

CERVICAL CANCER HEALTH DISPARITIES
AND CONTINUITY OF CARE AMONG
HISPANIC WOMEN

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ABSTRACT

Understanding modifiable risk factors is a critical step towards developing ethnoracially sensitive, targeted prevention efforts aimed at reducing cervical cancer incidence and mortality among Hispanic women. Existing theoretical/conceptual models of health disparities are limited by lack of specificity and failure to consider unique challenges associated with each ethnoracial group, as well as unique demands, stigma, or contexts associated with specific diseases. Using a combination of theoretical models, this review attempts to propose a comprehensive model of cervical cancer health disparities among Hispanic women that includes disease- and population-specific risk factors as related to primary, secondary and tertiary prevention of the disease.

Several aspects of Hispanic culture and experiences appear to be significantly impacting Hispanic women's cervical cancer preventive practices, diagnosis disclosure and post-diagnosis social support seeking. Cultural phenomena such as *marianismo*, an emphasis on chastity, *fatalismo*, and *familismo* along with other factors such as immigration status, language barriers, health insurance status, and social isolation appear to be important in identifying causes and correlates of observed cervical cancer health disparities and treatment. Several possible points of culturally sensitive intervention are identified to ameliorate cervical cancer health disparities among Hispanic women.

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CHAPTER 1 HEALTH DISPARITIES

Latinos have become the largest and fastest growing ethnic minority group in the United States (Cuevas, Sabina, & Picard 2010). Like other minority groups in the U.S., significant health disparities have been found to affect this population. Cervical cancer is one disease with pronounced health disparities among ethnoracial minorities. Incidence and mortality rates attributable to cervical cancer are higher among ethnoracial minorities as compared to non-Hispanic whites (Lim, 2010). Compared to all other ethnic groups, Hispanic women have the highest incidence of invasive cervical cancer and the second highest cervical cancer mortality rates, second only to African-American women (Tung, 2011). Incidence rates are almost twice as high among Hispanic women, compared to non-Hispanic white women (Espinosa del los Monteros & Gallo, 2011; O'Brien, Halbet, Bixby, Pimentel, & Shea, 2010). With incidence rates for Hispanic women at 11.8 compared to 7.2 among Whites (Siegel et al., 2015). The age adjusted mortality rates are also higher for Hispanic women: 4.3/100,000 for African American women and 3.0 for Hispanic women versus 2.4 for the general U.S population (Tung, 2011).

Factors such as money, power, prestige and social connection, provide majority culture individuals access to an array of health and wellness resources that can reduce disease morbidity and mortality; opportunities unavailable to disenfranchised minority group members. Likewise, the benefits of advances in medical care may not be dispersed evenly throughout the population, such that individuals who are not subject to

discrimination and stigma are more likely to reap the benefits of new medical discoveries. Potentially lifesaving resources are less likely to be rapidly dispersed to individuals of lower socioeconomic status and to ethnoracial minorities due to their disenfranchised status (Saldana-Ruiz, Clouston, Colen, & Link, 2013). These structural barriers contribute to increased disease burden for ethnic minority individuals, particularly those of low Socioeconomic Status (SES).

While health disparities and ethnoracial minority status are correlated, it is important to clarify that health disparities are not a direct function of ethnoracial minority status. Instead health disparities result from exposure to additional risk factors associated with ethnic minority status in the U.S. For example, chronic exposure to life stress, more common among ethnoracial minorities, mediates observed relationship between poverty and poor long term health outcomes. Thus, health disparities are not attributable to race or ethnicity per se, but instead to the chronic stressors associated with poverty, oppression, and disenfranchisement—factors correlated with race and ethnicity (Williams & Jackson, 2005). In addition to chronic stress, low SES is also associated with reduced access to health insurance coverage, further limiting opportunities to access quality medical care, thereby increasing disease, prevalence, burden and morbidity (Williams & Jackson, 2005).

A multiplicity of factors are believed to be responsible for observed health disparities experienced by disenfranchised populations, including those associated with low SES and ethnoracial minority status, such as residing in poor urban neighborhoods, exposure to chronic stressors, and lack of access to quality healthcare (Dressler, Oths, & Gravlee, 2005). Fortunately, most of the risk factors associated with health disparities are

modifiable, and thus amenable to prevention and early intervention, potentially decreasing incidence, mortality, and diminished health functioning. Although race and ethnicity are not modifiable they are highly correlated with other individual and environmental risk factors that are modifiable, such as chronic stress exposure, health risk behaviors, access to high quality medical services and utilization of preventative health care screenings. Understanding modifiable risk factors contributing to cervical cancer risk is a critical step towards developing ethnoracially sensitive, targeted prevention efforts aimed at reducing cervical cancer incidence and mortality among Hispanic women.

Theoretical Models

Over the past four decades, researchers, practitioners, and policy makers have proposed various theoretical models to explain observed health disparities among ethnoracial minorities (Derose, Gresenz, & Ringel, 2011). Dressler, Oths et al. (2005) identified five general models that have been used to explain observed health disparities among ethnoracial minorities: 1) Racial-Genetic Model; 2) Health Behavior Model; 3) The Socio-Economic Model; 4) The Psychosocial Stress Model; and 5) The Social Constructivist Model. The racial-genetic model posits that health disparities are simply a matter of differences in the genetic makeup of individuals of different races. Although this model has not completely disappeared, it is less common in current literature, perhaps due to the acknowledgment from the scientific community that race is not a biological construct (Daniel & Rotimi, 2003; Dressler, Oths et al., 2005).

The health behavior model posits that the distribution of individual health risk behaviors among varying ethno/racial groups leads to health disparities. Dressler, Oths et

al. (2005) identify certain health risk behaviors that increase health disparities among ethnoracial minorities including; high caloric intake in conjunction with little physical activity; smoking; excessive alcohol intake; and consumption of high risk dietary items such as high sodium and/or low potassium intake. There is substantial evidence that health behaviors can be potent contributors to disease, however there is little evidence that health risk behaviors alone can explain health disparities (Dressler, Oths et al., 2005)

The socioeconomic model emphasizes the effects of socioeconomic status on health and the overrepresentation of some ethno/racial groups in lower socioeconomic positions. Low SES is linked with residing in low income communities that often lack safe opportunities for physical activity, and options for quality medical care (Doyle, Kelly-Schwartz, Schlossberg, & Stockard, 2006; Williams & Jackson, 2005). Low SES is also linked with chronic stress and poor health behaviors (Doyle et al., 2006; Griffin, Friend, Eitel, & Lobel, 1993; Williams & Jackson, 2005). There is evidence that SES moderates the relationship between race ethnicity and health outcomes (Acevedo-Garcia, Soobader, & Berkmen, 2005). Some researchers argue that the confounding of SES and racial disparities is a function of health risk behaviors often exhibited by low SES individuals. When considering the confounding of low SES with certain high risk health behaviors, it is evident that SES alone cannot explain health disparities.

The minority psychosocial stress model highlights the effects of stress associated with minority group status on health status. Studies applying this model often differentiate between institutional racism and perceived racism and their effects on health (Dressler, Oths et al., 2005). Institutional racism is the system of structured inequality that places minorities lower in social economic status, whereas perceived racism is the

conscious perception of racism and the distress associated with this perception. This model has been praised for highlighting what is unique about the experiences of minority communities and how that generates particular stressors that in turn impact health and disease (Dressler, Oths et al., 2005). For example when comparing Caucasian women and Black women in the same high stress employment positions, the Black women who perceived discrimination in the work place had children with lower birthweight (Oths, Dunn, & Palmer, 2001). The psychosocial stress model when applied to health disparities typically focuses on the individual and individual perceptions and not on broader social and cultural phenomenon that generate stressors (Dressler, Oths et al., 2005).

Finally the social constructivist model emphasizes that race is a social construct and that the intersection of racially stratified social structures with the cultural construction of goals affects health outcomes. Investigators examined the everyday goals and aspirations for a good life in a community of Brazilians (Dressler, Ballieiro, & Ernesto Dos Santos, 1999). Individuals who were better able to approximate these goals and aspirations (cultural consonance) had lower blood pressure. An interaction effect between cultural consonance and skin color was also found, such that persons with darker skin color and higher cultural consonance were found to have lower blood pressure than white Brazilians at any level of cultural consonance (Dressler, Ballieiro et al., 1999). Thus the struggle to attain goals, which are culturally constructed, can have implication on health when those goals are limited by racial stratification (Dressler, Oths et al., 2005). This theory considers how broader social and cultural norms effect an individual's health however it lacks focus on the individual and how individual health behaviors can also impact health.

While the development of health disparities conceptual models have increased understanding of the causes and correlates of health disparities, none of the extant models are sufficiently comprehensive in explaining the range of factors influencing health disparities at multiple levels, ranging from institutional and structural to individual and cultural. To develop a more comprehensive model of health disparities, elements of existing models must incorporate a range of explanatory variables at different levels of analysis.

The Ecological Systems Theory of Child Development (Bronfenbrenner, 1978) has been applied to various aspects of psychology including health disparities. Theoretical/conceptual models situate health disparities in an ecological context that considers environmental factors occurring at various levels of existing social/ institutional structures, environmental conditions, and individual characteristics. Specifically, attention to a variety of macro-level, meso-level and individual-level risk factors are necessary to fully appreciate the range of factors influencing health disparities. Macro-level social structures include constructs such as racism and the economy. Meso-level environments, may include unsafe or unsupportive work environments and dangerous or disadvantaged neighborhoods that contribute to chronic stress exposure. Individual-level factors, include health risk behaviors, perceptions and dispositions such as smoking or willingness to follow through with doctor recommendations (Schnittker & Mcleod, 2005). Multilevel models are more comprehensive than models conceptualizing health disparities only in relationship to one level of ecological or environmental risk. Although more inclusive, these models still fail to capture important intersections between macro-level, meso-level and individual risk. It is important to consider how Macrostructural

conditions shape the symbolic and material realities of people's lives, and through which those realities shape their responses to health risk factors (Schnittker & Mcleod, 2005).

For example racism has symbolic and material implications for an individual, these implications help shape the way an individual might participate in health risk behaviors.

Existing models appear to be narrow in their explanations of health disparities in that they focus too narrowly on specific factors, rather than multidimensional factors. For example, although the socioeconomic model is helpful in identifying causes and correlates of health disparities, it does not adequately address the impact of individual health behavior or the impact of stress associated with minority status. A deeper and more complete understanding of health disparities require the development of integrated models explicating the direct and interactive effects of various constructs existing at each ecological level.

Existing theoretical/conceptual models of health disparities, such as those reviewed above, are limited by lack of specificity and failure to consider unique challenges, burdens and strengths associated with each individual ethnoracial group, as well as unique demands, stigma, or contexts associated with specific diseases some of which are stigmatized due to the nature of disease transmission. The population-specific experience of a Hispanic woman, will likely differ significantly from that of an African-American woman or Asian woman as a function of varying cultural norms, beliefs and social experiences. Likewise, there is variability as a function of disease-specific factors. For example, while breast and cervical cancer are both the same disease, i.e., cancer, there is a significant stigma associated with cervical cancer, resulting in differences in disease disclosure rates and support seeking behaviors among women with cervical

versus breast cancer, which is not a stigmatized disease. Thus, to move forward, conceptual models of health disparities ought to become both population- and disease-specific, incorporating macro-level, meso-level, and individual risk factors.

Using a combination of Andersen's Health Care Utilization Model (1968) and Sorensen's Health Behavior Modification Model (Sorensen, 2003) along with The Health Behavior Model, The Socioeconomic Status Model, The Psychosocial Stress Model and the Social Constructivist Model, this review attempts to propose a comprehensive model of cervical cancer health disparities among Hispanic women that includes disease- and population-specific risk factors, along with multilevel ecological considerations.

Understanding factors that affect an individual's access to and use of health care is an important first step in understanding health disparities because disparities are likely heavily impacted by barriers to access to health care and an individual's predisposition to use health services such as screening and follow up care. Andersen's behavioral model was developed to explicate factors affecting individual's access to, and utilization of health care services, thus potentially contributing to observed health disparities (Andersen, 1968; 1995)

According to Andersen (1968; 1995) healthcare utilization is a function of three factors: 1) individual predisposition to utilize services; 2) enabling factors facilitating or impeding services use and 3) individual's unique health care needs. This model of healthcare services utilization can be applied to better understand and identify potentially modifiable cervical cancer health risk behaviors for population and disease-specific communities. Applying Andersen's model to cervical cancer among Hispanic women, the following three points of intervention/prevention can be identified in order to reduce

health disparities among this specific population, i.e., Hispanic women at risk of cervical cancer: 1) utilization of cervical cancer screening services; 2) cancer diagnosis disclosures, and 3) follow through with pre-cancer or cancer treatment recommendations. To intervene more effectively by changing healthcare utilization practices, it is first necessary to more fully understand each of these three intervention entry points, particularly with respect to the unique characteristics of this population and disease specific target audience.

Predisposing Factors Influencing Health Services Utilization

An individual's predisposition to utilize health care services (or not) includes a range of health-related beliefs, such as perception of personal cervical cancer susceptibility, and willingness to expend resources on health care.

Health behavior predispositions are likely to influence personal decisions about seeking primary care services, in addition to affecting compliance with health care provider recommendations for preventative screenings and post screening follow up care. Predisposing factors also include social structures, such as residential segregation, culture and demographic factors such as race, ethnicity, gender, and age. These cultural and systemic factors influence important beliefs related to health care utilization. For example, cultural norms such as *marianismo* i.e., the notion that women should be selfless and self-sacrificing (Sterling & Sadler, 2009) can be predisposing factors because accepted cultural norms influence health care utilization. If a woman ascribes to *marianismo* she may be unwilling to take time to visit the doctor if it means inconveniencing any family member in any way. Other relevant cultural norms, which will be discussed in detail, include *familismo*, *fatalism*, and *machismo*.

Sociodemographic factors such as ethnicity and race serve as predisposing factors via their link to lower social economic status and residential segregation, creating barriers to high quality health care services and the economic resources to pay for them.

Enabling Factors Facilitating or Inhibiting Service Use

Enabling factors include both personal/family and community factors, these factors are important because they can either enable an individual's use of health care services or inhibit it. Personal/family factors, which will be discussed in more detail below, include access to health insurance, preventative care, the ability to get time off of work to seek medical care, the ability to secure childcare while attending an appointment, language barriers, immigration status, family and social support. Community factors include the availability of hospitals or clinics that offer culturally sensitive services in the patient's primary language and the community attitudes about health care. For example, in a community where health education is low and *fatalismo* (i.e., a cultural belief that health outcomes are determined by fate) is a common belief, reduced use of health care services would be expected because of these beliefs. The cultural norm of *fatalismo* can have an impact not only on an individual's predisposition to certain health behaviors but it can also be an inhibiting factor that can deter an individual's health care utilization. In the same way communities where *familismo*, *marianismo*, and *machismo* are common beliefs, you would expect to see an enabling or inhibiting effect caused by these cultural norms.

Individual Health Care Needs

Andersen's final component reflects an individual unique health care need including both personal perceptions of health care need and the healthcare provider's

assessment of patient needs. Health beliefs discussed above, affect the attitudes, values and knowledge about health and health services which likely influences subsequent perceptions of need and utilization of health care services (Andersen, 1995). It is important to consider how individuals judge a given health problem and whether or not they judge it to be sufficiently important to seek professional help. An individual's predispositions might impact how they perceive and evaluate a given health problem, but other factors will impact this as well, such as family or friends' advice and doctors' recommendations. For example, if a Hispanic woman does not understand what factors impact her susceptibility to cervical cancer, she may underestimate her need for cervical cancer screening. However if she has a family member that has had cervical cancer she may be more knowledgeable of her risk, and therefore more willing to seek screening. Factors such as race and insurance status may also directly or indirectly influence healthcare providers' determinations of patient need. If a patient has little or no insurance coverage healthcare providers may be less likely to make a diagnosis this is rare and requires expensive care.

Social Contextual Considerations

More recently models have moved beyond individual risk factors to address social and structural factors influencing health disparities (Derose et al., 2011). It is likely that health disparities result from a combination of individual and social contextual factors that impact individual's day to day experiences including social, cultural and material resources (Sorensen, 2003; Shelton, Goldman, Emmons, Sorensen & Allen, 2011). Andersen's model has been criticized for insufficient attention to social networks, social interactions, and culture (Andersen, 1995). Andersen argues that these factors are part of

the social structure component within the predisposing factors section of his model. However this does not seem to capture the impact that social context and interpersonal factors have on health outcomes. Sorensen's model can be applied to supplement the lack of focus on social context and culture in Andersen's model.

Sorensen (2003), has created a conceptual frame work that draws on both the behavioral science literature and social epidemiology to identify potential avenues by which health behaviors may be influenced. While health behaviors alone cannot fully explain health disparities, adherence to recommended health guidelines reduce the risk of acquiring chronic disease (Sorensen, 2003).

Sorensen's framework seeks to elicit individual behavior change while considering social contexts, aimed at reducing disparities in risk related behaviors. Sorensen's model includes demographic characteristics but unlike Andersen's model it has a strong emphasis on interpersonal factors. Interpersonal factors such as friendship and family responsibility are considered modifying conditions. Other modifying conditions emphasized in the model include organizational characteristics such as job strain and neighborhood characteristics such as safety. Finally Sorensen includes societal factors such as discrimination. To elicit health risk behavior change it would be important to target the above mentioned interpersonal factors, while considering that social norms and social support are mediating variables (Sorensen, 2003).

Using Andersen's and Sorensen's models as conceptual frameworks, the current review of cervical cancer health disparities among Latinos, will examine social contextual, predisposing, enabling, and need based consideration pertaining to cervical

cancer health risk disparities among Hispanic women. These models will be applied to primary, secondary, and tertiary aspects of Latina's cervical cancer experience.

CHAPTER 2

HISPANIC WOMEN AND HEALTH DISPARITIES

Primary Prevention

Cervical cancer is the third leading cancer accountable for death in women worldwide and is the second leading cancer in women worldwide (Clemmens, Knafl, Lev, & McCorkle, 2008). There are over 11,000 new cases of cervical cancer diagnosed in the United States each year (Clemmens et al., 2008). Due to aggressive screening and early detection practices however, cervical cancer is not associated with high rates of mortality among most populations of women in the United States (Clemmens et al., 2008).

Compared to all ethnic groups Hispanic women experience the highest incidence of invasive cervical cancer and have the second highest cervical cancer mortality rates (Espinosa del los Monteros & Gallo, 2011; O'brien et al., 2010). Hispanic women have cervical cancer incidence and mortality rates which are 50% to 70% higher than those among White women (Siegel et al., 2015). The elevated risk of Hispanic women may be influenced by lower SES, chronic stress and residential segregation (Derose et al., 2011; Williams & Jackson, 2005). Hispanic women's health may also be negatively affected by additional factors, such as language barriers; social isolation; immigration status; lack of insurance; poor screening practices; and cultural beliefs, such as the value placed on female virginity/chastity, and *fatalismo*.

While some aspects of culture might increase risk, cultural values are not always barriers, but can also service as enabling or protective factors for health services utilization (Anderson, 1995). Sorensen (2003) underscores the role of social support and social norms as important mediating factors in eliciting positive health behavior change. While culture can be a protective factor and social support may lead to a positive increase in desired health behaviors, factors such as social isolation, language barriers, immigration status, and certain cultural beliefs may negatively impact Hispanics women's likelihood to participate in primary preventative health care practices. Primary prevention involves interventions aimed at preventing a disease before it manifests. This section will discuss many variables that negatively affect the predisposition of Hispanic women to participate in preventative health practices.

The subsequent section addresses relevant secondary and tertiary prevention practices for reducing the incidence of and mortality from cervical cancer among Hispanic women. Secondary prevention refers to activities or practices implemented following diagnosis with the goal of stopping the progression of the illness. Tertiary prevention includes helping individuals manage the effects of long term illness and improve quality of life after illness. This paper will discuss health disparities impacting Hispanic women as they pertain to primary, secondary and tertiary prevention of cervical cancer.

Screening Practices

The introduction of cervical cancer screening practices such as Pap smears reduced cervical cancer incidence rates by 60 to 90% within three years of implementation (Duggan et al., 2012). According to a CDC report in 2010 following

Asian (75%), Hispanic women are least likely to have received screening in the last three years (78%) as compared to African Americans (85.6%) and Whites (83.4%) (Moore de Peralta, Holaday, & McDonell, 2015). Some studies attribute the higher rate of cervical cancer diagnosis among Hispanic women to lower rates of Pap smear screenings and delays in recommended follow ups after abnormal Pap smear test findings (Duggan et al., 2012). Several factors have been associated with reduced utilization of screening and follow up, including poverty, lack of health insurance, clinician recommendation, lack of access to health care providers, acculturation, language barriers, and lack of education regarding risk of not participating in cervical cancer screening and follow up practices (Duggan et al., 2012). Barriers to preventative practices among Hispanic women translate to higher incidence and later stage diagnosis of cervical cancer. Immigration status may also be a barrier to screening in Hispanic women. Cervical cancer screening practices are more frequent among U.S born women than they are among immigrants who have been in the U.S for less than 10 years, with 73% of immigrants participating in screening practices compared to 89% of U.S born women (Carrasquillo, & Pati, 2004)

Cultural influences also seem to heavily influence screening practices. For example, Hispanic women who had never had a Pap smear were more likely to endorse cultural beliefs such as *familismo*, *fatalismo* and *machismo* (i.e., a strong or exaggerated sense of masculinity stressing attributes such as physical courage, virility, domination of women, and aggressiveness) compared to Hispanic women who were routinely screened (Arredondo, Pollak, & Costanzo, 2008). A focus group study of Hispanic, African American and White women of lower SES found that 70% of the women believed that three factors increased cervical cancer susceptibility; 1) number of sexual partners, 2) the

presence of sexually transmitted disease, and 3) the frequency of sexual activity (Guilfoyle, Franco, & Gorin, 2007). Cultural views regarding modesty, womanhood, and values of purity and chastity may cause feelings of embarrassment about sexuality that influence participation in cervical cancer screening practices (Ashing-Giwa, Padilla, Bohorquez, Tejero, Garcia, & Meyers, 2006). Thus for Hispanic women endorsing cultural values of chastity, screening for cervical cancer may be associated with perceived promiscuity and sexually transmitted disease, thus reducing their willingness to engage in screening practices and timely follow up procedures.

Immunization

HPV vaccinations are an important aspect of cervical cancer prevention. Yet initial compliance rates have been low in the United States compared to developing nations and female minority adolescents have lower rates of HPV vaccine immunization than White female adolescents. According to the 2010 National Vaccination Survey, vaccination series completion rates were 60.8% for Black adolescents, 69.4% for Hispanic Adolescents and 74.8% for White adolescents (McKeever, Bloch, & Marrell, 2014). Barriers to health care access, such as poverty, and poor knowledge among patients and their families limit the effectiveness of HPV vaccinations. Parents who declined to vaccinate their daughters stated that they refused because the vaccination might encourage sexual promiscuity (McKeever et al., 2014). Hispanic families endorsing cultural values of chastity might be especially unwilling to vaccinate their daughters because they may believe a vaccination might send the message that they are encouraging or condoning sexual activity.

Social Isolation and Screening Practices

Lack of social support decreases participation in cervical cancer preventative screening practices. Latino women in Brazil reporting intermediate levels of social support were 70% more likely to participate in cancer screening practices, compared to women reporting high levels of social support, who were 84% more likely to be screened, compared to those with the lowest reported levels of social support (Silva, Griep & Rotenberg, 2009). Adjusting for SES and occupational variables, those reporting high levels of social support were 58% more likely to participate in cancer screening practices, compared to those that reported lower levels of social support (Silva et al., 2009).

When comparing four groups of Hispanic women in the United States (Mexican, Cuban, Puerto Rican and Central American) for all groups except Puerto Rican women, high social integration was associated with more recent screenings (Suarez, Ramirez, Villarreal, Marti, & McAlister, 2000). Compared with women in the lowest social integration category, women in the highest category were 1.8 times more likely to have had a recent Pap smear. Moore de Peralta et al. (2015) found that *familismo* (i.e., a cultural value emphasizing importance of close family relationships and support) was a strong predictor of Hispanic women's compliance with Pap smears. These data support the idea that *familismo* and social support are important factors influencing Latina's predisposition to engage in cervical cancer preventative practices. It also highlights the need for a campaign aimed at soliciting family members to encourage their mothers, daughters and sisters to participate in screenings.

Because family is a fundamentally important part of Hispanic culture, public service campaigns promoting the message that screenings can protect the lives of

mothers, daughters, sisters, or aunts would likely be effective at improving screening participation rates. Public service campaigns should not stop at simply suggesting that women encourage their family to get screenings but should also explain the importance of providing enabling support to do so, such as providing transportation to the clinic or offering child care to ease potential burdens and barriers to making and keeping screening appointments. A television commercial campaign aired during prime time hours on a channel watched by many Hispanic women, such as Univision, might be an effective strategy to reach the target audience of women, encouraging them to support screening among their female friends and family members. This type of commercial campaign may strike a chord among Hispanic women, not only encouraging screening but also reducing the shame and stigma associated with cervical cancer that leads to lack of screening.

Language Barriers

Language barriers may also contribute to observed cervical cancer health disparities among Hispanic women (Lim, 2010). Language barriers have been found to reduce the quality of care; impose barriers to accessing care and create dissatisfaction with received care (Lim, 2010). In an interview study of the sexual and reproductive health care use of undocumented Mexican migrants, language was cited as the primary obstacle to receiving care; language barriers prevented women from finding health care providers and affected their perception of the quality of care they received (Deeb-Sossa, Díaz Olavarrieta, Juárez-Ramírez, García, & Villalobos, 2013). Surveyed women expressed concerns about whether health care providers fully understood their ailments (Deeb-Sossa et al., 2013).

About 16 million people speak Spanish at home and have limited English proficiency, speaking English less than very well, with nine million speaking English not at all or not well (Fernandez & Perez-Stable, 2015). With Hispanic physicians being a slim minority, Hispanic patients might have difficulty finding a doctor who is culturally sensitive to their needs and can communicate in their primary language. For example in California where 33% of the population is Hispanic, only 4% of doctors are Hispanic (Jordon, 2007). It is also important to note that very few health providers employ interpreters (Borrayo, 2007). Even when interpreters are provided, communication issues still create barriers to receiving adequate care. For example, research has found that Hispanic women who used the services of interpreters still felt that they were not able to express themselves as well as they would have liked (Shelton et. al., 2011). Specifically, they felt that certain things were lost in translation, particularly their frustrations regarding their health related concerns. Consequently, women reported feeling neglected, expressing concern that they may have missed obtaining vital information regarding their health. Lack of knowledge and language barriers may also influence screening practices such that individuals who do not speak English may be unable to communicate their wishes regarding screening practices (Woloshin, Schwartz, Katz, & Welch, 1997). Likewise providers may be unable to discuss or offer screening practices effectively if they do not speak Spanish and/or are ill informed about culturally competent practices. Interventions that involve providing more bi-cultural Spanish speaking health care workers are necessary to help increase awareness of the need for cervical cancer screening and to help Hispanic women communicate that they would like to be screened.

Immigration

Undocumented Hispanic women have to deal with the stress attributed to their lack of legal status in the United States. In an interview study of Hispanic and African American women who had received abnormal mammogram results, Shelton et al. (2011) found that many Hispanic women experience stress on a regular basis due to the fact that they work illegally in the U.S. Lacking job security and being dependent on their incomes to survive, and living paycheck to paycheck, undocumented women are less likely to miss work for screening or treatment purposes or for follow up treatment after abnormal Pap results. Many women also reported stress and fear associated with medical visits due to their undocumented status (Shelton et al., 2011). Berk and Schur (2001) found that 39% of undocumented Hispanic immigrants in metropolitan areas were fearful about accessing medical services because of their undocumented status. Those reporting fear were less able to access medical and dental care, prescription drugs and eyeglasses. Of note, these were linguistically isolated, undocumented Hispanic immigrants, because all households where English was spoken or where an English speaking child older than 14 years of age lived, were excluded from the survey. Berk and Schur (2001) also found that those living in larger metropolitan areas expressed less fear of accessing medical care due to their undocumented status, with 34% of those surveyed in Los Angeles expressing concern, and 35% in Houston, compared to 44% in Fresno and 45% in El Paso.

Naturalization status is also linked to cervical cancer screening. Echeverria and Carrasquillo (2006) found that naturalized citizen Latina women were slightly less likely to have received a Pap test, compared to U.S born Latina women. However a much bigger difference was found between non-naturalized Latinas, as compared to U.S born

Latinas, with non-naturalized Latinas less likely to report Pap smear screening than U.S born Latinas, even after adjusting for sociodemographic differences and access to care variables. Interestingly, the remaining disparities disappeared after adjusting for acculturation level. Preventative interventions should target less acculturated, linguistically isolated undocumented immigrants. Given their high risk status for failing to seek screening and follow-up care. In most states in the U.S, the only form of identification that undocumented immigrants can acquire is a *matricula consular* from the Mexican consulate. The Mexican consulate might be a good place to target undocumented immigrants for preventative screening practices. Informational brochures can dispel misconceptions related to the fear of possible deportation or other negative consequences brought on by accessing health care as an undocumented immigrant. These informational brochures may also include information on cervical cancer and who is susceptible to cervical cancer to encourage screening by helping women evaluate their cervical cancer risk.

Recent immigrants may not be familiar with risk factors for cervical cancer. Out of 743 Hispanic immigrants in Alabama, 36% did not perceive themselves to be at risk for cervical cancer, 33.9% did not know if they were at risk, while only 30.4% perceived themselves to be at risk (Garces-Palacio & Scarinci, 2012). Perceived susceptibility to cervical cancer was associated with perception of personal exposure to HPV/STI, and having a relative with cervical cancer (Garces-Palacio & Scarinci, 2012). Thus many immigrant Hispanic women might be unaware of their risk of developing cervical cancer or what factors increase a women's risk of developing cervical cancer.

Social Isolation and Immigration

Undocumented status might lead to feelings of social isolation. In an interview study of Hispanic and African American women who had received abnormal mammogram results by Shelton et al. (2011) immigrant Hispanic women often reported feelings of social isolation. The experience of social isolation was amplified because women were not able to travel to their home countries to visit family members due to documentation issues. Of those that did have the proper documentation to visit family members, some reported that financial difficulties stopped them from doing so (Shelton et al., 2011). It is important to note that these sentiments were discussed in relation to abnormal mammogram results, perhaps abnormal cervical cancer results would lead to even more intense feelings of social isolation due to the stigma/shame some associate with this disease.

Insurance

Research suggests that approximately 34% of Hispanic women are uninsured compared to only 24% of African American women and 14% of non-Hispanic white women (Borrayo, 2007). Under the Affordable Care Act (ACA) health differences in insurance rates between Whites and Hispanics have narrowed, but Hispanics continue to face larger gaps in coverage (Buchmueller, Levinson, Levy, & Wolfe, 2016; McMorrow, Long, Kenny, & Anderson, 2015). By the end of 2014, after the ACA open enrollment period, uninsured rates for Hispanics fell from 40.1% to 31.8%, uninsured rates for Blacks fell from 25.5% to 17.2% and uninsured rates for Whites fell from 14.8% to 10.5%. It is important to note that undocumented immigrants are not eligible for

Medicaid and cannot purchase subsidized coverage in the ACA marketplace (McMorrow et al., 2015).

Insurance is the most important predictor of regular access to a health care provider among undocumented Mexican American immigrants (Nandi et al., 2008). Lack of insurance and limited health care access can lead to delays in screening and treatment-seeking and to diagnosis of disease at a later stage (Borrayo, 2007). After interviewing Hispanic and African American women with abnormal mammogram results, Shelton et al. (2011) found that many women without health insurance who received free care felt that the level of care they received was of reduced quality. Their perception of reduced quality of care may lead Hispanic women to avoid preventative screening or follow up doctor office visits. It would be important to investigate whether Hispanic uninsured women who received abnormal Pap smears felt similarly regarding the level of free care that they received.

Marianismo

Marianismo is the belief in Hispanic culture that women should be selfless and self-sacrificing, always putting the well-being of others, especially their family members before themselves. The word *marianismo* is derived from the name of the Virgin Mary or Maria. *Marianismo* reflects the worth of women based on how well they embody the qualities of modesty, devotion, chastity and virginity (Sterling & Sadler, 2009). After interviewing many Hispanic and African American women who had abnormal screening mammograms Shelton et al. (2011) found that women learned to adopt this belief from their culture, specifically from other family members. Women who endorsed this belief were less likely to miss work or turn down household responsibilities and chores to take

care of their own health needs (Shelton et al., 2011). Women endorsing this belief might be less likely to focus on their own health, thereby avoiding routine cervical cancer screening and treatment practices because they view themselves as self-sacrificing and beholden promoting the needs of their family members instead of themselves.

Marianismo is also associated with a cultural emphasis on chastity (Sterling & Sadler, 2009). A meta-synthesis of Latina's attitudes on cervical cancer prevention found significant endorsement of the belief that submitting to a cervical cancer screening was improper behavior, in addition to reporting embarrassment about exposing their genitals for medical examination. Culturally embedded beliefs about the appropriate roles for women in Latino culture, particularly beliefs surrounding modesty purity and chastity limit engagement in cervical cancer screening and treatment due to shame and embarrassment (Corcoran & Crowley, 2014). In addition to women's shame and embarrassment, husbands were sometimes unsupportive, expressing jealousy regarding gynecological appointments (Corcoran & Crowley, 2014). Male sexual jealousy and propriatariness represent culturally mediated Hispanic beliefs associated with *machismo*, as well as those rigidly defining male and female gender roles. Feelings of embarrassment and the lack of support from spouses might lead Latinas to avoid Pap smears altogether in service of managing their husband's jealousy. Interventions aimed at improving Latina's participation in cervical cancer screening practices might consider targeting male spouses to de-stigmatize the disease and normalize the need for screenings as part of a healthy family initiative.

Fatalismo

Fatalismo is the cultural belief that events are predetermined by fate and therefore must be endured rather than changed. Andersen (1995) considers health beliefs to be a predisposing characteristics to health care utilization. If a woman does not believe that a health care screening can change her fate related to a cancer diagnosis she might be predisposed to skip this screening. Studies have found that following a cancer diagnosis Hispanic women are more likely than non-Hispanic Whites to believe that there is nothing that one can do to prevent or halt death (Espinosa del los Monteros & Gallo, 2011). Fatalistic beliefs that all health outcomes are the product of God's will and therefore unalterable, are a serious barrier to accessing secondary and tertiary cancer treatment. Because of *fatalismo*, many Hispanics believe that only an intimate relationship with God is important for maintaining and restoring health (Jurkowski, Kurlanska, & Ramos, 2010).

While *fatalismo* and relinquishing control to God may impede women from obtaining health screenings for cervical cancer, insufficient economic resources and lack of knowledge about the pivotal role of preventative cervical cancer screenings may further deter Latinas from obtaining necessary routine care (Espinosa del los Monteros & Gallo, 2011). Moreover, a culture supporting fatalistic beliefs about health is unlikely to promote health screening practices (Espinosa del los Monteros & Gallo, 2011). The poor health outcomes often experienced by Hispanic women may reinforce the belief that nothing can be done to alter the course of cancer once diagnosed (Espinosa del los Monteros & Gallo, 2011).

Harmon, Castro, and Coe, 1996 (cited in Espinosa del los Monteros & Gallo, 2011) examined the relationship between *fatalismo* and cervical cancer screenings, in a sample of church going Hispanics, finding that *fatalismo* predicted time since last Pap smear, after controlling for age, education, family cancer history, insurance coverage, and acculturation. Stronger beliefs in *fatalismo* were associated with longer duration between Pap smears. Similarly in a sample of newly diagnosed invasive cervical cancer patients, *fatalismo* was associated with decreased odds of obtaining a Pap smear examination prior to diagnosis, even after controlling for the length of time living in the United States, medical insurance coverage and level of education (Behbakht, Lynch, Teal, Degeest, & Massad, 2004). Thus, Hispanic cultural values, such as *fatalismo* and values supporting female virginity and chastity are likely to serve as significant deterrents to routine cervical cancer screening, and may thus contribute to the disproportionately high incidence of, and mortality from cervical cancer among Latinas. These cultural perspectives can lead to health related beliefs that can significantly impact a patient's predisposition to use or avoid preventative and post-diagnosis health care services.

Secondary and Tertiary Prevention

From 2004 to 2008 Hispanic women were shown to have the highest cervical cancer diagnosis rates in the United States with an age adjusted incidence of 12.5 of every 100,000 compared to 7 of every 100,000 in non-Hispanic white population (Duggan et al., 2012). Not only are incidence rates higher but mortality rates are also higher for Hispanic women, with 2.9 of every 100,000 Hispanic women compared to 2.1 of every 100,000 non-Hispanic white women dying from cervical cancer annually (Duggan et al., 2012). It is evident that Hispanic women are diagnosed with cervical

cancer at disproportionately high rates. However, once an individual has been diagnosed with cervical cancer there are a variety of factors that can positively influence survival and quality of life during cancer recovery. Thus, in terms of secondary and tertiary prevention, it's important to understand more about the factors influencing survivorship/mortality among Hispanic women diagnosed with cervical cancer. This next section will explore some relevant factors.

Social Support

As mentioned earlier a supportive social and interpersonal environment may reduce the anxiety and depression often associated with cervical cancer diagnosis. However a significant other that is unsupportive and unreceptive, or whom the patient perceives as unsupportive or unreceptive may distract from the cognitive processing of a cancer diagnosis, which can be traumatic, resulting in unresolved emotional problems (Hipkins, 2004). While social support are central sources of emotional support for many individuals, social relationships can also be extremely stressful. Relationship stress undermines health through behavioral, psychosocial, and physiological pathways (Umberson & Montez, 2011). This is why it is important for patients to seek out supportive individuals and avoid stressful interpersonal relationships after cervical cancer diagnosis.

Research supports that speaking about cervical cancer experiences only with individuals that are supportive and avoiding the topic with those that are unsupportive is beneficial (Clemmens et al., 2008). In an interview study of 19 Caucasian cervical cancer survivors, all women reported that either family or friends provided the social support that they needed to cope with and get past difficult times related to their cervical cancer

diagnosis (Clemmens et al., 2008). Thus, social support is an important enabling factor that can positively influence cervical cancer patients' survival and quality of life after diagnosis.

Hispanic co-survivors explained that they did not have the skills to deal with the depression they and/or their family members with cancer were experiencing after their family member's diagnoses (Marshall et al., 2011). Thus, interventions should not only target individuals diagnosed with cervical cancer but also close family members to help improve the quality of the social support received by these women. These interventions might include family counseling or informational brochures about what to expect after diagnosis and throughout the stages of treatment. Given the collectivist nature of Latino Family structures, involving family members, such as mothers, sisters, and husbands might improve women's participation in cervical cancer treatment.

Social Isolation and Chastity

While Hispanic culture emphasizes the importance of close family ties and social support, it also strongly promotes the values of female virginity and chastity (Cuevas, et al. 2010). Sterling and Sadler (2009) report that Hispanic women are heavily influenced by cultural mores or traditions promoting *marianismo*. The emphasis on chastity of *marianismo* may lead some Hispanic women with a cervical cancer diagnosis to avoid discussion of their diagnosis, in the spirit of adopting the "strong woman" role. The fact that cervical cancer, in part, is linked to sexually transmitted infections leads to stigmatization for Hispanic women (Ahing-Giwa et al., 2006) Consequently it is possible that Hispanic women might not feel comfortable or able to talk about their cervical cancer concerns with family and friends, leading to feelings of social isolation and

unprocessed cognitive distress after diagnosis. Latinas might feel that disclosures related to problems associated with sexuality may lead to stigmatization, shame, and rejection by family, choosing instead to keep their distress and concerns to themselves. Hispanic women attribute cervical cancer to having had many sexual partners and vaginal infections, conditions invoking shame and stigma (Chavez, McMullin, Mishra, & Hubbell, 2001). Hispanic women may associate cervical cancer with promiscuity, and may not feel comfortable talking about their cervical cancer diagnosis with family members. It would be important to further investigate the links between beliefs in the value of chastity, *marianismo* and disclose reluctance and how this might impact recovery. Similarly, public health campaigns by de-stigmatizing cervical cancer might benefit the Hispanic community, thereby increasing opportunities for diagnosis disclosure and support-seeking among those with cervical cancer diagnoses.

Familismo

Hispanic culture has strong ties to *familismo*, a cultural value emphasizing importance of close family relationships and support. Hispanic families emphasize the value of the nuclear and extended family, promoting characteristics such as reciprocity, loyalty, support, and solidarity (Yoshioko, Gilbert, El-Bassel, & Baig-Amin, 2003). Research finds that *familismo* can have implications for quality of life and management of symptoms of Hispanics diagnosed with chronic illness (Ashing-Giwa et al., 2004; Perez & Cruess, 2011). In a focus group of breast cancer survivors Ashing-Giwa et al. (2004) found that Hispanic women discussed the importance of family support to their emotional well-being and treatment adherence. Yet studies have found that Hispanic women with cervical cancer are likely not to seek treatment or to drop out of treatment if

they feel it interferes with their ability to care for their families (Ashing-Giwa et al. 2006). It is apparent that *familismo* can contribute to both the support and stress levels of Hispanic women diagnosed with chronic illnesses, such as cervical cancer (Perez & Cruess, 2011). Thus, it is an enabling factor that can either facilitate or impede follow through with treatment recommendations after diagnosis.

Familismo and Social Support

Because Hispanic women value strong ties to their family members, they may prefer informal over formal support networks such as support groups (Yoshioko et al., 2003). This may mean that even if Hispanic women are not getting the social support they need from their families following cervical cancer diagnosis, they might still be unwilling to participate in formal support groups. Because *familismo* and characteristics of *marianismo* are so important to many Hispanic women, they may be unwilling to burden their families with their cancer diagnosis. Ashing-Giwa et al. (2004) found that Hispanic breast cancer survivors expressed concern about disclosing their illness and burdening family members. In an interview study of women who had received abnormal results following a mammogram Shelton et al. (2010) found that many Hispanic women said they would hide a cancer diagnosis to shield their family from the pain of knowing a close family member had cancer. Ashing-Giwa et al. (2006) found that Hispanic women with cervical cancer endorsed personal concerns about burdening their families. Thus, *familismo* and *marianismo* may lead to an unwillingness to disclose diagnosis information to family members leading to lack of social support for Hispanic women with a cervical cancer diagnosis.

Coping Techniques

According to Clemmens et al. (2008) after a cervical cancer diagnosis, many women reported; severe stress, emotional and sexual problems, and psychosocial problems related to the physical effects of the cancer. Coping strategies including meditation, physical activity, levity, guided imagery, education, prayer, non-cancer support groups, and retreating from social contact have been found to be helpful. (Clemmens et al., 2008). After getting the results of an abnormal Pap smear, it was found that coping via catharsis (expression of emotion) was associated with greater psychological distress, whereas coping via acceptance was associated with less negative moods (Lauver, Kruse, & Baggot, 1999). Relaxation and diversion after receiving abnormal results and before undergoing a colposcopy, are associated with lower levels of psychological distress. More research on differences in use of coping strategies by individuals of different ethnicities is needed to identify how different coping mechanisms increase or decrease risk of cervical cancer morbidity and mortality.

Data from a problem-focused culturally and clinically tailored behavioral phone intervention with Latina cervical cancer survivors found that the intervention group reported more positive changes in physical well-being and overall enhanced quality of life (Ashing-Giwa, 2008). Emotional well-being outcomes did not differ significantly between the intervention and control groups. These finding suggest that Latina cervical cancer survivors can benefit from behavioral phone counseling, however these benefits may not generalize to all areas of recovery.

Physical symptoms of cervical cancer survivors such as vaginal stenosis (a shortening of the vaginal opening), odor, bleeding/discharge, fatigue, nausea, abdominal

pain, and difficulty controlling urine, were positively correlated with depression (D'Orazio, Meyerowitz, Stone, Felix, & Muderspach, 2011). Of 54 low-income, immigrant Latina cervical cancer patients, 67% endorsed symptoms comparable to diagnosable depression (D'Orazio, et al. 2011). Cervical cancer patients often report high levels of depression and stress related to socioeconomic and immigration status (Meyerowitz, Formenti, Ell, & Leedham, 2000). Physical symptoms associated with radiation and practical barriers to receiving treatment significantly predict depression. Many studies have identified the physical side effects of radiation with reduced quality of life after diagnosis (Kirchheiner et al., 2015; Klee, Thranov, & Machin, 2000; Lisovaja, Rusakova, & Macuks, 2014). Interventions that specifically target depression after diagnosis and teach positive coping with physical symptoms of radiation are needed. Interventions that prepare patients for the side effects of radiation during and post treatment are needed. Preparing patients by providing information about treatment side effects, in a culturally relevant context, might increase treatment compliance and enhance quality of life during cancer treatment.

Positive Lifestyle Changes after Diagnosis and Treatment

European American and Hispanic American women, with a previous diagnosis of cervical or breast cancer, have been observed to implement healthy life style changes such as positive diet change, increase in exercise, and stress management techniques (Ashing-Giwa, Lim, & Gonzalez, 2010). These healthy life style changes while in treatment and throughout survivorship were positively correlated with reduced side effects from cancer treatment, improved physical and psychosocial wellbeing, enhancing self-esteem, and reduced relapse rates. Increased participation in exercise led to improved

affect, increased energy, increased immune system functioning, decreased nausea and over all improved quality of life. Further this study found a 24% lower likelihood of relapse among those with low-fat diets, compared to a control group. Sixty percent of cervical cancer patients who participated in psychotherapy during treatment found that complementary psychological treatment was a healthy activity capable of improving well-being (Ashing-Giwa et al. 2010). Thus, healthy life style changes including reduced fat in-take and complementary psychological care can significantly improve quality of life following cervical cancer diagnosis. Positive lifestyle changes after diagnosis were reported in 208 Caucasian invasive cervical cancer survivors' such as stronger religious beliefs (34.9%), improved diet (33.5%) and increased exercise activity (27.4%). Among the women reporting impact in spirituality and health promotion, the majority of women reported this impact as a positive one (Greenwald, & McCorkle, 2007). Thus, positive lifestyle changes, such as increased spirituality, healthy eating and increased exercise can improve quality of life after cervical cancer diagnosis. More research should be done to identify the pathways by which positive lifestyle changes improves quality of life among Hispanic women diagnosed with cervical cancer.

CHAPTER 3

SUMMARY OF REVIEW AND IMPLICATION FOR FUTURE RESEARCH

Further research is needed to address why this population is disproportionately burdened by cervical cancer, including the factors that lead to health disparities in incidence, morbidity and mortality. Structural barriers due to lack of health insurance and language issues significantly impact Hispanic women's access to care and the quality of care they receive (Borrayo, 2007; Deeb-Sossa et al., 2013; Lim, 2010; Nandi et al., 2008; Shelton et al., 2011; Woloshin et al., 1997). This review also highlights the significance of examining various aspects of Hispanic culture and experiences and their effects on cervical cancer as it relates to screening, diagnosis, treatment recommendations, diagnosis disclosure and quality of life. Cultural beliefs such as chastity, *familismo*, *marianismo*, and *fatalismo*, appear to have a significant impact on various health outcomes and health behaviors of Hispanic women influencing their predisposition to receive treatment (Ahing-Giwa et al., 2006; Ashing-Giwa et al., 2004; Behbakht et al., 2004; Corcoran & Crowley, 2014; Espinosa del los Monteros & Gallo, 2011; Jurkowski et al., 2010; Perez & Cruess, 2011; Shelton et al., 2011).

When considering these variables it is important to note that Hispanic culture is multidimensional, not all Hispanic people value cultural beliefs such as *fatalismo* and *marianismo*, of those that do, the significance that they give to these beliefs will differ. Furthermore U.S born Hispanic women and immigrant Hispanic women will have

different cultural experiences. Thus, future research would benefit from including acculturation constructs. An acculturation measure that can be used across heterogeneous groups is necessary. This measure should take into account endorsement of various cultural norms, birthplace, and language spoken, among other culturally relevant constructs. This would also allow researchers to examine differences among various subgroups of Hispanic individuals.

The influence of social support and coping on quality of life, psychological symptoms, and relapse incidence after cervical cancer diagnosis warrants further research. From reviewing the literature it is evident that social support improves not only pre-cancer screening practices, but also psychological distress following cervical cancer diagnosis and treatment. Disparities in the type (formal versus informal) and quality of social support may ameliorate or exacerbate health outcomes after cervical cancer diagnosis. Social support can affect treatment compliance, psychological distress and quality of life after diagnosis. Research should focus on identifying culturally relevant barriers to diagnosis disclosure. Social support has been implicated as an important ameliorating factor during the cancer recovery process (Clemmens et al., 2008; Hipkins, 2004). However, various Hispanic cultural norms may hinder Hispanic women's willingness to share their cancer experiences and receive the support they need (Ahing-Giwa et al., 2006). More research is needed to identify how Hispanic cultural norms interact and interfere with diagnosis disclosure and access to social support. Research should also evaluate the stigma associated with cervical cancer among the Hispanic community. It is important to understand both patients' individual experiences and

communities' level of understanding before making recommendations for practice related to diagnosis disclosure.

CHAPTER 4

UNIQUE CONTRIBUTION TO THE LITERATURE AND IMPLICATIONS FOR PRACTICE

In light of the alarmingly high rates of cervical cancer among Hispanic women, it is important for researchers to identify causes and correlates of these trends. The literature presented above regarding health disparities related to socio-economic status, residential segregation, and differences in health care workers treatment plans seem to be an important pieces of the puzzle. However, cultural factors are very important as well, particularly with respect to barriers to engaging in preventive practices, diagnosis disclosure, and post-diagnosis support seeking.

To date, no other review of Hispanic women cervical cancer health behaviors has provided a comprehensive review of multiple cultural norms and their effects on the continuum of care (i.e., primary, secondary and tertiary aspects of care). Exploring the impact of these cultural factors on primary, secondary and tertiary prevention of Hispanic women at risk of developing or diagnosed with cervical cancer may help in developing, culturally informed prevention and intervention practices. *Promotoras* are lay health workers that are already a part of the community and thus are sensitive to cultural factors impacting the community. *Promotoras* can be solicited to educate low income Hispanic women, especially in areas where immigrants typically live, where there tend to be fewer Spanish speaking health professionals (Luque, Mason, Reyes-Garcia, Hinojsa, & Meade, 2011). This may be a valuable asset in reaching parts of the community that might

otherwise be unreachable in public service campaigns addressing cervical cancer prevention.

For example, public health campaigns might profitably focus on educating Hispanic women on the causes of cervical cancer and who is at risk. Garces-Palacio and Scarinci, (2012) found that recent immigrants may be unaware of their susceptibility to cervical cancer. Thus educational intervention should be aimed at recent immigrants with little knowledge regarding HPV and those who have not had a relative with cervical cancer. A possible intervention to target this group might include a drive up clinic that provides information about cervical cancer including causes and prevention. This clinic could offer screening in a private location on the bus. Not all women would feel comfortable undergoing screening in this setting however they may be willing to hear a doctor, nurse, or *Promotora* speak about cervical health and may agree to make an appointment at a local clinic. This type of drive up clinic should target locations where undereducated, immigrant women might be such as the agriculture industry, factory work, or restaurant kitchens.

Since the introduction of the HPV vaccine, 27 states and the District of Columbia have considered making the vaccine a mandatory school vaccination, but only Washington DC and Virginia have enacted legislation to make this a requirement (McKeever et al., 2014). Mandatory vaccination could eradicate cervical cancer health disparities, and might be a viable strategy for prevention if implemented more broadly. However, until this happens, if at all, *Promotoras* may be solicited to encourage families to vaccinate adolescents. Because *Promotoras* are already trusted community members

they are in key positions to advocate for the need of immunization to significantly reduce the risk of contracting HPV.

The literature points to a significant need for Spanish speaking or bilingual and bicultural healthcare providers (Borrayo, 2007; Deeb-Sossa et al., 2013; Lim, 2010; Shelton et. al., 2011; Woloshin, et al. 1997). More Spanish speaking health care workers would likely be a strong enabling resource (Anderson, 1995) for Hispanic women with cervical cancer. It can improve many aspects of Hispanic women's cervical cancer experience such as; reduce risk, increase screening, and improve follow through with treatment plans. The University of California Los Angeles (UCLA) has created a program to support Spanish speaking physicians trained in other countries in passing the U.S medical licensing exam, provide stipends for studies in preparation of the exam and provide guidance in their application for residency programs (Jordon, 2007). These types of program should be replicated throughout the country.

Other interventions might find ways to reward bilingual doctors, nurses, nurse practitioners and other health care workers for working with underserved communities. For example they might be offered federal or state stipends to work with underserved Spanish speaking communities. These grants might persuade health care workers to work in communities they otherwise would avoid. A \$20,000 stipend might be given to health care workers who decide to commit to at least one year of work in a Spanish speaking underserved community. A similar stipend program is in place now to incentivize mental health practitioners to work in underserved communities (by the MFT Consortium of California). This program can be applied to incentivize bilingual health care workers to do the same. Some might argue that doctors might not be persuaded by this amount of

money as their potential for earning might be higher in more affluent communities, perhaps waiving a certain percentage of student loan debt might be more appropriate for those with higher income potential. According to the American Medical Association (as cited in Zhu & Metzler [2012]), the average medical student graduates with \$160,000 in debt, with 80% of medical students owing at least \$100,000. Bilingual doctors with student loan debt might be willing to work in underserved communities if it means a substantial portion of their debt is forgiven.

The fact that undocumented Hispanic women may avoid health care due to fears of deportation also needs to be addressed. More needs to be done to ensure Hispanic immigrants that they will not be deported for seeking health care services. This misconception needs to be eradicated.

Research has shown that more recent immigrants living in smaller cities have elevated concerns about deportation when using health care services (Berk and Schur, 2001). As discussed previously perhaps targeting undocumented immigrants at the Mexican consulate would be useful. Another useful intervention might be targeting undocumented immigrants at church. Religion is a big part of many Hispanic individuals' lives; they often place a lot of trust in religious leaders. Thus reaching out to religious leaders and asking them to dispel any myths regarding fear of visiting a doctor due to immigration status might be appropriate. Religious leaders would likely be receptive to this type of intervention as they are often looking for more ways to positively impact the communities they serve. Religious leaders would be asked to make a quick announcement during the Spanish language mass to encouraging Hispanic church goers to visit a doctor regularly and explain that health care workers are not concerned with

their legal status. *Promotoras* may also be effective in helping irradiate this misconception. An intervention that trains *Promotoras* on how to dispel this myth and gives them a platform for doing so may be an effective alternative.

More needs to be done to help Hispanic women cope with the physical symptoms related to radiation therapy. Physical side effects of treatment have been associated with depression for Hispanic cervical cancer survivors (Meyerowitz et al., 2000). Studies have shown that physical side effects associated with radiation often negatively impact the long term quality of life for cervical cancer survivors (Kirchheiner et al., 2015; Klee et al., 2000; Lisovaja et al., 2014). Interventions providing detailed information regarding the physical side effects a patient might expect could help patients prepare emotionally for the after effects of radiation. Health care workers that administer radiation therapy should be trained in tactfully explaining the possible side effects of the treatment. This training should be provided to health care workers when they learn how to administer radiation, and extended family members to facilitate the provisions of social support to diagnosed women.

After diagnosis individuals can be alerted to the benefits of seeking social support and can be given tips for how to disclose their diagnosis to supportive family members and friends. No other review has examined how multiple aspects of Hispanic culture effect diagnosis disclosure and in turn, social support for Hispanic women diagnosed with cervical cancer. Social support impacts both predisposition and factors that enable the use of health care services. Social support is not only important for primary prevention such as screening practices, but also for secondary prevention such as following treatment plans, and tertiary prevention aimed at improving quality of life after

diagnosis. *Familismo* supports close family ties and makes it unlikely for Hispanic women that subscribe to this cultural norm to turn to anyone outside of the family for support. Immigrant Hispanic women may have few family members in the country further reducing their access to social support. *Marianismo* promotes a sentiment of sparing family members from a painful diagnosis of cancer. The importance of chastity may make it difficult for Hispanic women to share about a disease that is related in any way to sexuality and may deter an individual from participating in screenings. All of these factors might mean that Hispanic women are lacking in sources of social support. To develop more effective culturally sensitive prevention and intervention efforts, it is necessary to identify the links between culture and diagnosis disclosure/social support in Hispanic women diagnosed with cervical cancer.

Many of these cultural barriers can also be strengths. Reframing aspects of *marianismo* and *familismo* in ways that helps encourage women to engage in preventative practices, follow through with medical recommendations, and disclose their diagnosis to family members may be effective ways to structure interventions. Commercial campaigns that promote sisterhood and support between women, specifically family members, regarding cervical cancer might begin to eradicate the stigma of cervical cancer. This may also make it easier to disclose a cervical cancer diagnosis if women see that other women can be supportive regarding this issue. Highlighting that *familismo* can mean encouraging family members to take care of their health needs and providing them with the support they need to do so would likely be an effective way to turn this cultural norm into a factor that helps improve cervical cancer outcomes.

An extension of this type of commercial campaign might leverage aspects of *marianismo* by explaining that women cannot take care of their families if they are not well enough to do so; this might encourage women to make time for their own health care, even if it means temporarily taking away time to care for their families. An example that can be used in the commercial campaign is that of the mother on a plane that is losing oxygen, if the mother attempts to put her child's oxygen mask on first she might lose consciousness before she does so, but if she put hers on first she can make sure she is awake to help her children put on her/his mask. This type of example might be very impactful for women that ascribe to cultural views such as *familismo* and *marianismo*. Commercial campaigns that use culturally grounded narratives could be beneficial. *Tamale Lesson* conveyed facts regarding the causes of cervical cancer and how to detect it using Hispanic cultural traditions such as *familismo*, by portraying a Mexican American family preparing tamales for a Quinceanera. Mexican American women who received *Tamale Lesson* a culturally grounded narrative video as opposed to a non-narrative video showed a significant increase in cervical cancer screening reducing disparities in cancer screening found at baseline (Baezconde-Garbanati et al., 2014). The non-narrative video included the same facts about cervical cancer, yet was not effective at reducing screening disparities. Narrative or storytelling interventions are more powerful and can be used to humanize and begin to destigmatize cervical cancer.

Because social support is such an important factor impacting whether clients adhere to treatment plans and improving quality of life after diagnosis it would be important to create interventions that educate not only the patient regarding social support but also their loved ones. Research on the co-experience of cancer has shown that family

members often feel they need additional resources. Research has shown that caring for individuals with a chronic illness such as cancer often leads to stress and depression (Grunfeld et al., 2004; Kim, & Schulz, 2008). Because Hispanic women are usually the primary caregivers and often believe in the importance of sparing family members of hardship, it might be especially difficult for family members of Hispanic women to deal with this reversal of roles. Thus culturally sensitive interventions should be created to help family members cope with caregiving and learn effective ways of providing social support. These interventions might involve family counseling services at low cost local clinics. These family counseling sessions can be aimed at redistributing responsibilities to allow for the cervical cancer patient to attend treatment without feeling guilty. These sessions might also help the family cope with any stress or depression regarding the cervical cancer diagnosis.

In conclusion, the literature supports that Hispanic women with cervical cancer have unique cultural experiences that effect primary, secondary and tertiary aspects of care. More research on these cultural phenomenon and their impacts on the continuum of care for this population is needed. Of particular importance should be the way that these cultural phenomenon impact diagnosis disclosure and social support for this heavily burden population. Culturally sensitive interventions such as the ones mentioned above should be implemented with these variables in mind.

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