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Hispanic Women and Mammography Screening Disparity:
Underlying Issues and Opportunities

Running Head: HISPANIC WOMEN AND MAMMOGRAPHY
Abstract

The American Cancer Society (ACS) reports that breast cancer (BC) is the most common cancer diagnosed, and the second leading cause of death for women in the United States (US), however for Hispanic Women (HW) it is the first leading cause of death (ACS, 2012). Mammography screening (MS) is the best way to identify BC early, when it is treatable, but HW experience large disparity in MS rates as a result of many cultural, psychosocial and economic disparities. The underlying issues are many, and they are complex.

Opportunities to improve MS in this population include culturally sensitive education of patients, provision of services and educational materials in Spanish language, and organized directed efforts to do so on the part of providers. Evidence points to many facilitators of MS in this population and provide the foundation of a plan to improve MS in the Adventist Health System.
Introduction

The population of Hispanic women (HW) in the US, Oregon and the local Multnomah County and Portland metro area is significant and experience many cultural, psychosocial and economic disparities and barriers to mammography screening (MS) that are not faced by other race or ethnic groups, or non-Hispanic white (NHW) women.

This discussion of the issues contributing to MS disparity among HW includes (1) demographic and statistical information about this population; (2) best practice guidelines and health care reform; (3) barriers for routine MS; (4) effective evidence based interventions; and (5) recommendations and plan to improve MS in this population of Multnomah County and the Portland Metro area.

Adventist Health System is located in Portland, Oregon and Multnomah County. The Adventist primary service area has 20% Hispanic population, largest of the metro area (Multnomah County Health Department, 2010). The health system runs a 302-bed hospital, two outpatient imaging centers, one free clinic for low income-uninsured patients, one urgent care and one emergency room, in addition to a large network of family practice clinics (Adventist Health, 2012).

The terms Hispanic and Latino are used interchangeably in the United States, and include people of Mexican, Mexican-American, Chicano, Puerto Rican, Cuban, South or Central America or other Spanish descent (CDC, 2011).

Demographics of Hispanic Women

Hispanic people in the United States number 52 million and comprise 16% of US population (US Census, 2012). “Facing ongoing discrimination and fearing harassment, many Latinos still refuse to identify to the array of canvassers, pollsters and surveyors
who come calling”, even those who are native born and in the country legally (Curry-Stevens & Cross-Hemmer, & Coalition of Communities of Color, 2012, p 17). This results in severe undercounting of Hispanics in this country.

US Census data also does not include the estimated 9 million Hispanics who live in the US without documentation. This is a considerable in number, totaling 17% of the official figure. Excluding such a large portion of Hispanics from population statistics distorts our interpretation and understanding of the population as a whole (Passel & D’Vera, 2009).

For example, only 30.7% of the 52 million Hispanics included in US Census reports were uninsured in 2009, but 59% of the additional 9 million undocumented Hispanics are uninsured (Curry-Stevens et al., 2012). When both documented and undocumented Hispanics are included the estimated percentage of Hispanics who are uninsured rises to 34.9%! From this example, it is obvious that US census data underestimates many economic disparities Hispanics experience.

Acknowledging official numbers vastly under estimate the size of the Hispanic population, for purposes of clarity in understanding, this analysis includes population statistics from US census data without the addition of statistics for undocumented Hispanics, unless specifically stated otherwise.

Other important US Census statistics for this population include:

- 2012-Median Age: 27 years, (US total: 36.9 years)
- 2010-Median household income: $37,759
- 2010-Poverty rate: 30.7% (up from 25.3% in 2009)
Breast Cancer in Hispanic Women

Breast cancer is the most common cancer diagnosed in women in the United States. It is the second leading cause of cancer death among all women, however for HW; BC is the first leading cause of death. Hispanic women are more likely to be diagnosed later, with larger tumors that often do not respond as well to treatment (ACS, 2012a; ACS, 2012b; Vona-Davis & Rose, 2009). HW are 20% more likely to die of BC than NHW women diagnosed at a similar age and stage (ACS, 2012b).

Routine MS is the most important tool in identifying breast cancer early, when the tumor is small and more easily treated; unfortunately wide disparity exists in MS rates in HW with just 68% of HW reporting biennial MS in 2010 (ACS, 2012b; CDC, 2012; NCI, 2012). In the Portland metropolitan area, the cost of one normal mammogram including radiologist fee to interpret the exam, is between $170-250 depending upon facility. Adventist Health charges $170, offers a 20% discount for cash payment upfront and a sliding scale discount depending upon income (Adventist Outpatient Imaging, Verbal Quote, October 11, 2012).

Best Practice Guidelines and Health Care Reform

The United States Preventative Services Task Force (USPSTF), an independent expert panel appointed by Health and Human Services, determines National standards for prevention services including MS. In 2009 the USPSTF made drastic changes to breast cancer screening recommendations, eliminating annual mammography for all women and routine MS for those aged 40-49. The new standards recommend:

- 2009-HW with less than high school education: 31.5% (Liao, et al., 2011).
• Biennial screening mammography for women aged 50 to 74 years,
• Biennial screening mammography before the age of 50 years only with careful consideration of the specific benefits and harms in the specific individual,
• Screening mammography in women 75 years or older is not supported by the evidence,
• Teaching breast self-examination (BSE) is no longer recommended” (USPSTF, 2012).

The ACS disagreed with the rationale behind this. They continue to support annual screening for all women over age 40, and are against discontinuing MS at an arbitrary age (ACS, 2012c).

Healthy People 2020 overarching goals include reduction of disparities. Breast cancer objectives are aimed at a) improving MS rates to 81% of USPSTF standards, b) reducing diagnosis and advanced stage, and c) reducing mortality (Healthy People, 2012). As shown in Figure A, women of all race/ethnicity fall short of the MS goal, however HW face drastic disparity with only 68% screened in the past two years (see Chart A) (ACS, 2012c; Bitler & Carpenter, 2012; CDC, 2012b).
The Patient Protection and Affordable Care Act (health care reform) offers some promise for improving MS because it includes resources dedicated to improve data collection, funds research in health disparities, supports education to increase diversity in racial and ethnic minority health care workers and to educate current health care workers in cultural competence. The law requires all new insurance plans to provide specific preventative care, including mammograms, at no co-pay or other cost, which will remove financial barriers for HW with insurance (Bitler et al., 2012, Whitehouse.gov, 2012). Health care reform however, isn’t the magic fix to low MS in HW, as the underlying issues are complex, multifactorial and interrelated.

Health care reform must include efforts to improve Patient Activation (the knowledge, skills, and confidence people need to manage their health and health care. Hispanics have the lowest activation levels of all ethnic and racial groups, significantly lower levels of activation than whites. Less-activated people are more passive when
encountering barriers to care, undergo fewer preventative care services, have less medical information and knowledge, ask fewer medical questions and are less likely to follow treatment recommendations and more often experience poorer outcomes (Cunningham, Hibbard, & Gibbons, 2011).

**Understanding Low MS in HW**

Multiple cultural, economic, and psychosocial issues create barriers to MS in HW. Cultural values and beliefs underlie the following barriers to MS: attitudes about the value of MS; perceived risk of developing BC; fear of undesired findings from MS; perceptions that BC is fatal when diagnosed; religious or spiritual beliefs toward cancer; procrastination; and/or embarrassment (Carter, Park, Moadel, Cleary, & Morgan, 2002; Lopez-McKee & Bader, 2011). Understanding Hispanic culture is a natural starting point in analyzing barriers to MS experienced by HW.

Important Hispanic cultural beliefs and values include *familismo* (family is central priority), *collectivismo* (social interdependence), *simpatia* (oriented toward congeniality), *personalismo* (value in personal interactions), *respeto* (respect and honor of authority and elders), and *confianza* (strong sense of trust) and *Pudor* (modesty, quality of reserve, humility, and modest appearance and behavior) (Borrayo, 2004). Health and illness are viewed as holistic and encompass “spiritual, moral, somatic, physiological, social, and metaphysical dimensions” (Borrayo, 2004, p 101). Health is viewed as a gift from God and illness as punishment for sin (Borrayo, 2004).

Modesty requires HW, especially older women, to remain covered and is the reason many HW believe only husbands or intimate partners should touch their breast, and that HW may feel compelled to ask their husband for permission (Simon, 2006;
Corcoran, 2012). Husbands and partners may discourage MS because they don’t want male providers to see or touch women’s breasts (Tejeda, 2007).

Fatalism, a feeling that cancer cannot be prevented, and that when it is diagnosed it is certain to be fatal, underlies the impression there is no value in MS, especially when the cost of time and money are considered. Fatalism contributes to procrastination. In the Hispanic culture that values social interdependence and has an overall higher rate of fatalism, MS is reduced. Women with a higher risk of BC due to family history are more likely to hold fatalistic views of cancer. These are women in greatest need and stand to benefit most from screening, but who are less likely to participate because of fatalism (Borrero et al., 2009; Schmidt, 2007 Simon, 2006).

Otero-Sabogal, Steward, Sobagal, Brown & Pérez-Stable (2003) identified the following features in HW with strong cancer fatalism: more recent emigrants, fewer than 7 years of formal education, no education in the United States, Catholic, have a small social network, very low income, have more children, and have poor access to medical care.

Spanish language alone has been shown to deter MS and advanced stage at diagnosis, with 22% of Hispanic, Spanish speaking women diagnosed at advanced stage, compared with just 10% of NHW women (Oliveira, Clark, Dunn & Managram, 2011).

Psychosocial and economic issues compound culture, especially in this population with nearly 31% poverty rate. Lack of insurance, not speaking English, and lower educational and low health literacy levels reduce MS; conversely longer length of time lived in the US, higher socioeconomic level, higher health literacy, and having health insurance improve MS (Otero et al., 2003). Multiple concurrent issues may be
synergistic such as in a) poverty that creates logistical issues including lack of child care or transportation, b) being un-documentated which interferes with obtaining health insurance, and c) HW with both low income and low health literacy for whom MS drops to 38% (ACS, 2012b).

Acculturation (the process of adopting the attitudes, values, customs, beliefs, and behaviors of new culture upon emigrating), improves many barriers to accessing care and decreases cultural barriers such as fatalism (Otero et al, 2003). Acculturation is a mixed blessing however, providing new risk for BC as time lived in the US increases. This is especially true for HW who migrate before age 20 because acculturation stimulates changes in diet and exercise habits that contribute to overweight and obesity associated with higher rates of BC (ACS, 2012a; Lawsin, Erwin, Bursac, & Jandorf, 2011).

Evidence Based Interventions to Increase MS

As discussed, strong evidence indicates cultural values and beliefs are strongly imbedded for HW. Culturally sensitive interventions have been shown more effective in encouraging MS. For example, due to the importance of respeto, or respect of elders and authority figures, providers who understand and honor cultural norms such as modesty are frequently rewarded with higher levels of trust, which adds to their ability to impact MS behavior (Borrayo, 2004). Not just providers, but all health care personnel, must provide culturally respectful care. Institutions should provide employee training in cultural sensitivity. According to Borrayo (2004) examples of ways to provide culturally appropriate care for HW include the following:

- Use Spanish speaking interpreters with HW who are not English language proficient,
• Consider the importance of modesty; close doors during private conversations, ask if they would like another person present in the room, be sensitive to any discomfort when discussing private, sensitive issues (Andrews, 2006).

• Involve family members,

• Show respect – Always be respectful, and explain without being condescending

• Get personal – Hispanics typically prefer being closer to each other in space than non-Hispanic whites do,

• Ask about their life (family, friends, and work) and share life stories and pictures,

• Encourage them to ask questions,

• Take seriously the responsibility and respect conferred on the provider,

• Respect traditional healing approaches – Hispanic patients may combine respect for the benefits of mainstream medicine, tradition, and traditional healing with a strong religious component (ACS, 2011).

Hispanic women who are knowledgeable about screening recommendations screen more often. The evidence is clear that Spanish speaking health workers and Spanish language educational material, regardless of format (verbal, written, and electronic forms of communication such as computer, DVD, or televised information), are important elements of efforts to address barriers based on language barrier, low literacy and low English language proficiency (ACS, 2007; Otero-Sabogal et al., 2003; Valdez, 2002). However written educational material alone, even when written in Spanish, isn’t highly effective because of low education and health literacy in HW.

Non-print formats, such as DVD offer inexpensive and easy alternatives, and can be given to women to view at home (Morrison, 2012). Spanish language videos played
in waiting rooms have also been shown effective (Valdez, Banerjee, Ackerson, & Fernandez, 2002).

Provider recommendation may be the single most important factor in MS among HW, therefore providers must be involved in attempts to address this disparity (Aldridge, Daniels, & Jukic, 2006). One area providers have the potential to impact MS is in reinforcing the importance of timely, ongoing screening. This is the case because knowledge is correlated with MS, but not with commitment to screening on time (Morrison, 2012).

Hispanic women who visited a physician's office were more likely to have had a mammogram than those who were seen in other types of healthcare facilities, such as emergency and urgent care settings. Because so many HW are transient health care consumers and access care only when ill, emergency rooms and urgent care centers should encourage all HW to establish a health care home and form a relationship with a primary provider, rather than seeking care in different places when becoming ill (Aldridge, et al., 2006).

Providers also experience barriers to providing breast health education and referrals for MS, including “time and financial constraints, lack of staff support, staff turnover, language and cultural differences, forgetfulness and bias” (Masi, Blackman, & Peek, 2007, p 3). Emergency room and urgent care clinics are particularly busy health care settings, where staff and providers are challenged to find time for preventative care interventions. Even so, these interactions provide optimum opportunities to stress the importance of having a primary care provider, to refer HW to Spanish speaking providers who accept Medicaid, and to integrate culturally appropriate breast health education and
refer for mammography. One efficient way to do so is through the use of bilingual health educators or medical assistants designated to work with HW during wait times (Aldridge, et al., 2006).

A highly successful approach was studied in a community clinic for low income people with a large population of HW. Bilingual medical assistants were a key component of this project, responsible for initiating a conversation about MS and assessing for prior mammogram during the initial intake assessment. The patients chart was flagged with mammography history, and if the patient was due for MS the medical assistant pre-completed the mammography order, leaving it ready for provider signature. Depending on age, mammography screening increased 350-400% in this group of HW (Zapka, et al., 1993).

Beech et al., (2007) report very positive results in the use of Spanish speaking care coordinators or patient navigators who provided quarterly telephone contact that included preventative care counseling, and support scheduling appointments. Telephone contact was reinforced with written information in Spanish that was sent by mail.

Proven methods of reinforcing ongoing screening include use of reminder letters or post cards written in Spanish and the use of case managers or patient navigators to track screening and coordinate appointments and to address financial and logistical barriers (Beech et Al, 2007; Massin-Short et al., 2010; Morrison , 2012).

Prevention education for HW is effective beyond the health care setting, in places where HW gather for other purposes such as in community centers and churches. These efforts are particularly helpful to HW who lack a health care provider or clinic home. Public Spanish language television is an effective way to reach large numbers of HW, to
provide prevention education as well is information on where to obtain mammograms and other health care services (Aldridge, et al., 2006).

**Community Partners in Hispanic Health**

In Oregon Familias en Acción, initially funded by the Lance Armstrong Foundation in 2007, coordinates a patient navigation program to support Hispanics living with cancer and other chronic health conditions. This program has been highly successful in assisting patients both with and without insurance. Hispanic patient navigators, fluent in Spanish provide education, support with financial barriers, reducing financial barriers to quality treatment. This program assists HW with palpable breast masses in need of MS and further care, but does not have a program aimed solely at improving MS in HW (Familias en Accion, 2012).

Up until June, 2012, the State of Oregon Breast and Cervical Cancer (BCCP) Program provided free MS for all women meeting the USPSTF guidelines, but facing severe funding deficits the criteria was drastically changed and only women with palpable masses are now eligible. For many years, BCCP has been the primary provider of free MS for low income and uninsured women. Today there is no large-scale program replacing BCCP, thus large numbers of low income, uninsured women have no alternative source of free MS (Oregon BCCP, 2012).

**Plan for Adventist Health**

“The fact that BC continues to be the leading cause of cancer deaths among (Hispanics) calls for aggressive but innovative approaches to educate them about BC and to motivate them to participate in early BC detection procedures” (Borrayo, 2004, p 101). Any plan increase utilization of MS in HW, regardless of health care setting (public
health clinics, urgent care settings, or emergency rooms) requires interventions that are culturally sensitive and includes education, removal of barriers, and referral.

Based on the evidence, a plan that could be carried out by Adventist Health must include the following components:

1. Education of providers and staff on important cultural values and beliefs, and effective skill sets in working with HW,

2. All providers and staff must consider culture and respect cultural norms when working with HW (close doors, ask if they want someone in the room with them, consider modesty, include family, etc.),

3. Spanish speaking staff (providers, nurses, medical assistants, ancillary and clerical) when possible. Spanish speaking interpreters should be used whenever HW are not English language proficient.

4. Educational materials in Spanish a variety of formats, written, DVD to send home with patients, DVD to play in waiting rooms, posters in Spanish posted in clinic locations.

5. Every facility (community clinic, urgent care, emergency room, and imaging centers) must maintain a current and accurate list of Spanish speaking providers who accept Medicare, information about low income public health clinics that offer primary care, and list of facilities offering discount mammography should be available to give HW as indicated.

6. Each facility must provide appropriate information about other services the health system provides, linking services such as the emergency room
and urgent care with the community based clinic for low income and uninsured patients, and the patient navigator.

7. Strong relationships with community partners such as Familias en Acción must be established and maintained, to support inter-agency collaboration to meet the needs of HW.

8. Educational information targeting HW should be provided in other locations, beyond health care facilities, such as local Hispanic community centers and churches.

9. Patient navigators who speak Spanish, or who have access to Spanish interpreters, should reinforce efforts made during clinic visits, by helping to assist with barriers to care, transportation, scheduling appointments and providing telephone reminders.

10. Each care setting should initiate a well-defined, evidence-based standard procedure, ideally including the use of Spanish speaking staff, or interpreters if no staff members speak Spanish, to talk with HW about MS, determine when any prior mammogram occurred, pre-complete the mammography order and communicating this to the provider.

11. Imaging centers should reinforce ongoing screening include use of reminder letters or post cards written in Spanish.

12. Ongoing data collection to monitor levels and trends of MS among HW. Consistent program evaluation is necessary to determine levels of improvement and for insight to when additional efforts must be added to remove MS disparity in this population.
Conclusion

The fact that BC continues to be the leading cause of cancer deaths among HW calls for aggressive but innovative approaches to educate them about BC and to motivate them to participate in regular MS. This issues that explain low rates of MS in HW are complex and interrelated. Community based solutions require broad-based efforts across health care settings and must include community agencies focused on Hispanic health issues. Fortunately considerable evidence exists pointing to facilitators and barriers to MS which provide reason for optimism on the part of those who are committed to reducing MS disparity and improving BC outcomes in HW. Integrating an evidence based plan into current practice offers potential improvement, particularly if several different approaches are integrated simultaneously, on large scale across health care settings. This coupled with health care reform and the ongoing commitment of community agencies can make a real difference. I am optimistic that the potential to resolve this disparity is within reach.
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