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## ***Creando Nuestra Salud (Creating Our Health) - Results and Findings from a Breast Cancer Education Program with Rural Hispanic Women***

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### **ABSTRACT**

*Rural Hispanic females practice breast-self exams (BSE) and other breast health screenings less than women from all other racial or ethnic groups. Questions remain as to why these women do not practice these important breast health behaviors. A qualitative design was used to assess the knowledge, attitudes, beliefs and barriers to breast health activities among 288 rural Hispanic women. Results revealed that along with external barriers such as transportation and money, internal barriers (shame of being seen naked, discomfort of touching their own breasts, and lack of knowledge) had a greater effect on their practice of breast health activities. The discussion section advocates for health care educators to emphasize overcoming internal barriers in interventions aimed at rural Hispanic females. The article describes an existing intervention, as well as champions the breast self-exam, as an activity that holds promise as a feasible and cost-effective method for achieving increased early breast cancer detection by rural Hispanic females.*

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### **Introduction**

On a given day, approximately 511 women in the United States will have been diagnosed with breast cancer (Department of Health and Human Services, 2007). Of these newly diagnosed breast cancer cases 39 (8%) of these women will be of Hispanic origin (Department of Health and Human Services, 2007). According to the American Cancer Society, these 39 Hispanic females, on average, will be five years younger (than the group as a whole) and will have been diagnosed with larger breast tumors, in a later stage of growth (American Cancer Society, 2008). Researchers have yet to determine why these differences exist between Hispanic and other women who have been diagnosed with breast cancer. Although the age of first child, use of oral contraceptives, and genetics have been investigated, internal barriers that prohibit early detection behaviors have not been adequately explored. In fact, the research regarding breast cancer perceptions in the Hispanic community is scant. A minimal amount of research has been conducted to elucidate how knowledge, attitudes and beliefs impact breast health screening behaviors of Hispanics females; especially those under the age of forty, living in rural areas.

This article describes a community assessment that involved interviews with rural, Hispanic women

in Florida and Kentucky to gain insight into their knowledge, attitudes, beliefs and behaviors regarding breast cancer. Secondly, this article will describe a multi-faceted educational outreach program, which included training a network of *promotoras*, developing two *fotonovelas* and establishing a community "Health Navigator," to assist with increasing health clinic assess among rural Hispanic females.

In the summer of 2006, the RWHP designed *Creando Nuestra Salud* [Creating Our Health]; a Spanish-language assessment aimed at unearthing Hispanic females' perspectives and behaviors in regards to breast cancer and cancer in general. The findings from this project expand upon existing information about breast cancer within the Hispanic community and should be used to develop public health interventions for this under-served population.

Most importantly, we hope that these results will prompt more rural Hispanic females to practice early detection behaviors, such as breast self-exams, clinical exams and mammography. Particular emphasis should be placed on increasing participation of young Hispanic women in breast self-exams and accessing clinical breast services, since initiating breast health practices at a young age can potentially ensure a lifelong commitment to breast

health (Borrayo & Guarnaccia, 2000). If more programs focusing on early detection are enacted, tomorrow's 39 Hispanic females diagnosed with breast cancer will have the opportunity for a better prognosis.

**Purpose**

The *Creando Nuestra Salud (CNS)* assessment was developed in response to a needs assessment conducted by *Alianza de Mujeres Activas* [Active Women's Alliance] (AMA) – a RWHP partner organization. AMA promotoras surveyed Hispanic females in two North Central Florida counties (Volusia and Putman) to identify health issues of concern. An overwhelming majority responded that breast cancer was their primary concern. The purpose of the CNS assessment was to uncover the thoughts and realities of women, especially those under the age of 40. Previous research has typically studied female ages 40 and older – the age recommended for initiating mammography screening.

**Methods**

The CNS Assessment interviews were conducted by 28 trained Lay-Health Workers (also called *Promotoras*) throughout their communities. *Promotoras* used a Spanish-language assessment questionnaire which included 40 open-ended questions. The questionnaire was developed specifically for this study. All interview questions were reviewed by experienced health-professionals in the fields of Public Health and Medicine as well as the RWHP's project partners.

**Results**

The CNS assessment team interviewed 288 Hispanic females in four locations: Lexington, Kentucky; Crescent City, Bradenton; and Pierson, Florida. Eighty-six percent of the sample was under the age of 40, with the largest percentage of respondents between the ages 30-39 (29.1%). Seventy-five percent of the sample listed Mexico as their country of origin while 14.7% were born in the United States. Table 1 illustrates the sample of participants from each site.

**Table 1. Description of Study Participants**

	Lexington, KY	Crescent City, FL*	Bradenton, FL	Pierson, FL	TOTAL
N of respondents	83	47	64	94	288
Country of majority % and secondary %	Mexico (68.8%) Peru (5.0%)	Mexico (53.2%) US (44.7%)	Mexico (86.3%) US (12.6%)	Mexico (84.4%) US (7.8%)	Mexico (75.5%) US (14.7%)
Mean age	41	15	28	36	30
N of years in US (%)	>6 (50.6%)	>6 (23.9%)	>6 (39%)	Not Asked	>6 (26.4%)

\* The Crescent City, FL outreach was in partnership with *Project Claridad*, an organization that served youth.

*Breast Cancer Knowledge, Attitudes, Beliefs*

The interviewed participants indicated that they experienced 'fear' (32.6%) when thinking about breast cancer, while 13.4% associated death or thoughts about their own mortality. The women's responses exhibited a lack of understanding as to the causes of breast cancer. Forty-one percent of the responses were scattered among 24 variables from 'not breast-feeding' to 'poor blood circulation.' The number of responses received as to the causes of breast cancer mirrored the number of published studies linking breast cancer to numerous carcinogens or life events. The two responses that were cited most frequently were 'genetics' (13.2%) and 'golpe,' (11.0%) with translates into English as

'trauma to the breast;' however over 30% responded that they did not know what caused breast cancer.

*Breast-Self Exam Practices*

A majority of the women (64.6%) had conducted a breast self-exam (BSE) at least once prior to the assessment interview; however, only 29.4% of those who had conducted a breast self-exam did so monthly. The females who had never examined their breast (35.4%) provided 33 different reasons for not practicing the BSE. A majority of the responses as to why they did not practice the BSE can be categorized as internal barriers such as not knowing what to look for (25.5%), not knowing the right technique (14%)

and discomfort with touching their own bodies (1.4%).

#### *Mammography and Clinical Breast Exams*

Whereas a majority of our sample had conducted a breast self exam, few reported receiving either mammograms or clinical breast exams. Less than a quarter of our sample had received a mammogram (20.8%) or clinical breast exam (15.6%), and for those participants over 40 years of age that had received a mammogram, only 10% responded that they received them annually. While monetary barriers prevented the majority of our sample from completing clinical visits (37%), our sample answered shame (34.7%) and being seen naked and touched by a doctor (15.1%) as reasons that prevented them from partaking in annual clinical services. The participants' responses lent credence to the fact that Hispanic females may face internal barriers such as shame and embarrassment when confronted with the choice of having a clinician examine their breast. According to Juarbe (2008) Hispanics often possess a number of internal factors that regulate their initiation of health behaviors. These internal barriers coupled with known external barriers can prevent any women, but in this case Hispanic females, from initiating breast health activities.

#### *Breast Cancer Education Preferences*

To guide the development of a culturally sensitive program, the sample was asked a series of questions about their preferences in receiving an educational outreach. When asked how they would like to receive education regarding breast cancer, 53.8% named their friends as the preferred educational method (whereas 31.6% said that they preferred to receive health education from a family member). Twenty-six percent believed that breast health education should occur at church functions and when asked what specific breast health related topics the educational outreach should focus on, women listed the causes of cancer (70.6%) and how to examine their breast (28.5%) as key topics.

#### *Educational Outreach Program Development Implementation*

The results of the assessment revealed that rural Hispanic females are in dire need of information concerning breast health and early detection screening options. The women reported that they preferred to have this information delivered by trusted members of the community [family and friends] with whom participants could identify and rely on. The assessment responses affirmed the fact that culturally sensitive educational outreach was needed, and that the information needs to address the

internal barriers that rural Hispanic females face when practicing breast health activities.

In response to the findings, the RWHP developed a holistic educational outreach to address the community's needs and the assessment findings for both educational approach and content. Two *fotonovelas* on early breast cancer detection: *El Susto de Marta* and *Lo que dicen mis amigas sobre el cáncer del seno*, were crafted out of the communities' stories that were shared during the assessments and at Community Exchange Sessions (CES) (small community member gatherings where discussion regarding breast health issues as well as basic breast health education were conducted). The CES were designed to further explore key CNS assessment findings. The two *fotonovelas* were created to address the misconceptions and internal barriers participants experienced in regards to breast health activities. *El Susto de Marta* (Marta's Scare) chronicles Marta's journey after she detects a lump in her breast during her breast-self examination. *Lo que dicen mis amigas sobre el cáncer del seno* (What My Friends are Saying about Breast Cancer) depicts Hispanic women from different backgrounds sharing advice and facts on breast cancer and early detection. Both *fotonovelas* contain illustrated steps on how to perform a breast self-exam and feature messages that urge women to obtain breast health services.

Both *fotonovelas* were evaluated by members of the community during community events, such as church functions and community celebrations. Months later, in conjunction with the creation of the *fotonovela*, the RWHP trained the CNS assessment *promotoras* as well as new *promotoras* to carry out breast cancer educational sessions based upon the two *fotonovelas*. *Promotoras* were trained to provide educational counseling, regarding breast health, using interactive, non-formal educational activities and also use the *fotonovelas* as teaching tools. The *fotonovelas* used in these one-on-one educational sessions were also left with the women at the completion of each encounter. Additionally, *promotoras* were provided with an extensive referral guide regarding breast health services in their respective communities and were trained to refer participants to the providers. Although a large part of the *Promotoras* work was peer education, referrals were a key component as well.

With a referral mechanism integrated into the educational outreach, the RWHP established a "Health Navigator" within the project communities. The Navigators were highly trained *promotoras* who supported the outreach work of the *promotor* team. The Navigator's role was to increase access to services of those women educated by the *promotoras*.

The Navigators worked to alleviate some of the scheduling, support and language issues that the participants who requested special assistance experienced when attempting to obtain clinical services. The “Health Navigator” also assisted participants who experienced breast abnormalities to obtain breast health services such as mammograms and biopsies.

### Discussion

The results of the assessment suggest that rural Hispanic females are concerned about their breast health; however, they face a number of obstacles in initiating breast health screenings. Although many of the obstacles cited could be overcome via increased financial support of rural health, the funding mechanisms available to rural Hispanic females are scarce. As a group, these women experience many external barriers to obtaining clinical services such as transportation, lack of health care insurance and funds to pay out-of-pocket for these services. In addition to these barriers, many ‘safety-net’ providers, that offer breast health services at a reduced or free rate, are strained with waiting lists between 4 to 12 weeks for appointments. Although there are some options available to obtain health services, providing documentation that their income is 300% below the poverty line to meet funding eligibility requirements is not always feasible. As such, the RWHP feels that the BSE is a realistic early detection strategy for rural Hispanic women, since many of these women may not have the opportunity to utilize clinical services as a detection strategy. The educational intervention, which arose out of the study findings, focused on the BSE because it provided a way for these females to practice breast health and overcome some of the internal barriers, faced by these women, through role-modeling. Although many health entities are moving away from championing the breast self-exam (Kosters & Gotzschke, 2008), the BSE represents a cost-effective and practical method of early detection for this population, regardless of age. In fact, the majority of respondents in these assessments believed that women should begin examining their breast before the age of 18.

Of special interest to the RWHP were the beliefs, behaviors and attitudes of women under the age of 40. Since Hispanic females tend to be diagnosed with larger tumors at a younger age, the participation of females under the age of 40 was paramount if decreasing breast cancer morbidity with the Hispanic community is to be achieved. The participation of youth *promotoras* and the targeting of women under the age of 40, with a special emphasis on those younger than 20, has yielded increased

communication between mothers and daughters. Women in these communities have shown an increased level of comfort in talking to each other about breast health issues and now know where to obtain breast health services. These females are also more aware of their risk susceptibility and understand that action needs to be taken to ensure breast health for themselves and future generations. In two counties, CNS has resulted in three clinics partnering with the CNS program, to facilitate easier access to services. In these small communities where the CNS program exists, these are great outcomes.

### Conclusion

Internal barriers are difficult to address when attempting to facilitate behavior change. The obstacle in addressing these difficulties stems from the fact that unlike external barriers, internal barriers are intimate. Several studies have suggested that Hispanic females experience numerous internal barriers that affect their health locus of control (Bundek, Marks, & Richardson, 1993; Richardson, Marks, Solis, Collins, Birba, & Hisserich, 1987; Sugarek, Deyo, & Holmes, 1988) and conclude that education can effectively engage these difficulties (Borrayo & Guarnaccia, 2000). Education, in any form, that lists the steps to complete a breast-self exam or how to schedule an appointment would remedy knowledge deficits regarding the BSE and clinical services; however, be ineffective in addressing internal barriers within Hispanic females. Spanish-language materials from government health organizations that only summarize research and recommend clinical visits do not change behavior nor curb the rate of tumors detected during later stages of growth. In fact, breast cancer materials that do not address the internal barriers of their readers, could be seen as classified as counterproductive if the female perceives the act as being “shameful.”

The RWHP believes that internal barriers can be addressed in education materials that combat internal perceptions, for example, by presenting role models who show the reader that the breast self-exam is a realistic action that can be achieved. These barriers can be further diminished with the utilization of *promotora* (lay health worker) programs that also model healthy breast behaviors and integrated actions to assure access to services.

Destructing internal barriers should be of greater concern for health providers since these barriers are ultimately the final hurdles to overcome when encouraging an individual to partake in a new behavior. The fear and anxiety coupled with lack of knowledge about breast cancer, calls for educational programs addressing breast cancer within the rural

Hispanic community. Educational interventions need to be multi-dimensional, culturally sensitive, and present health information at the health literacy level of the target population.

### Addendum

The RWHP is committed to improving breast health within rural Hispanic communities. The *Creando Nuestra Salud* breast health intervention has continued via funding from the Susan G. Komen for the Cure® and The American Cancer Society Florida chapter. Currently over 40 new *promotoras*, as well as existing *promotoras*, are conducting one-on-one breast health educational sessions, with the goal of educating 500 Hispanic females during a 3-month campaign. In the future, the RWHP intends to reproduce the successes of *Creando Nuestra Salud* in other rural communities throughout the United States.

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