are resources in my community for low and no cost cervical cancer screenings.

_____ (1) True _____ (0) False

16. If my family member has cancer I am at higher risk for Cervical Cancer.

_____ (1) True _____ (0) False

17. Getting a Pap test is very painful.

_____ (1) True _____ (0) False

18. Women who do not have sexual intercourse do not need to get a Pap test.

_____ (1) True _____ (0) False

19. Pap tests are for women in childbearing years, older women do not need it.

_____ (1) True _____ (0) False

20. The following are risk factors for Cervical Cancer:
1. Giving birth to many children
 2. Having many sexual partners
 3. Having sex with a partner who has many partners
 4. Having a weak immune system
 5. All of the above
 6. None of the above
21. Recovery from cervical cancer depends on
1. The stage of cancer
 2. The type of cancer
 3. The size of the cancer
 4. All of the above
 5. None of the above

Cervical Cancer Literacy Assessment Tool^c

Conciencia

1. Si bien hay varios diferentes nombres para cada tipo de cáncer los puedes contraer todos de la misma forma.

_____ (1) Verdadero _____ (0) Falso

2. El cáncer de cuello uterino es prevenible.

_____ (1) Verdadero _____ (0) Falso

3. El cáncer de cuello uterino es un cáncer de crecimiento lento.

_____ (1) Verdadero _____ (0) Falso

4. El cáncer de cuello uterino no tiene síntomas que usted pueda sentir.

_____ (1) Verdadero _____ (0) Falso

Conocimiento y Cernimiento o Tamizado

5. Una mujer debería empezar a tener una prueba de pap después que se haga sexualmente activa o cuando cumpla 21, cualquiera que ocurra primero.

_____ (1) Verdadero _____ (0) Falso

6. Una mujer debería realizar una prueba de pap cada tres años si sus previos resultados fueron normales.

_____ (1) Verdadero _____ (0) Falso

7. Si una mujer tuvo una prueba de pap en el pasado con resultados que fueron anormales, ella no necesita continuar realizando pruebas de pap regularmente

_____ (1) Verdadero _____ (0) Falso

8. ¿Un examen pélvico es solo otra palabra para una prueba de pap?

_____ (1) Verdadero _____ (0) Falso

9. Una mujer se encuentra en riesgo de contraer cáncer del cuello uterino si ella tiene una relación sexual sin protección.

_____ (1) Verdadero _____ (0) Falso

10. Yo debería solicitar una prueba de pap a mi proveedor de cuidado de salud si yo tengo:

- 6. Sangrados después de la relación sexual
- 7. Sangrado entre periodos
- 8. Sangrado después de la menopausia
- 9. Todos los de arriba
- 10. Ninguno de los de arriba

11. Yo debería solicitar una prueba de pap si:

- 7. Yo tengo flujos con olor.
- 8. Yo tengo dolor en el área de mi pelvis.
- 9. Yo tengo relaciones sexuales dolorosas.
- 10. Yo tengo malestar, dolor de espalda o mala salud.
- 11. Todos los de arriba
- 12. Ninguno de los de arriba.

Prevención y Control

12. Usar condones decrece las posibilidades de una mujer de contraer la infección por el VPH el cual es el principal factor de riesgo del cáncer del cuello uterino.

_____ (1) Verdadero _____ (0) Falso

13. Cambios pre cancerígenos y cánceres tempranos de la cervix generalmente no causan dolor.

_____ (1) Verdadero _____ (0) Falso

14. Cuando se detecta temprano, el cáncer del cuello uterino puede ser curado.

_____ (1) Verdadero _____ (0) Falso

15. Hay recursos en mi comunidad para realizar cernimiento o tamizado de cáncer del cuello uterino a bajo o no costo.

_____ (1) Verdadero _____ (0) Falso

16. Si un miembro de mi familia tienen cáncer yo tengo altos riesgos de tener cáncer del cuello uterino.

_____ (1) Verdadero _____ (0) Falso

17. Realizar una prueba de pap es muy dolorosa.

_____ (1) Verdadero _____ (0) Falso

18. Las mujeres que no tienen relaciones sexuales no necesitan hacer una prueba de pap.

_____ (1) Verdadero _____ (0) Falso

19. Las pruebas de Pap son para mujeres en edad de concebir, mujeres mayores no lo necesitan.

_____ (1) Verdadero _____ (0) Falso

20. Los siguientes are factores de riesgo para el cáncer del cuello uterino:

- a. Dar a luz muchos niños
- b. Tener muchas parejas sexuales.
- c. Tener relaciones sexuales con una pareja quien tiene muchas parejas.
- d. Tener un sistema inmune débil.
- e. Todos los de arriba
- f. Ninguno de los de arriba

21. Recuperarse del cáncer del cuello uterino depende de

- a. La etapa del cáncer
- b. El tipo de cáncer
- c. El tamaño del cáncer
- d. Todos los de arriba
- e. Ninguno de los de arriba

List of key/words phrases

Cervical cancer is:

- Reproductive system cancer in females (borderline correct, may need more specific details)
- Cancer in the cervix and surrounding area
- Cancer of the cervix
- Cancer of the neck of uterus
- Cancer in your uterus (borderline correct, may need more specific details)
- Abnormal cells growing in cervix
- Fast growing cells specific to cervical region
- Cancer in lining of cervix

Risk factors for cervical cancer:

- Genetic
- Hereditary
- HPV
- Not using condoms
- Unprotected sex
- Having many sexual partners
- Multifactorial comorbidities
- Infection with STD/HIV
- Smoking
- Having many children
- The use of birth control pills longer than 5 years

8. CURRICULUM VITA

Crystal Costa is from the unique southwest border town of El Paso, TX that borders both Mexico to the south and New Mexico to the west. Before becoming a master's of public health candidate at the University of Texas at El Paso (UTEP), she served internationally for a little over two years as an education Peace Corps Volunteer in Madagascar. Her undergraduate degree in Linguistics allowed her to teach English as a second language abroad. She also held other critical roles that centered on serving as a health educator, teacher trainer, mentor, and a cross-cultural exchange ambassador. Her interests involve working with both underserved and underrepresented populations to build capacity among community leaders and members in fundamental public health matters with an emphasis on environmental justice, health advocacy, health education, and health communication. Most currently, her research involves working with an interdisciplinary team on a child lead study and examining Latino/Hispanic cancer health disparities among US Latinx peoples living along the US-Mexico border. She hopes to continue onto a doctoral program upon completion of her first graduate degree.