Reducing the Excess Burden of Cervical Cancer Among Latinas: Translating Science into Health Promotion Initiatives

Lourdes Baezconde-Garbanati, Sheila T. Murphy, Meghan Bridgid Moran, and Victoria K. Cortessis

University of Southern California

Abstract

Purpose: Although deaths from cervical cancer are declining, Latinas are not benefiting equally in this decline. Incidence of invasive cervical cancer among Los Angeles', California Latinas is much higher than among non-Latina Whites (14.7 versus 8.02 per 100,000). This paper examines cervical cancer screening among Latinas. Methods: Ninety-seven women of Mexican origin participated in 12 focus groups exploring barriers to screening. Saturation was reached. **Results:** All participants knew what a Pap test was and most knew its purpose. More acculturated participants understood the link between HPV and cervical cancer. More recent immigrants did not. There was confusion whether women who were not sexually active need to be screened. Most frequently mentioned barriers were lack of time and concern over missing work. Lower income and less acculturated women were less likely to be aware of free/lowcost clinics. Older and less acculturated participants held more fatalistic beliefs, were more embarrassed about getting a Pap test, were more fearful of being perceived as sexually promiscuous, and were more fearful of receiving disapproval from their husbands. Conclusions: Latinas are informed regarding cervical cancer screening; rather they encounter barriers such as a lack of time, money and support. Health promotion interventions can be enhanced via peer-to-peer education, by addressing barriers to cervical cancer screening with in-language, culturally tailored interventions, and working with clinics on systemic changes, such as extended clinic hours.

© 2013 Californian Journal of Health Promotion. All rights reserved. *Keywords: Latinas, cervical cancer, barriers, health disparity, translational research*

Introduction

Morbidity and Mortality from Cervical Cancer

Cervical cancer is the third most common female cancer in the world. It is causally linked to the Human Papillomavirus (HPV). HPV is the agent of the most common sexually transmitted infection worldwide (Globocan, 2008). An estimated 530,000 new cervical cancer diagnoses and 275,000 cervical cancer deaths occur annually (Globocan, 2008), and these numbers are rising. The World Health Organization (WHO) projects over 610,000 new cervical cancer diagnoses and 322,000 cervical cancer deaths in 2015 (Globocan, 2008).

A screening test to detect abnormal cells on the cervix - commonly known as the Papanicolaou or "Pap" test- was introduced in the 1940s. In

subsequent decades cervical cancer incidence mortality declined dramatically and in industrialized nations where screening and appropriate follow-up became widespread. In these areas, routine screening not only reduced cervical cancer mortality, but also prevented a cervical cancer epidemic that rising HPV infection rates would have caused if screening had not been introduced (Peto, Gilham, Fletcher, & Matthews, 2004). By contrast, effective screening remained far less available in resource-poor areas – including Latin American nations - where cervical cancer occurs at disproportionately high rates, and is often the leading or second leading cause of cancer death among women (Globocan, 2008).

In the United States, where screening has been widely available, cervical cancer incidence declined over 75% by 2008 (Globocan, 2008).

However this dramatic decline did not occur in all segments of the population, and incidence rates among Latinas have long exceeded those of other major racial/ethnic groups (Barnholtz-Sloan et al., 2009; Benscomo, 2009). Latinas experienced the highest invasive cervical cancer incidence rates (11.4 per 100,000) of any group except Vietnamese, and twice the incidence rates of non-Latina White women (7.9 per 100,000) (American Cancer Society, 2009). Cervical cancer mortality in the US has similarly declined, but mortality rates among Latinas have remained significantly higher (3.4 deaths per 100,000) over the years than among non-Latina White women (2.5 deaths per 100,000 (Abraido-Lanza et al., 2004; Haynes et al., 1999; Scarinci et al., 2010). Epidemiologic projections (Saraiya et al., 2007) paint an unsettling picture, which we are already witnessing, of exponentially increasing cervical cancer deaths among Latinas.

The relatively high cervical cancer mortality among Latinas is primarily due to delayed detection of cervical lesions, often after highly treatable pre-neoplastic lesions that can be detected by Pap test have progressed to invasive cancer. Even among women diagnosed with invasive cervical cancer, Latinas are more likely than non-Latina White women to be diagnosed at an advanced stage (del Carmen et al., 1999; Saraiya et al., 2007; Scarinci et al., 2010), where there are fewer treatment options. This has profound implications, because the five-year survival rate is far lower among women whose cervical cancer has progressed to regional (less than 60% survival) or distant (less than 40% survival) sites by the time of diagnosis, compared to those diagnosed with localized disease (greater than 80% survival) (American Cancer Society, 2009).

Adherence to Screening Guidelines

Adherence to cervical cancer screening guidelines is less common among Latinas than non-Latina White women, hindering early detection (Abraido-Lanza, Chao, & Gates, 2005). Nationally, non-adherence with recommended follow up among Latinas has been reported in several studies to range from 20% to as low as 90% non-adherence compared to only 16% non adherence among non-Latina White women (Duggan et al., 2012, NCI, 2009/2010 Update). Considering the availability of low cost and no cost Pap tests, it is alarming to see that in 2008, approximately 10% of Latinas living in the US had never had a Pap test (Nasseri, Cress, & Leiserowitz, 2006). In 2009 only 74.6% of Latinas who were eligible for a Pap test reported having one during the previous three years compared to 81.4% of non-Latina Whites, a proportion that remained relatively stable from 1993 until 2008 when most recent available data were collected (National Cancer Institute at the National Institutes of Health; National Health Interview Survey, Duggan et al., 2012; American Cancer Society, 2009).

Barriers to Compliance with Screening

Barriers to compliance with screening guidelines and follow up for the treatment of early lesions has been associated with inadequate access to cancer information, low rates of health insurance, and no regular source of medical care (Buki, Jamison, Anderson, & Cuadra, 2007). These barriers have consistently been found to be predictive of low levels of cancer screening among immigrant groups in California (Pourat, Kagawa-Singer, Breen, & Sripipatana, 2010). These contribute to widening the health disparities gap within and between groups of diverse women.

Cultural Barriers. Other barriers such as acculturation to the U.S. culture, lack of knowledge about the need for regular screening via Pap tests, about U.S. guidelines for screening, and older age also contribute to disparities in cancer screening. Acculturation is the process of adaptation to the host culture. It is not a linear process, but functions within multiple dimensions. Some women in the lower acculturation dimension tend to be more traditional, may lack the most up to date information on cancer screening guidelines, as they tend to have less access to information and services than more highly acculturated Latinas. Fluency in English (Padilla, 1980) has also been shown to play a key role in cancer screening. Immigrant women face a myriad of issues closely tied to the acculturative process, which in turn contributes to some of the barriers they face. These include lack of fluency in English,

stress of acculturation, being foreign-born. Many Latinas, even those with Basic English language skills, are not able to carry a full conversation in English. When seeking health care, this becomes a barrier. Being foreign-born (born outside of the U.S.) is also a factor that can influence cancer screening. Depending on number of years in the U.S. foreign born women may also be less acculturated, have less English language proficiency, and may not have a tradition of preventive care in their home countries. All these are tied to the complex combination of barriers one finds among Latinas that prevent them from coming in for cancer screening in a timely fashion.

Several studies have confirmed this reporting that more acculturated Latinas were more likely to obtain cervical cancer screening than their less acculturated counterparts (Shah, Zhu, Wu, & Potter, 2006; Watts et al., 2009). Moreover, because foreign-born Latinas receive Pap screening less frequently than either US-born Latinas or non-Latina White women (Goel et al., 2003; Nasseri et al., 2006), their cervical cancer incidence and mortality far exceed rates among their US-born Latina And non-Latina White counterparts (Seeff & McKenna, 2003).

Knowledge barriers. One recent study (Han et al., 2012) showed that Peruvian Spanish speaking women were significantly also less likely to know that HPV causes cervical cancer compared with the general population of Non-Latina White women. These women were also more likely to express being embarrassed of getting a Pap test, and afraid, and lacked knowledge regarding if the HPV vaccine was safe or effective. The literature also suggests that many Latinas lack knowledge about the need for screening (Warren, Londono, Wessel, & Warren, 2006), resulting in lower rates of Pap tests, and inadequate follow-up to abnormal findings.

Age differences. Age has likewise been shown to make a difference. In one study (Fernandez-Esquer, Espinoza, Ramirez, & McAlister, 2003), Latinas over 40 years of age were more likely to endorse inaccurate beliefs about cervical cancer and Pap tests than younger women. In another study, Cantero, Richardson, Baezconde-Garbanati and Marks (1999) found that older and less educated women preferred not to know whether they had cancer or a malignant disease. These older women believed if it was God's will they got cancer, there was nothing they could do about it. So they preferred not to know.

The purpose of the present study is to reexamine persistent barriers to cervical cancer screening among Latinas living in Los Angeles County, identify new barriers or trends, and make recommendations for the elimination of cancer related disparities for this vulnerable and rapidly expanding segment of the population.

Methods

Theoretical Model

We employed Fishbein and Capella's (2006) Integrative Model of Behavioral Prediction (IMBP) as a theoretical framework. IMBP acknowledges both proximal barriers (acculturation, language barriers, lack of insurance) and more distal barriers (such as education, transportation). The research for this study, which forms part of a larger initiative (RO1CA144052) funded by the National Cancer Institute (NCI), extends the Integrative Model by incorporating community level factors.

Participants

In order to participate, women had to meet the following inclusion criteria: ages of 21-45 years old, self identified as Latina of Mexican origin, not work in a health-related field, and have never been diagnosed with cervical cancer. Women for this study were recruited from the greater Los Angeles area. We recruited women through newspapers, interpersonal communication, and with flyers in both English and Spanish language. We also approached women for recruitment in locations that are popular among Latinos in Los Angeles, such as Plaza Mexico, and asked them if they would like to participate in a study. Flyers were also posted in various public places, and LAC+USC Medical Center. In addition women were recruited through community agencies. Staff at various community agencies informed women about the study. In turn other women shared the

information with each other. Further, we recruited through a research agency (Viramontes Marketing Communications, Inc.), an agency that specializes in running focus groups among Latinos and other vulnerable populations in Los Angeles. Participants signed consent forms and were compensated \$75 for their time. Participants represented various levels of education, including some high school and various levels of English proficiency. We recruited women regardless of income level.

Procedures

Twelve 90-minute focus groups were conducted from 2009 to 2011 with Los Angeles County Latinas. Focus groups were conducted in both Spanish and English based on women's preferences. All women completed a brief screening questionnaire querying inclusion criteria and provided informed consent. Human subjects' protection requirements and protocols in compliance with our institution's Internal Review Board (IRB) were followed. The focus groups ranged in size from 7 to 10 participants and included a total of 97 women of Mexican origin. A structured guide was prepared and used by moderators to consistently elicit experiences and perspectives across groups (Morgan, 1997).

Measures

Specific questions focused on measuring three main areas: (1) general barriers to staying healthy, (2) specific perceived barriers to regularly obtaining a Pap test and (3) knowledge and beliefs about Pap tests. Sample questions included: (1) Who is susceptible to cervical cancer? (2) Have you heard of the Human Papilla virus (HPV)? (3) How many of you have had a Pap test or smear? (4) Why might some Latina women like you not get a Pap test? (5) If you wanted to get a Pap test today, would you know where to go or who to call? The groups were moderated by three of the authors, who extensive experience in designing, have moderating and analyzing focus groups. A recorder took notes during the session. All discussions were videotaped and transcribed and, as necessary, translated into English.

Analysis

Data were analyzed using framework analysis (Krueger, 1994; Ritchie & Spencer, 1994) whereby the researchers familiarized themselves with the data, identified a thematic framework. compared and indexed the data, and then charted and mapped specific quotes from the data. One investigator categorized the data by themes. Other investigators provided feedback on the thematic categories and in a reiterative process, collapsed categories or added new ones for examining the data. Authors prioritized overarching themes, as well as sub-thematic categories within each theme. We discussed discrepancies and reached consensus. This was facilitated by the fact that this team of investigators has been working together using these methods for over four years as part of a larger initiative for cervical cancer screening. No real names were used in reporting of results to protect confidentiality.

Results

Demographic analyses revealed that most participants had a high school degree or less. Approximately 27% of participants were under 30 years of age, 41% were between the ages of 31-40, and 32% were between 40-45 years of age. Half of the participants spoke Spanish at home, while 17.9% spoke Spanish and English equally and 32.1% spoke English. Over ten percent (13.8%) had not had a Pap test in the previous three years, only 2.9% had never had a Pap test. Over half (52.6%) of participants had no health insurance, although 67.6% did have a regular source of care.

The 12 focus groups yielded in-depth qualitative information regarding levels of knowledge and beliefs about cervical cancer screening and Pap tests among Mexican origin Latinas in Los Angeles. Table 1 summarizes the barriers to cervical cancer screening revealed in the focus groups by barrier category and language preference of group members (Spanish, Spanish/English equally, or English-speaking). It identifies new trends that challenge some prior assumptions.

Table 1

Barriers to Cervical Cancer Screening Expressed in Focus Groups by Barrier Category and Language Preference

Barrier		Language Spoken at Home	
	Mainly Spanish	Spanish and English equally	Mainly English
Knowledge and Beliefs			
Uncertainty regarding who should get screened	Frequently	Rarely	Rarely
Uncertainty regarding how frequently women should get screened	Frequently	Rarely	Rarely
Lack of knowledge about how HPV is sexually transmitted	Frequently	Rarely	Rarely
Lifestyle			
Lack of money	Frequently	Frequently	Frequently
Too many responsibilities/lack of time	Frequently	Frequently	Sometimes
Cultural			
Fear of results	Frequently	Sometimes	Rarely
Embarrassment	Sometimes	Sometimes	Sometimes
Systemic			
Mistrust of doctors	Sometimes	Sometimes	Sometimes
Previous negative experiences with Pap test	Sometimes	Rarely	Sometimes
Cold and unwelcoming exam rooms	Sometimes	Sometimes	Sometimes

Persistent Lifestyle Barriers to Getting a Regular Pap Test

Lack of time/too many responsibilities. By far the most prominent barrier mentioned was the lack of time. Many respondents described waiting over three hours even with an appointment to see a doctor. Moreover, almost every woman reported being overwhelmed with responsibilities, such as work and family and, as a consequence, not being able to find time to maintain their own health. Although most of the women acknowledged that their health should be a priority and wanted to take care of themselves, the Latinas in our focus groups reported that they simply could not find the time in their hectic daily schedules to fit in a Pap test. Sally, 32 described her life as "high stress:" [I'm] working eight, nine [hours]...you come home and. You got to clean, you got to cook, give the

baby a bath. [I] It's the whole Latina mommy routine where you put yourself last."

In addition to family, some women also prioritized work over health particularly those who needed to work to support their families. In many cases, the women reported being so busy at work that they could not take time away. For example, Teresa, 27, reported *"[I experience] work overload…in the last four months, I have not had the time to take a lunch break."* These findings were consistent between Spanish and Spanish/English-speaking participants, but appeared only sometimes among the Englishspeaking women.

Lack of money. Not having the ability to pay was a significant barrier to cervical cancer screening and follow-up care. The loss of money due to having to miss work to be screened was the second most frequently mentioned obstacle. While concern about where to go for free or low cost screening was frequently a barrier among the Spanish-speaking participants and less acculturated women. The majority of the more acculturated English-speaking Latinas were aware of clinics where they could get a Pap test at low or no cost. However, as one Mexican born English-speaking respondent noted, even if she could afford an appointment for a Pap test and could get it at low or no cost, she could not afford follow-up care: "The main problem in my case is money. Money to go to the doctor, buy the medicine... what's the point of going to the doctor so he can give you medication you can't buy?" (Sofia, 40). In sum, more acculturated respondents were much better informed even if they lacked medical insurance.

Knowledge and beliefs. Almost all participants possessed at least some knowledge about cervical cancer and the Pap test (which most understood was to prevent cervical cancer). At the same time, there was uncertainty regarding who was at higher risk for cervical cancer. Many women thought that cervical cancer did not discriminate – that all women were at risk. As Isabel, 23 said: *"I believe cancer does not choose ages and it's for anyone."* Only a few women identified sexual activity as a risk factor. As a result, there was widespread uncertainty

among participants as to who should get a Pap test and how frequently it should be done. For example, there was confusion as to whether virgins over the age of 21 and older women who were no longer sexually active should still be screened. Spanish-speakers more frequently than Spanish/English or English-speakers expressed uncertainty regarding how frequently someone should be screened.

Cultural Barriers to Pap Tests

Mothers. Some Latinas reported that other women in their culture - particularly the older generation - associated Pap tests with sex. These women worried that their mothers would think they were being sexually promiscuous if they had a Pap test, and often associated this stigma with the Catholic faith. Maria, 33, noted that, "[Pap tests are] controversial because it's associated with premarital sex, and then premarital sex is associated with Catholicism...a lot of traditional Hispanic mothers would gasp, 'Why do you want one?' Or 'what are you doing?" However, as the mothers became more acculturated and less "traditional" our participants reported a shift toward being more supportive of cervical cancer screening and taking care of oneself more generally.

Husbands. Some Latinas in this study reported that their husbands or boyfriends might not approve of them getting screened. These women pointed to machismo culture, noting that their husbands would not want someone else looking "down there." Ana, 32 noted, "...the husband probably feels only he should be the one that, you know...That's only for the husband and that's it." However, although some women cited that their husbands or mothers might disapprove of them getting a Pap test, and that this could affect other women, none of the respondents reported these cultural factors as barriers to their own personal screening.

Fear of results. Taken together, data compared across the multiple focus groups showed that some of the Latinas in our study reported they are nervous and scared of what the result of the Pap test will be, and that this might prevent them from getting screened. Ana, 32, reported, "[A

barrier for me is] fear, like hopefully they don't find something. I know I worry or I worried much more before when I was much more sexually active." However, although other women also feared the results of the test, for them it was not a barrier to getting screened. Nevertheless, even among those for whom this was not a barrier, they did recognize that it might be a reason why other women might not get screened. As Cristina, 29, commented, "[others I know] say, when you don't go to a doctor they find all these bad things. When you don't go to see a doctor, everything is good, you're fine, you're okay, and once you go, you are sick, they find all these bad things with you." Fear was more frequently mentioned Spanish-speakers, expressed among only sometimes among Spanish/ English speaking participants and only rarely among the Englishspeaking women. However, comparison of data across both Spanish and English-speaking groups showed that in general, most women in all groups still wanted to put "effort" into taking responsibility for their own health.

Perceptions of Control Over One's Health

persistent Despite these barriers, most participants felt they could and should take responsibility for their own health. Although women acknowledged they faced many significant barriers to staying healthy, the majority felt they were still able to make a difference in their health by seeking preventive care, exercising and eating more healthily. If the women were not eating more healthily, they often reported it was because they lacked "discipline" and "willpower" or were "making excuses." Fatalistic attitudes suggesting that they had little control over their health occurred primarily among the older and less acculturated Spanish-speaking participants, and less so among the more acculturated women in the English-speaking groups.

Systemic Barriers to Getting a Regular Pap Test

Mistrust of doctors. A comparison of data across all focus groups revealed that the majority of Latinas in our study felt they could be active participants in their health and often do research by talking to friends and family and looking

things up online or in books. Many participants revealed they try to treat themselves first using home remedies before going to the doctor. Many participants also showed a strong preference for working together with their doctors. They did not appreciate it when a doctor did not listen or dismissed their concerns--an experience that several women reported. "[I do research online] and tell [the doctor] ... this is what I think I have, and they give it to me [yell at mel. And that leads me to not trust the doctor" (Adriane, 26). Others harbored a mistrust of doctors that stems from being misdiagnosed, or from negative experiences of friends and family with the medical system. "My main [barrier] is trusted in doctors because sometimes they can misdiagnose vou...The doctors have never helped me" (*Carmen*, 33). Many of the women also suspected that the doctors they were seeing were inferior or as one of our respondents put it "not every doctor is first in their class" (Gabby, 22).

Negative Experiences with Previous Pap

Tests. In addition to a general wariness of doctors, both Spanish and English-speaking Latinas reported negative experiences associated with having a Pap test that might keep them from returning when their next screening is due. As Pilar, 44 said, "The last time I went, it hurt, and I didn't want to go back." The women also overwhelmingly reported that a Pap test was "embarrassing;" many also felt they were "invasive and demeaning." While much of the feelings of embarrassment were simply due to having someone look at them "down there," many Latinas cited more specific factors such as lack of privacy and comfort in the exam room (e.g. wearing a paper robe, room temperatures that were too cold), long wait times and doctors and staff who did not listen or were inconsiderate. "It was linoleum and cold and uncomfortable, and nurses coming in and out, and I was a little like, 'Can you close the door?" (*Maria*, 33).

Discussion

Prevention of cervical cancer, based on screening followed by treatment of early

abnormalities, is one of the most effective approaches to cancer control ever implemented. Findings from this study point to a series of perceived and persistent barriers that impede Latinas' access to this important preventive care, thereby contributing to their cancer burden and furthering cancer disparities. Our study challenges some prior assumptions and helps explain previous findings as described below.

Lack of time was shown to be the greatest barrier to Pap test screening. Although lack of time had previously been reported as a barrier, new to the literature on Latinas is that lack of time comes from overwhelming competing demands and responsibilities that go beyond family, to include responsibilities in the work place. Many of the women in this study cited a busy lifestyle as a major barrier to staying healthy and getting a Pap test (Buki et al., 2007; Fernandez-Esquer et al., 2003; Nelson, Geiger, & Mangione, 2002; Pourat et al., 2010). Most literature attributes the lack of time to family responsibilities. This study makes a significant contribution to the literature as it shows it is a combination of factors including family and work that prevent women from being screened. Developing programs that may help reduce stress and extending clinic hours so women can go in for screening when they are off from work, might yield mechanisms to better control daily hassles and facilitate screening for women.

Lack of money and costs were also cited as barriers to cancer screening. Prior studies found that women were concerned about the cost of the screening exam (Buki et al., 2007; Fernandez-Esquer et al., 2003; Nelson et al., 2002; Pourat et al., 2010). However, this study clarifies and adds context to prior findings. Although the cost of the screening exam is still a persistent barrier among Spanish-speakers, participants in this study, overall, noted it was the cost of missing wages that was a greater barrier. This study helps to further explain the meaning of "costs" and lack of money for this group.

The majority of the Latinas were aware that Pap tests were to detect abnormal cells and that if left untreated could result in cervical cancer. However, there was widespread uncertainty across groups regarding who should be getting a Pap test, how frequently, and the link between cervical cancer and sexual activity. A recurrent misperception was that Pap tests are most important for women who are currently or were recently sexually active. Health messages should therefore stress that cervical cancer risk persists for many years. Moreover, more recent immigrants were not well informed regarding where to go for low/no cost cervical cancer screening in Los Angeles. Tailored health promotion efforts need to address differences in knowledge within groups by acculturation status and promote free screenings.

Cultural barriers have often been linked to health disparities in this population (Nelson et al., 2002; Ramirez, Suarez, Laufman, Barroso, & Chalela, 2000; Shah et al., 2006). A common finding on Latinas is the importance of "marianismo" which D'Alonso and Sharma (2010) describe as the sacrificial character of Latinas that moves them to "always put family first". Our focus groups underscored this tendency --referred to by one respondent as "the Latina mommy" syndrome. But although these values do exist our participants did not see them as a barrier to obtaining care. This may signal a shift away from traditional cultural barriers to grounded getting screened. Culturally interventions provided in-language and tailored to the specific knowledge and experiences of a heterogeneous Latina population need to be explored further.

Strategies that empower women to make decisions for their own health might prove to be useful in the implementation of best practices for Latinas in terms of cervical cancer screening. The promotores de salud model (lay health care providers), an empowerment model, has been shown in multiple studies to help Latinos move to action adopting healthier lifestyles (Balcazar et. 2012). The use of the promotores de salud model in cervical cancer screening and HPV uptake might empower Latinas to take better care of their health, if not for themselves, for their families.

The literature suggests that Latinas often feel a sense of fatalism with respect to health such that if it is God's will, there is nothing they can do to avert a negative outcome (Cantero et al., 1999;

D'Alonzo & Sharma, 2010; Devaney et al., 2009; Villegas, Lemanski, & Valdez, 2010). Although fatalism was discussed among the less acculturated Spanish-speakers, we found that the majority of women wanted to take charge of their own health. Further research is warranted to examine the meaning of this and learn whether it prevents women from screening.

One area for future study is a better understanding of "self efficacy". According to Bandura (1994), self-efficacy is a person's belief that he/she may be able to succeed in a particular situation. It provides individuals with a sense of greater control over one's destiny and helps individuals move beyond a sense of "fatalism", that it is God's will. In this study women wanted to take charge of their own health. They wanted to have some control over their own health. A better understanding of "self efficacy" might provide strategies to improve women's health when there is a fatalistic view of the disease, if warranted. Self -efficacy provides the individual with the capacity to decide upon a specific course of action that helps the individual manage potential threatening situations, giving women a greater sense of control. Future studies might include not just a greater understanding of "fatalism" but also of "self efficacy". This could provide strategies for implementation in practice settings, which might in part result in more positive outcomes.

Another unique contribution of our study to the literature is our finding regarding the mistrust of doctors and negative experiences with previous Pap tests. The literature on Latino patients focuses on the cultural value of "respeto" in which doctors are highly regarded and typically seen as playing a pivotal role in communicating cancer information (Chong, 2002; Marin & Marin, 1991). In contrast, women in our study often feared being misdiagnosed or reported negative experiences with the medical system. They felt some of the doctors they were seeing were not "first in their class" and disliked it if doctors dismissed their thoughts on what might be causing an illness. They at times did not feel heard by their doctors. If this sentiment is widespread and holds across levels of acculturation, cancer communication that relies on doctors, that are seen by their patients as less caring, may be less effective than receiving an important health message from another valued source of health information in the community or in a person-to-person approach with valued members of their social network. This finding calls for a need to also improve doctor-patient communication. It is a significant finding as it provides insights into the doctor-patient relationship and communication strategies that might be optimal in conveying cancer related information to patients. Findings signal to the need to improve the doctor-patient relationship.

This relationship can be enhanced by training providers to participate in "active listening". In "active listening" the doctor repeats back to the patient what he/she has heard in a manner of confirming he/she has heard and interpreted the information correctly. Currently in the market there is a toolkit "Teach-Back" toolkit, which teaches providers to support patients and their families through the care continuum. It is a useful tool to ensure the health care providers have explained information clearly to the patient, and that the information has been understood. Utilizing this technique, the providers ask the patients and/or family members to explain in "their own words" what they need to know or do. It teaches the provider to communicate in a caring way. It is a way to check patient understanding and to repeat instructions if needed. (http://teachback.slashwebstudios.com). Our findings may provide mechanisms to strengthen and enhance doctor-patient communication. This type of information can be introduced into the medical curriculum and can be the subject of enhanced continuing medical education, as doctors strive to have better communication with their patients, especially those at high risk for disease such as cervical cancer.

Interventions that target health promotion and changes to the health care system and low costto free clinics might be critical to having women comply with screening guidelines. In particular extended hours at free or low cost clinics or availability of services during the weekend might facilitate cancer screening. Making hours convenient as well as the availability of key

targeted locations, close to where women live and work, might also facilitate this process. Current health promotion interventions could benefit from using GIS mapping and spatial analyses to understand where services might be best located to provide better access to health care for cancer screening.

Peer to peer education, for example, via promotoras de salud (lay health care workers) may be an effective mechanism for eliminating persistent barriers that contribute to health disparities. The "promotoras de salud" social intervention model has proven to be effective in disseminating key health information to Latinas (Walton, Calvo, Flores, Navarrete, & Ruiz, 2009). Health promotion experts and community leaders can support the development of partnerships with health care service agencies and community members in order to better intervene in the elimination of cervical cancer disparities.

Limitations

Several limitations should be considered. First, Latinas in our focus groups were exclusively from Los Angeles and of Mexican origin, limiting the generalizability of our findings. While our findings challenged important assumptions from the previous literature, future research is required to investigate whether findings hold over time. Also, instead of an acculturation scale, we used income and language preference as a proxy to acculturation. Future studies need to account for place of birth, and length of time in the US to more fully comprehend the disparities faced by this population. Finally, the focus of this study was on barriers to Pap test screening and did not address women's perceptions regarding the Human Papillomavirus (HPV) vaccine, whose uptake has been slow among Latinas in the U.S.

Conclusion

Some of these findings have implications for the translation of scientific findings into health promotion efforts. Our results can help inform physicians, health educators, clinic staff and administrators of specific barriers that can be alleviated with some systemic change approaches. Doctors and health educators may benefit from this research by having a better understanding the issues Latinas face. Persistent barriers identified in this study included: cost, lack of knowledge, lack of English proficiency, worries about cost of coming in for screening, and time constraints. This study adds to the literature as it found that cost and time barriers where related to inability to leave work because of potential loss of wages. Understanding these barriers and their impact on Latinas is critical especially if any follow up is needed should there be abnormal findings.

Health promotion messages can be tailored to clinic decision-makers as well that can incorporate systemic changes. Some of these changes could include: increasing visibility of where to access services, decision-making on optimal location of services, extended hours of services, making Pap tests available in specific locations close to where Latinas live and work in the community, and having services in-language available. Translating science into community initiatives takes approximately eight years. The sooner we can translate knowledge from scientific findings into health promotion initiatives, the more lives will be saved and the costs to the system will be reduced.

Acknowledgements

The authors wish to acknowledge Paula Amezola de Herrera, Dr. Joyee Chatterjee, Flor del Hoyo, Quynh-Minh Tran and Rachel Adams for their support on various aspects of this paper. We also wish to thank Dr. Robert Haile and Dr. Sandra Ball-Rokeach, Co-PIs, and Janet Villarmia at the Norris Comprehensive Cancer Center, University of Southern California (USC) for their support of this project. We wish to express our appreciation to Mariana Amatullo, Elena Salij, Elisa Rufino, Sean Donahue and the students at the Art Center College of Design -Designmaters program for development of the campaign that led to this research, Es Tiempo. We wish to thank Dr. Jennifer Unger for reviewing earlier versions of this paper. This research was supported in part by Award P30CA014089 to the Norris Comprehensive Cancer Center by the National Cancer Institute (NCI), -"Transforming Cancer Knowledge, Attitudes and Behavior Through Narrative" -

Award R01CA144052 (Murphy/ Baezconde-Garbanati), and Barriers to Cervical Cancer Prevention in Hispanic Women: A Multilevel Approach" - Award R01CA1553326 (Murphy/Ball-Rokeach) from the NCI. The content is solely the responsibility of the authors and does not represent official views of the NCI or of the National Institutes of Health.

References

- Abraido-Lanza, A., Chao, M., <u>Acculturation and cancer screening among Latinas: results from the</u> <u>National Health Interview Survey. Ann Behav Med. 2005 Feb ;29:22-8</u> 15677297
- American Cancer Society, 2009, American Cancer Society: Cancer Prevention & Early Detection Facts & Figures, Atlanta, GA: American Cancer Society; 2009:i–64. Cancer facts and figures. Available from: URL:

http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acsp c-036845.pdf

- Balcazar, H., Wise, S., Rosenthal, L., Ochoa, C., Rodriguez, J., Hastings, D., Flores, L., Hernandez, L., Duarte-Gardea, M. (2012). An ecological model using promotores de salud to prevent cardiovascular disease on the US-Mexico border: The HEART Project. Prev Chronic Dis, 9: 110100. DOI: <u>http://dx.doi.org/10.5888/pcd9.110100</u>.
- Bandura, A. (1994). Self-efficacy. In V. S. Ramachaudran (Ed.), *Encyclopedia of human behavior*, 4. New York: Academic Press, pp. 71-81.
- Barnholtz-Sloan, J., Patel, N., Rollison, D., Kortepeter, K., MacKinnon, J., & Giuliano, A. (2009).
 Incidence trends of invasive cervical cancer in the United States by combined race and ethnicity. *Cancer Causes & Control*, 20(7), 1129-1138. Doi 10.1007/S10552-009-9317-Z
- Buki, L. P., Jamison, J., Anderson, C. J., & Cuadra, A. M. (2007). Differences in predictors of cervical and breast cancer screening by screening need in uninsured Latina women. *Cancer*, 110(7), 1578-1585. Doi 10.1002/Cncr.22929
- Cantero, P. J., Richardson, J. L., Baezconde-Garbanati, L., & Marks, G. (1999). The association between acculturation and health practices among middle-aged and elderly Latinas. *Ethnicity and Disease*, *9*(2), 166-180.
- Center to Reduce Cancer Health Disparities (accessed 2012), Examples of Health Disparities. Http://crchd.cancer.gov/disparities/examples.html (National Cancer Institute).
- Chong, N. (2002). *The Latino patient: a cultural guide for health care providers*. Yarmouth, Maine: Intercultural Press.
- D'Alonzo, K., & Sharma, M. (2010). The influence of marianismo beliefs on physical activity of mid-life immigrant Latinas: a Photovoice study. *Qualitative Research in Sport, Exercise and Health*, 2(2), 229-249. Doi: 10.1080/19398441.2010.488031
- Del Carmen, M. G., Montz, F. J., Bristow, R. E., Bovicelli, A., Cornelison, T., & Trimble, E. (1999). Ethnic differences in patterns of care of stage 1A(1) and stage 1A(2) cervical cancer: a SEER database study. *Gynecological Oncology*, 75(1), 113-117. Doi: 10.1006/gyno.1999.5543S0090-8258 (99) 95543-9 [pii]
- Devaney, J., Seto, L., Barry, N., Odette, F., Muraca, L., Fernando, S., Angus, J. (2009). Navigating healthcare: gateways to cancer screening. *Disability and Society*, 24(6), 739-751. Doi: 10.1080/09687590903160233
- Duggan, C., Coronado, G., Martinez, J., Byrd, T., Byrd, T., Carosso, E., Lopez, C., Benavides, M., Thompson, B. (2012). Cervical cancer screening and adherence to follow up among Hispanic women study protocol – a randomized controlled trial to increase the uptake of cervical cancer screening in Hispanic women. Bio-Medical Central Cancer Open access journal (BMC Cancer), 2012, 12, 170. On line journal. http://www.biomedcentral.com/1471-2407/12/170.
- Fernandez-Esquer, M. E., Espinoza, P., Ramirez, A. G., & McAlister, A. L. (2003). Repeated Pap smear screening among Mexican-American women. *Health Education Research*, 18(4), 477-487. Doi 10.1093/Her/Cyf037

- Fishbein, M. & Cappella, J.N. (2006). The role of theory in developing effective health Communications. Journal of Communication, 56, S1-S17.
- Flores, B. (2009). Preventing cervical cancer in the Latina population. J. Women's Health, 18 (12), 1935-43.
- Globocan. (2008). Cervical Cancer Incidence and Mortality Worldwide in 2008 Summary. From International Agency for Research on Cancer http://globocan.iarc.fr/factsheets/cancers/cervix.asp
- Goel, M. S., Wee, C. C., McCarthy, E. P., Davis, R. B., Ngo-Metzger, Q., & Phillips, R. S. (2003). Racial and ethnic disparities in cancer screening: the importance of foreign birth as a barrier to care. *Journal General and Internal Medicine*, 18(12), 1028-1035. Doi: 20807 [pii]
- Han, C., Ferris, D., Waller, J., Tharp, P., Wlater, J., Allmond, L. (2012). Comparison of knowledge and attitudes toward human papillomavirus, HPV vaccine, Pap test, and cervical caner between Peruvian women and those from the U.S. J. Low Genit Tract Dis, 2012, 16 (2) 121-6.
- Krueger, R. A. (1994). *Focus groups: a practical guide for applied research*. Ann Arbor, MI: University of Michigan.
- Los Angeles County Department of Public Health, O. o. W. s. H. (2010). *Health Indicators for Women in Los Angeles County: Highlighting Disparities by Ethnicity and Poverty Level*. Los Angeles: Retrieved from http://www.publichealth.lacounty.gov/owh/docs/Health-Indicators-2010.pdf.
- Lihua Liu (2010), Special data runs from SEERS Registry Data for purposes of this paper, University of Southern California, Los Angeles, CA.
- Marin, G., & Marin, B. (1991). *Research with Hispanic populations*. Ann Arbor, Michigan: Sage Publications.
- Morgan, D. L. (1997). *Focus groups as qualitative research / David L. Morgan* (2nd ed.). Thousand Oaks, Calif.: Sage Publications.
- Nasseri, K., Cress, R. D., & Leiserowitz, G. (2006). Cervical Cancer in California (pp. 76). Santa Barbara, CA: Public Health Institute, Tri-Counties Cancer Surveillance Program.
- National Cancer Institute at the National Institutes of Health. Cervical Cancer. Retrieved June 6, 2011, 2011, from http://www.cancer.gov/cancertopics/types/cervical/
- NCI (Producer). (2009/2010 Update). Cancer Trends Progress Report. *Cervical Cancer Screening*. Retrieved from

http://progressreport.cancer.gov/doc_detail.asp?pid=1&did=2007&chid=72&coid=717&mid=

- Nelson, K., Geiger, A. M., & Mangione, C. M. (2002). Effect of health beliefs on delays in care for abnormal cervical cytology in a multiethnic population. *Journal of General Internal Medicine*, 17(9), 709-716.
- Padilla, A. M. (1980). The role of cultural awareness and ethnic loyalty in acculturation. In A. M. Padilla (Ed.), Acculturation: Theory, Models, and New Findings (pp. 47-84). Boulder, CO: Westview Press.
- Peto, J., Gilham, C., Fletcher, O., & Matthews, F. E. (2004). The cervical cancer epidemic that screening has prevented in the UK. *Lancet*, *364*(9430), 249-256. Doi: 10.1016/S0140-6736 (04) 16674-9S0140673604166749 [pii]
- Pourat, N., Kagawa-Singer, M., Breen, N., & Sripipatana, A. (2010). Access Versus Acculturation Identifying Modifiable Factors to Promote Cancer Screening Among Asian American Women. *Medical Care*, 48(12), 1088-1096.
- Ramirez, A. G., Suarez, L., Laufman, L., Barroso, C., & Chalela, P. (2000). Hispanic women's breast and cervical cancer knowledge, attitudes, and screening behaviors. *American Journal of Health Promotion*, 14(5), 292-300.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. G. Burgess (Eds.), *Analyzing Qualitative Data*. New York: Routledge.
- Saraiya, M., Ahmed, F., Krishnan, S., Richards, T. B., Unger, E. R., & Lawson, H. W. (2007). Cervical cancer incidence in a pre-vaccine era in the United States, 1998-2002. *Obstet Gynecology*, 109(2 Pt 1), 360-370. Doi: 109/2/360 [pii] 10.1097/01.AOG.0000254165.92653.e8

- Seeff, L. C., & McKenna, M. T. (2003). Cervical cancer mortality among foreign-born women living in the United States, 1985 to 1996. *Cancer Detection and Prevention*, 27(3), 203-208. Doi: S0361090X0300062X [pii]
- Scarinci, I., Garcia, F., Koetz, E., Partridge, E., Brandt, H., Bell, M., Dignan, M., Ma, G., Daye, J., Castle, P. (2010). Cervical Cancer Prevention: New Tools and Old Barriers. Cancer, 116 (11), 2631-2542, Doi 10.1002/cncr. 25065.
- Shah, M., Zhu, K. M., Wu, H. Y., & Potter, J. (2006). Hispanic acculturation and utilization of cervical cancer screening in the US. *Preventive Medicine*, 42(2), 146-149. Doi 10.1016/J.Ypmed.2005.10.002
- Suarez, L. (1994). Pap Smear and Mammogram Screening in Mexican-American Women the Effects of Acculturation. *American Journal of Public Health*, 84(5), 742-746.
- Teach Back (2013). Always Use Teach-Back. <u>http://teachback.slashwebstudios.com</u>. Accessed February 4, 2013.
- Villegas, J., Lemanski, J., & Valdez, C. (2010). Marianismo and Machismo: The Portrayal of Females in Mexican TV Commercials. *Journal of International ConsumerMarketing*, 22(4), 327-346. Doi: 10.1080/08961530.2010.505884
- Walton, A., Calvo, Y., Flores, M., Navarrete, L., & Ruiz, L. (2009). Promotoras: observations and implications for increasing cervical cancer prevention and screening in the Hispanic community. *Journal Southern California Medical Association*, 105(7), 306-308.
- Warren, A. G., Londono, G. E., Wessel, L. A., & Warren, R. D. (2006). Breaking down barriers to breast and cervical cancer screening: A university-based prevention program for Latinas. *Journal of Health Care for the Poor and Underserved*, 17(3), 512-521.
- Watts, L., Joseph, N., Velazquez, A., Gonzalez, M., Munro, E., Muzikansky, A., Del Carmen, M. G. (2009). Understanding barriers to cervical cancer screening among Hispanic women. *American Journal of Obstetrics and Gynecology*, 201(2), 199 e191-198. Doi: S0002-9378 (09)00510-9 [pii]10.1016/j.ajog.2009.05.014

Author Information

*Lourdes Baezconde-Garbanati, PhD, MPH Keck School of Medicine of USC University of Southern California Email: <u>baezcond@hsc.usc.edu</u> Phone: 323-442-8231

Sheila T. Murphy, PhD Annenberg School of Communication and Journalism University of Southern California

Meghan Bridgid Moran, PhD Keck School of Medicine of USC University of Southern California

Victoria K. Cortessis, PhD Keck School of Medicine of USC University of Southern California

* corresponding author