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**"If I Needed It, They Would Have Sent Me:"
Cancer Screening, Knowledge and
Adherence Among Older Hispanic Women**

by Linda M. Hunt

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University of Texas Health Science Center, San Antonio

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**If I needed It, They Would Have Sent Me: Cancer
Screening, Knowledge and Adherence Among Older
Hispanic Women**

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Cancer Screening, Knowledge and Adherence
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The **Julian Samora Research Institute** is committed to the generation, transmission, and application of knowledge to serve the needs of Latino communities in the Midwest. To this end, it has organized a number of publication initiatives to facilitate the timely dissemination of current research and information relevant to Latinos.

- *Research Reports*: **JSRI**'s flagship publications for scholars who want a quality publication with more detail than usually allowed in mainstream journals. These are produced in-house. Research Reports are selected for their significant contribution to the knowledge base of Latinos.
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- *Statistical Briefs/CIFRAS*: for the Institute's dissemination of "facts and figures" on Latino issues and conditions. Also designed to address policy questions and to highlight important topics.
- *Occasional Papers*: for the dissemination of speeches, papers, and practices of value to the Latino community which are not necessarily based on a research project. Examples include historical accounts of people or events, "oral histories," motivational talks, poetry, speeches, technical reports, and related presentations.

“If I Needed It, They Would Have Sent Me:” Cancer Screening, Knowledge and Adherence Among Older Hispanic Women

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Abstract

The purpose of this study was to explore factors, other than patient knowledge, that might explain low use of cervical and breast cancer screening among Hispanic women. A questionnaire was used to assess knowledge of screening recommendations and self-reported adherence among 70 older Hispanic women in Texas. Most had high knowledge levels, but this did not predict adherence. Fourteen women, all with high knowledge levels, also answered a semi-structured qualitative interview. Barriers to screening discussed in qualitative interviews included transportation, time, cost, and believing screening to be unnecessary following previous negative screening, or when sexual activity is absent. Reminders and referrals from primary care providers were key to reported adherence. Establishing policies and procedures to assure consistent cancer screening reminders and referrals may improve rates of cancer screening among women similar to those in our study, especially in settings where there is little opportunity to develop long-term patient-provider relationships.

“If I Needed It, They Would Have Sent Me:” Cancer Screening, Knowledge and Adherence Among Older Hispanic Women

Despite recent dramatic reductions in rates of invasive cancer among women in the U.S., Hispanic women living in this country have incidence and mortality rates for cervical cancer two to three times as high as the national averages (Canto & Chu, 2000; National Cancer Institute, 2001). While incidence of breast cancer is slightly lower for Mexican-American women than non-Hispanic whites (13.5 and 15.8 per 100,000 respectively), mortality rates for Hispanics are still quite high. These trends may be due to Hispanic women using cancer screening less frequently and allowing greater intervals between screenings than do women in other groups (Lazcano-Ponce, Alonso de Ruiz, Lopez-Carol, Vaquez-Manriquez, & Hernandez-Avila, 1994; Marks, Garcia, & Solis, 1990; Martin, Calle, Wingo, & Heath, Jr., 1996; Pearlman, Rakowski, Ehrich, & Clark, 1996; Texas Department of Health, 1991).

A good deal of recent research and intervention development has focused on trying to understand and improve cancer screening among Hispanic women. The primary thrust of these efforts has been on identifying practical and conceptual barriers to screening (Harmon, Castro, & Coe, 1996; Hubbell, Chavez, Mishra, & Valdez, 1996; Martinez, Chavez, & Hubbell, 1997; Morgan, Park, & Cortes, 1995; Ramirez, Suarez, Laufman, Barroso, & Chalela, 2000; Secker-Walker, Vacek, Hooper, Plante, & Detsky, 1999; Suarez, 1994) and developing educational and motivational campaigns to encourage women to use cancer screening (Ramirez, Suarez, Laufman, Barroso, & Chalela, 2000; Vellozzi, Romans, & Rothenberg, 1996; Yancey & Walden, 1994; Zavertnik, 1993). However, the relationship between patient knowledge, attitudes and beliefs and their cancer screening behavior is not straightforward. These factors have not been consistently shown to be specifically associated with low adherence to cancer screening (Harlan, Bernstein, & Kessler, 1991; Modiano, Villar-

Werstler, Meister, & Figueroa-Valles, 1995; Perez-Stable, Sabogal, Otero-Sabogal, Hiatt, & McPhee, 1992), nor has patient knowledge and motivation been found to reliably predict cancer screening behavior (Coughlin, 1998; Fox, Stein, Gonzalez, Farrenkopf, & Dellinger, 1998; Ornstein, Garr, Jenkins, Rust, & Arnon, 1991; Zimmerman, 1997). We are left with the question: What factors, other than patient knowledge, may also contribute to lower rates of cancer screening among Hispanic women?

In an effort to identify such factors, we conducted an exploratory study of a group of older low-income Hispanic women in San Antonio, Texas. We selected only women who were already knowledgeable about cancer screening recommendations, and divided our sample between those who reported timely screening and those who did not. Using open-ended interview techniques, we explored the circumstances under which the women reported having actually used cervical and breast cancer screening services in the past, and reasons they gave for not having had regular screening. By limiting this study to women with substantial knowledge about cancer and cancer screening recommendations, we were able to identify several factors, other than knowledge, which may affect whether or not such women pursue cancer screening.

Methods

The study consisted of two phases. In phase one, community recruitment was undertaken to identify women who had high levels of knowledge about cancer screening recommendations. In phase two, open-ended interviews were conducted with a subsample of women identified as having high knowledge levels, but divided between those who reported having adhered to those recommendations and those who had not.

Data Collection

The National Hispanic Leadership Initiative on Cancer (NHLIC) conducted a community education intervention among low income Hispanics in several cities in the United States, including San Antonio. With the cooperation of NHLIC staff, we recruited women for phase one of the study through the same churches, libraries, and senior activity centers that had participated in their project.

We administered a brief questionnaire to a convenience sample of 70 women from six of these locations. They were all low-income, self-identified Mexican or Mexican-Americans, over 50 years of age, with no previous history of cancer. The questionnaire included socio-demographic and general health information questions, as well as cancer screening knowledge and adherence items. The questionnaires were administered at the recruitment sites, and were read to the individual in either English or Spanish, according to her preference. Permission was obtained at that time to contact the women later should they be chosen for the in-depth interview of phase two.

To assess cancer screening knowledge, we asked how often women over 40 should have four types of cancer screening: mammography, clinical breast examinations, self-breast examinations, and pap/pelvic examinations. Women were classified as having "high" knowledge if their questionnaire responses were consistent with the current recommendations of the American Cancer Society (ACS) for women over 40 years old (Smith, Mettlin, Davis, & Eyre, 2000) for at least three of the four types of cancer screening.

To assess level of adherence we asked when was the last time they had each of these examinations, and how many times they had had them within the past five years. We classified women as having "High" adherence if they reported completing at least three of these cancer screening behaviors at a frequency consistent with the ACS recommendations. Those who did not were classified as having "low" adherence.

Based on their responses to the phase-one questionnaire, we selected 14 women for the in-depth interviews of the second phase of the project. All those interviewed in phase two had high knowledge of cancer screening recommendations; six had high adherence levels and eight had low adherence.

In the open-ended interviews of phase two, the women were asked a set of standardized questions and were encouraged to answer as expansively as they cared to. These questions focused on their understandings, interpretations, experiences and personal history regarding mammography, clinical breast examinations, pap/pelvic examinations, and self-breast examinations. For example, we asked what made it easier and harder for them to have the screening tests done, and about their personal experiences surrounding the first and last times they had pap tests and mammography. We also asked general questions about their concepts, expectations and perceptions regarding cancer and cancer screening; their sense of personal risk, and how they applied this knowledge to themselves in their decision to pursue, or not pursue, cancer screening.

These interviews took place in the women's homes or another quiet location of their choice. To ensure consistency, all phase two interviews were conducted by one interviewer (KBD), in English or Spanish, based on the interviewee's preference. The tape-recorded interviews ranged from one to two-and-a-half hours in length.

Analysis

Data from both phases of the study were entered into an SPSS database (Norusis, 1993) which was used to generate simple descriptive statistics of the samples from each phase. For the phase one sample we also assessed general associations between knowledge and adherence levels and various dichotomized socioeconomic variables, using Fisher's Exact Test (2-Tail). This statistic was chosen because it is useful for testing associations in small samples with small expected values (Fisher & van Belle, 1993). In examining these correlations our goal is simply to describe the relationship

TABLE 1
Demographic Characteristics of Community Recruitment Subjects (n=70)
And Open-ended Interview Subjects (n=14)

	<i>Community Recruitment Subjects (n= 70)</i>		<i>Open-Ended Interview Subjects (n=14)</i>	
	n	Percent	n	Percent
Age				
56-65 yrs	18	26%	4	29%
66-77 yrs	33	47%	7	50%
76-85 yrs	17	24%	3	21%
86-90 yrs	2	3%	0	0%
Education				
0-8 yrs	48	69%	9	64%
9-12 yrs	15	21%	4	29%
13+ yrs	7	10%	1	7%
Language of Interview				
English	32	46%	7	50%
Spanish	38	54%	7	50%
Marital Status				
Married	27	38%	5	36%
Divorced/Widowed/Separated	41	59%	8	57%
Never married	2	3%	1	7%
Insurance				
No Insurance	5	7%	1	7%
Medicare/Medicaid	40	57%	4	29%
Private Insurance	24	34%	9	64%
Missing Data	1	2%	0	0%
Knowledge of ACS Recommendations				
Low (< 3 Correctly Named)	6	9%	0	0%
High (≥ 3 Correctly Named)	64	91%	14	100%
Adherence to ACS Recommendations				
Low (< 3 Recommendations Followed)	16	23%	8	57%
High (≥ 3 Recommendations Followed)	54	77%	6	43%

between these variables for this particular sample. We do not intend to imply any predictive power.

The core of our analysis focused on the content of data from the phase two open-ended interviews. Analysis of this material took place in several steps (Miles & Huberman, 1994). First, we wrote summaries of each case, and then developed a method for displaying the interview data, building

initial matrixes of blocks of text (quotations and summations) for each patient. These matrixes included general statements about facilitators and barriers to screening behaviors, as well as more specific factors associated with reported screening histories. Next, we identified trends and patterns between cases, which we then summarized into higher-level matrixes, contrasting informants grouped by level of adherence.

All phases of data processing and analysis were cross-checked for consistency in coding and classification during conference sessions in which all project staff participated. Any anomalies or discrepancies were addressed and resolved during these sessions.

Results

The women interviewed in both phases of the study were similar in their demographic characteristics. According to program staff, these characteristics are typical of women attending the community programs from which they were recruited. Participants ranged in age from mid-50's to 90, with a mean age of 70. Most of the women had low levels of education, with less than eight years of schooling, and were about evenly divided between Spanish and English speakers. The majority of women were widowed, divorced, or separated. Nearly all had some form of health insurance, however, those in the phase one group relied more on Medicare/Medicaid, while the phase two group included a higher percentage of women with private insurance (See Table 1).

Ninety-one percent (64/70) of the women answering community recruitment questionnaire of phase one had high knowledge of cancer screening recommendations; that is, they correctly named at least three of the ACS screening recommendations for women over 40. Thus, while women included in phase two of the study were pre-selected to be those with high knowledge, this level of knowledge was quite common among all the women we interviewed in these community programs. More than three-fourths (54/70, 77%) of the women surveyed in the community programs reported what we have defined as "high" adherence to breast and cervical cancer screening recommendations, having followed at least three of the ACS recommendations. Still, fully 20% (13/64) of those with high knowledge reported low levels of adherence.

Using the chi square test, we examined associations between various socioeconomic variables and levels of knowledge and of adherence, for the community recruitment questionnaire (Table 2). Due to the very small number of women in the "low knowledge" category, these figures must be interpreted with caution. Still, it is interesting to consider the associations we examined. Neither level of education nor insurance status were significantly associated with knowledge or adherence levels, while age and marital status were. Women under 75 were more likely to have both high knowledge and high adherence, and unmarried women reported significantly less adherence than did married women.

It is noteworthy that we did not find a significant relationship between levels of knowledge and levels of adherence. It would seem that factors other than knowledge of screening recommendations affect the adherence of these women.

In the open-ended interviews of phase two, we asked the 14 women (who were all knowledgeable about screening recommendations) what made it easier or more difficult for them to have cancer screening tests. Table 3 summarizes the facilitators and barriers they identified, contrasting the responses of those reporting high versus low adherence.

Not surprisingly, women reporting high adherence named fewer barriers to cancer screening than did those with low adherence. The high adherence group mentioned primarily practical barriers, such as lack of transportation or time, or the cost of the tests. In contrast, those reporting low adherence identified more conceptual barriers to screening, including not believing in the benefit of screening, and feeling that they were not personally at risk, either because their previous screenings had been negative, or because they were no longer sexually active. In that most (80%) of the women over 75 were unmarried, such concepts may help explain why older and unmarried women were found, in our analysis of the phase one questionnaire responses, to be significantly less likely to report being adherent.

TABLE 2
*Selected Demographic Characteristics by Knowledge and Adherence
for Community Recruitment Subjects (n=70)*

	Low Knowledge (n=6)	High Knowledge (n=64)	Low Adherence (n=16)	High Adherence (n=54)
	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>	<i>n (%)</i>
Age				
75 years	1 (2%)	50 (71%)	8 (11%)	43 (62%)
>75 Years	5 (7%)	14 (20%)	8 (11%)	11 (16%)
	<i>X²=10.48 df=1 n=70 P=.005*</i>		<i>X²=5.79 df=1 n=70 P=.024*</i>	
Education				
0-8 yrs.	5 (7%)	43 (61%)	13 (19%)	35 (50%)
9 or more	1 (2%)	21 (30%)	3 (4%)	19 (27%)
	<i>X²=.664 df=1 n=70 P=.657</i>		<i>X²=1.547 df=1 n=70 P=.358</i>	
Marital Status				
Married	0 (0%)	27 (39%)	1 (2%)	26 (37%)
Not Married	6 (8%)	37 (53%)	15 (21%)	28 (40%)
	<i>X²=4.121 df=1 n=70 P=.075</i>		<i>X²= 9.145 df=1 n=70 P=.003*</i>	
Health Insurance				
Not Insured	6 (9%)	57 (82%)	15 (22%)	48 (70%)
Insured	0 (0%)	6 (9%)	1 (1%)	5 (7%)
	<i>X²=.626 df=1 n= 69 P=1.00</i>		<i>X²= .157 df= 1 n=69 P=1.00</i>	
Adherence				
Low Adherence	3 (4%)	13 (19%)		
High Adherence	3 (4%)	51 (73%)		
	<i>X²= 2.742 df=1 n=70 P=.128</i>			

Both adherence groups identified similar factors as facilitating their cancer screening behavior. These included: wanting reassurance about their health or their families encouraging them to be screened, and having transportation, insurance, the time to go for tests, and access to a female provider. Women in the low adherence group additionally noted that they would be more likely to go for screening if they experienced symptoms.

In addition to these general questions about facilitators and barriers to cancer screening, we also asked the circumstances under which the women had actually come to have cancer screening in the past. We asked: "When was the first Pap Screening Test

you ever had? Tell me about that. Why did you have it done at that time?" We repeated these questions for their most recent Pap test, as well as for their first and last mammography. The women's answers to these four questions are especially revealing. Table 3 presents a summary of their answers to these questions.

Two points seem critical. First, for women in both the low and high adherence groups, by far the most commonly named factor influencing their actual screening behavior was whether or not they had received a referral for the test from their primary care provider. Women who well knew the cancer screening recommendations for women in their age

TABLE 3
Barriers and Facilitators to Cancer Screening and Reasons Had Past Screenings
for Open-Ended Interviews Subjects (n=14)
(Note: Subjects could identify more than one reason, so totals may exceed 14)

	Low Adherence (n=8)	High Adherence (n=6)	Total
Barriers			
Not trust or believe in the tests	5	0	5
Procrastination	3	1	4
Provider did not recommend	4	0	4
No Time/Family Obligations	0	4	4
No symptoms	2	2	4
Past screenings were negative	3	0	3
Not sexually active so not at risk	2	0	2
Ashamed/embarrassed	2	0	2
Other (transportation, cost)	1	1	2
Facilitators			
Wants reassurance	1	3	4
Family or Provider encourages	3	1	4
Has transportation	2	4	6
Has insurance	2	1	3
Female provider	0	1	1
Has time to go	0	2	2
If has symptoms	2	0	2
Reasons had Past Screenings*			
Provider said to go	17	10	27
Annual Routine	0	7	7
Heard it's good to go	5	4	9
Afraid of Cancer	2	4	6
Family Encouraged	2	2	4

**(Combines responses to four questions: Reasons given for having had first pap, last pap, first mammography, and last mammography.)*

group, but had failed to have timely cancer screening, often made comments such as: "Well, I had an appointment last month for my blood pressure medication. He didn't tell me I needed to have a Pap. I figured that if I needed it, he would have sent me." Or conversely, those who were up-to-date in their cancer screening made remarks like: "When I come in for my annual checkup, my doctor

just automatically does a Pap test. So that's how I always get it done." Thus, whether or not these women received consistent and timely recommendations and referrals for cancer screening was a central factor determining whether or not they reported actually following the recommendations with which they were already familiar.

A second important point is that women in the high adherence group were more likely to report that they had established an annual routine that included cancer screening. While for many, like the woman quoted above, this was part of their having an annual general checkup, several others noted that they knew when it was time for their screening because they would receive reminder postcards or a phone call from the clinic they normally attended.

Discussion

The purpose of this study was to develop an in-depth understanding of the concepts and experiences of a small group of older Hispanic women who were knowledgeable about cancer screening recommendations, exploring the circumstances under which they reported following or not following those recommendations. Due to the small sample size, limited sampling frame, and spontaneous nature of the topics discussed, our findings cannot be generalized to a larger population without further research. We also should note that relying on self-reports of screening may overestimate actual screening behavior. Still, we have gained some insight into how knowledge of screening recommendations comes to be enacted, at least for this small group of women.

We found that knowledge of cancer screening recommendations was already quite high among the women who answered our questionnaire in the community programs. It is likely that these high knowledge levels are due, at least in part, to the community's recent participation in the NHLIC cancer screening education intervention. Nevertheless, 20% of those with high knowledge of the screening recommendations did not report adhering to them, indicating that knowledge alone many not assure adherent screening behavior.

The open-ended interviews gave us some insight into this apparent anomaly. We found that women in both the high and low adherence groups emphasized practical considerations such as time, cost and transportation; in discussing their use of cancer screening services. The low adherence group also mentioned some conceptual barriers to screening,

such as not believing in the tests themselves, or thinking that the tests are not necessary for women who are not sexually active, who have no symptoms, or who have had normal tests results in the past.

While the facilitators and barriers named by these women are of interest, perhaps more telling are the circumstances under which they reported actually having received screening tests in the past. Both the high and the low adherence groups indicated that primary care providers' recommendations and referrals played a key role in their screening behavior. Many women in the high adherence group had come to view annual testing as routine because they received consistent annual referrals and reminders. At the same time, several women in the low adherence group said they assumed they didn't need the tests because their primary care provider had failed to recommend them. Indeed, receiving a recommendations from a primary care provider was the principal reason given by the low adherence group for having had any cancer screening tests at all. It seems that, while knowledge of screening recommendations did not assure adherence among these women, a primary care provider discussing cancer screening with them, assisting with referrals, and/or establishing an annual screening routine was crucial to the past screening behavior they reported.

The fact that minority poor women are unlikely to have a long-term relationship with a primary care provider (Berk & Bernstein, 1982; Cornelius, 1997; McCourt & Pearce, 2000; O'Malley, Mandelblatt, Gold, Cagney, & Kerner, 1997; Phillips, Mayer, & Aday, 2000), could help explain, at least in part, the low rates of cancer screening reported for Hispanic women. Many recent studies have found that having a regular source of health care is a key predictor of use of cancer screening services, particularly for older and minority women (Bindman, Grumbach, Osmond, Vranizan, & Stewart, 1996; Caplan & Haynes, 1996; Carney, Dietrich, & Freeman, Jr., 1992; Ettner, 1996; Kagawa-Singer & Pourat, 2000; Kelaher & Stellman, 2000; Laws & Mayo, 1998; Mandelblatt et al., 1999; O'Malley, Mandelblatt, Gold, Cagney, & Kerner, 1997; Zambrana R.E., N. Breen, S.A. Fox, & M.L. Gutierrez-Mohamed,

1999). This may be because women without a regular provider are less likely to consistently receive referrals, reminders and recommendations. They also would not have the opportunity to develop a provider-patient relationship adequate for identifying, discussing and correcting concepts and beliefs that may present barriers to screening. These propositions are supported by recent studies which report improvements in cancer screening rates through programs that provide cancer screening education to primary care providers, establish a system of reminder phone calls or postcards to patients, and enhance communication between providers and within the health care system (Burack et al., 1994; Burack et al., 1998; Costanza et al., 1992; Taplin et al., 2000).

Our findings draw attention away from the usual focus on patient knowledge and motivation as determinants of cancer screening among older Hispanic women, and instead point toward possible inadequacies in provider-patient relationships and clinic procedures which may be disproportionately affecting this population. Further research with a representative sample would be necessary before the generalizability of these findings can be checked. Still, our study indicates that cancer screening for older Hispanic women might be enhanced if consistent and reliable referral procedures are followed. Establishing explicit institutional policies and procedures for achieving this goal would seem especially important in clinic settings where the primary care provider has little opportunity to develop long-term relationships with patients.

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