

PERCEPTIONS OF BREAST AND CERVICAL CANCER RISK AND SCREENING AMONG DOMINICANS AND PUERTO RICANS IN RHODE ISLAND

This study explored perceptions of cancer, risk, and screening among Dominicans and Puerto Ricans in Rhode Island. Qualitative interviews were conducted with a community-based sample of 147 adults. Perceived risks for breast cancer were predominantly associated with carelessness about health care, trauma to the breast, and breastfeeding. Cervical cancer risks were mostly attributed to carelessness about health care and sexual behaviors. A strong sense of fatalism and embarrassment coexisted with positive beliefs about check-ups and screening. Participants cited *confianza* (trust, confidence) in their doctor, and their doctor's provision of information and explanations, as important factors in decreasing embarrassment and increasing their likelihood of getting screened. While familiarity with mammography and Pap testing was great among participants, many did not practice sustained, regular screening, and held misconceptions about tests and screening guidelines. Respondents' perceptions of having sufficient information often did not correspond to their having the accurate information necessary to promote informed screening decisions. (*Ethn Dis.* 2004;14:32–42)

Key Words: Qualitative Research, Breast and Cervical Cancer Screening, Cancer Risk Perceptions, Cancer Screening Barriers, Puerto Ricans, Dominicans, Hispanics

From the Department of Family Medicine, Brown Medical School (REG), Institute for Community Health Promotion, Brown University (PMR), Providence; Center for Primary Care and Prevention, Memorial Hospital of Rhode Island (REG), Pawtucket, Rhode Island.

Address correspondence and reprint requests to Roberta E. Goldman, PhD; Memorial Hospital of Rhode Island; Center for Primary Care and Prevention; 111 Brewster Street; Pawtucket, RI 02860; 401-729-2924; 401-729-2494 (fax); Roberta.Goldman@mhri.org

Roberta E. Goldman, PhD; Patricia Markham Risica, DrPH

INTRODUCTION

Hispanics are the fastest growing “minority group” in the United States,¹ a demographic factor highly significant to the fields of preventive and primary care medicine because Hispanics are less likely than non-Hispanic Whites to engage in preventive care and cancer screening.^{2–4} Studies have also found that Hispanics are more likely to delay seeking care after experiencing symptoms.^{5–7} Although mammography and Pap testing rates are increasing among Hispanics overall, the rates still lag behind those for other groups and government targets.^{2–3,8} While Hispanics do have lower breast cancer incidence than non-Hispanic Whites, they bear an increased risk of developing invasive cervical cancer.² Studies have shown that lower screening rates among Hispanics account for later stage diagnoses of cancer.^{9–11} And Hispanics, who are disproportionately represented among the poor and uninsured, have in general been found to have larger size breast tumors and lower survival rates for both breast and cervical cancer.^{9,12–14}

Numerous studies have been conducted on the barriers that impede the use of preventive health and screening services by Hispanics. Hispanic women often pay less attention to their own health than the health of other family members, worrying that a diagnosis of cancer may make them a burden on others in their family.^{15–16} Within many Hispanic communities, sexual matters are considered private, and women with traditional values are expected to be naïve about sexual issues.^{17–18} The absence of disease symptoms, or not feeling sick, have been shown to impede Hispanic women's desire to screen for breast cancer.¹⁶ Yielding to fatalism has also been

reported to curtail participation in cancer screening.^{16,19–22} Other barriers to breast and cervical cancer screening found for Hispanic women are: fear or misconceptions about causes of cancer or effectiveness of treatment²³; perception of being at low risk^{16,24}; high cost and lack of health insurance^{19,22,25–26}; lack of knowledge about screening tests and guidelines^{6,27–28}; lack of recent physical exam²⁸; not having medical conditions that require seeing a doctor²⁹; lack of physician referral for the test or no regular provider or site of care^{13,19,25,30–31}; not speaking English⁸; lack of English literacy³²; not being sexually active³³; and fear of pain³⁴ or of finding cancer.^{35–36} For Hispanics, emotions surrounding shame and embarrassment have been found to amplify other barriers.^{37–38}

While there are certainly some commonalities among Hispanics of different national origins, the tendency to lump all participants identifying themselves as Hispanic masks important cultural, social, economic, historical, and experiential differences within the unique Hispanic designate that may influence health perceptions and behaviors.^{39–40} The term “Hispanic” was created largely as an administrative and political category and as such can be expected to have limited use for understanding health perceptions and decisions. The generic referent of Hispanic tends to simplify and, as Oboler⁴¹ writes, homogenizes and makes one dimensional the culturally and socially varied experiences of 23 million people—many of whom have little in common outside of the Spanish language. In an attempt to move away from this trend of merging ethnic heritage for convenience, the current study explores how Dominicans and Puerto Ricans, in particular, view and conceptualize the subjects of cancer risk and screening.

Studies have shown that lower screening rates among Hispanics account for later stage diagnoses of cancer.⁹⁻¹¹

Dominicans and Puerto Ricans speak Spanish and share a common region of origin, the Spanish Caribbean Islands. Historically, they were part of the same immigration experience that brought not only Spaniards to the Americas, but included the large importation of slave labor from Africa. Puerto Rico and the Dominican Republic are today culturally defined by this experience, as the fusion of Spanish and African ideas and customs have created a unique island identity. The history of intermarriage between Africans and southern Europeans is also evident in the phenotypic variation exhibited by both the people of Puerto Rican and Dominican descent. The differences between Dominicans and Puerto Ricans are largely administrative and political, extending to their distinct immigration histories to the United States and their status within the host country.

The views of Puerto Ricans and Dominicans on cancer, reported in this paper, are really not "exotic" when examined cross-culturally. Non-biomedical beliefs about cancer and treatment were common in the United States in the 1960s and 1970s when the disease was largely viewed as a death sentence.⁴² People of all cultural backgrounds have constructed alternative rationales and metaphors for the origin and treatment of illnesses such as cancer. Consequently, even notions that are irrational from the biomedical perspective are endowed with meaning as these beliefs, or "folk" explanations, circulate in the community.²¹ In the United States over the last 2 decades, increased public attention to issues of cancer and prevention, and better information dissemination have

contributed significantly to combating much of the mythology related to cancer.

Yet, non-biomedical perceptions of cancer are still prevalent, as seen within the ethnic communities of Rhode Island where many participants in this study live and work. The persistence of these views is due in large part to isolation from the English informational mainstream and the lack of equivalent Spanish-language media attention to cancer prevention and screening. Additional factors that have been cited for the isolation of Latinos in general are: 1) the recent immigration of many individuals from these groups; 2) linguistic barriers to information access and the inability to speak directly with providers; and 3) a general suspicion and distrust of often conflicting information emanating from unfamiliar institutions and organizations.⁴³ These factors compound communication problems between health-care providers and many Spanish speaking people. This paper reports findings from a qualitative study of the perceptions around breast and cervical cancer risk and screening among 2 specific ethnic groups: Spanish speaking Dominicans and Puerto Ricans living in Rhode Island.

METHODS

Prior to the development of the qualitative interview scripts, we spent a year increasing our familiarity with the Rhode Island communities where the Dominicans and Puerto Ricans who participated in this study lived. During this period, we conducted preliminary research on Dominican and Puerto Rican organizations in Rhode Island, and also met with a wide range of community leaders and professionals serving the Hispanic community. This preliminary period also allowed us to better understand the physical, social, political, and economic setting of this study, and provided community members an oppor-

tunity to have input in the research from the outset. During this year, we approached and recruited the formal and informal community leaders who would form the project advisory committee. All members of the advisory committee were drawn from, or were associated with, the Rhode Island Dominican and Puerto Rican communities. These individuals provided immeasurable information and logistical support for the research: they assisted us in identifying and refining issues that would be explored in the study, helped formulate the interview script in English and Spanish, "spread the word" about the study so that other members of the community were aware of the project, assisted with recruitment, and later participated in interpretation of the findings. Through the suggestions and advice of the advisory committee, in combination with general ethnographic research that we conducted during that first year, we gained a good sense of how health dynamics were constructed at the local level.⁴⁴

For this qualitative study, semi-structured interviews using open-ended questions were conducted in-person. A total of 147 adults living in Rhode Island who self-identified as either Dominican or Puerto Rican ethnicity: 36 Dominican women and 38 Dominican men; 38 Puerto Rican women and 35 Puerto Rican men. Table 1 describes participant characteristics. A purposive, stratified sample⁴⁵⁻⁴⁸ where the theoretical framework and specific aims of the study guided selection of participants was utilized to include: the 2 ethnic groups, both genders, having or not having a spouse/intimate partner, and age requirement of 18 years and over with an over-sampling of people over age 40. The study was also designed to ensure that there was a wide representation of people with varying numbers of years living in the United States mainland, living with and without children, and currently employed and not employed.

Table 1. Participant characteristics

Participant Characteristics	Females (N=74)	Males (N=73)
Ethnic background (%)		
Dominican	48.6	52.1
Puerto Rican	51.4	47.9
Age (%)		
<40	43.2	37.0
40 or older	56.8	63.0
Years in the mainland United States (%)		
<5 years	16.2	31.5
5–15 years	37.8	39.7
16–25 years	21.6	2.7
>25 years	24.3	26.0
Main language spoken in home (%)		
Spanish	89.0	94.5
English	2.7	4.1
"Spanglish"	8.2	1.4
Speak enough English to get by (%)	66.2	58.3
Relationship status (%)		
Single	32.4	9.7
Married	32.4	48.6
Consensual union	12.2	15.3
Separated	5.4	6.9
Divorced	8.1	9.7
Widow/Widower	8.1	2.8
Novio/Novia especial (special girl/boyfriend)	1.4	7.0
Years of school (%)		
<7 years	17.6	28.8
7–12 years	63.5	57.5
>12 years	18.9	13.7
Currently employed (%)	24.3	49.3
Have health insurance (%)	68.9	78.1
Consider themselves religious or spiritual (%)	93.2	93.2
Consider themselves healthy (%)	60.8	74.0
Have sufficient income for weekly basics (%)		
Yes	39.2	56.2
No	60.8	43.8
Have sufficient income for basics but find it difficult to support family/household (%)	(N=28)	(N=39)
Yes	53.6	43.6
No	46.4	56.4

Interviewing began in October 1998 and continued through September 1999. Recruitment was conducted in a wide variety of community venues. In order to avoid biasing the sample toward individuals who have an existing relationship with a healthcare site or provider, we deliberately refrained from recruiting at healthcare facilities. This precaution was necessary because having routine health care is a predictor of hav-

ing had Pap testing or mammogram.^{8,49–50} Furthermore, in Rhode Island, Hispanics are more likely than people of other ethnic groups not to have had a recent routine physical examination.⁵¹

The interview script was designed to elicit participants' perceptions, attitudes, beliefs, and experiences on health care and self-care, cancer, prevention, and screening. In collaboration with the ad-

visory committee, the questions were developed simultaneously in English and Spanish to enhance appropriateness of phrasing in Spanish; the interview instrument was pilot tested and modified before finalization. The 2-hour interviews were most often conducted in the participants' homes, or when this was not possible, in another community setting. Interviews were offered in Spanish and English; however, all participants, including those who said they were bilingual, chose to do the interview in Spanish. A signed informed consent in Spanish was obtained. Interviews were audio-taped and professionally transcribed.

All stages of analysis were conducted in the original Spanish, although quotes included in this paper were translated into English. Transcripts were read to acquire general familiarity with content and to isolate broad themes.⁵² *Atlas.ti* qualitative data management software was used to facilitate line-by-line coding.⁵³ An initial, theory-driven topical-code list was developed using a combination of inductive and deductive approaches, although the coding scheme remained flexible to accommodate new codes as necessary. Coders were extensively trained in the background and theoretical framework of the study, coding process, and definitions of each code. Coding was not an endpoint in analysis; rather, codes were used as indexing devices to facilitate the retrieval of interview data on desired topics for further analysis.⁵⁴ Coded transcripts were checked for quality, accuracy, and concordance in the assignment of codes.

RESULTS

Results from this research support many of the findings from other studies that have examined cancer screening among Hispanics in recent years.^{15–16} The findings, however, also provide additional insights into communication and perceptual issues among Domini-

Table 2. Perceptions of breast cancer risk: themes and subthemes, by gender, age, and order of frequency mentioned

Rank Order	Women Under Age 40	Women Age 40 and Older	Men Under Age 40	Men Age 40 and Older
1.	Blows to the breast	Careless about health care —Not getting checkups	Trauma to the breast —Blows —Bites or squeezes during sex	Careless about health care —Not going to doctor after feeling pain —Not following doctor's advice
2.	Breastfeeding —Milk accumulation —Too much breastfeeding —Never breastfeeding	Not performing BSE frequently	Careless about health care —Not going to doctor after feeling pain —Not following doctor's advice	Trauma to the breast —Blows —Bites during sex
3.	Careless about health care —Not getting checkups	Breastfeeding —Milk accumulation —Baby biting breast —Too much breastfeeding	Breastfeeding —Generally a risk —Milk accumulation —Causes a lump to develop —Baby biting breast causes infection	Breastfeeding —Generally a risk —Too much breastfeeding —Baby biting breast causes a lump to develop
4.	Breast enhancement or reduction	Blows to the breast	Heredity	No fault—"even women who have not had sex or drink alcohol are at risk"
5.	Heredity	Expending excessive force	Other —Women are weaker than men —Breast is weak part of body —Excessive force —Dietary fat —Smoking —Breast enhancement —Not supporting breasts in post-partum period —Poor hygiene —Lumps of fat in breast	Other —Dietary fat —Drink alcohol —Smoking —Breast enhancement
6.	Other —Unsupportive bra —Smoking —Eating well-done meat —It just happens	Heredity		
7.		Other —Smoking —Dietary fat —Not exercising —It just happens		

cans and Puerto Ricans. Tables 2 and 3 list participants' perceptions about breast and cervical cancer risk. Considerable overlap in beliefs emerged among Dominicans and Puerto Ricans, with most differences related to which perceptions were mentioned more frequently between gender and age groupings.

In general, participants displayed less familiarity with cervical cancer than with breast cancer, in some part due to confusion over the specific part of the body affected. Many women and men had not heard of cancer of the "cervix," though many used the term "vaginal

cancer" in their responses once they recognized which generalized area of the body we were referring to. Barriers to screening and perceptions about risk reported in this paper include factors in the health informational/services and community/individual domains. Results from the qualitative interviews are presented from these 2 domains to show how insufficient information or ineffective communication between healthcare providers and patients can contribute to a greater reliance on alternative biomedical explanatory information about cancer and cancer screening in the Dominican/Puerto Rican community.

Health Informational/Services Domain

Informational barriers refer to limitations on an individual's access to sufficient and accurate information for making decisions about health care. Results in this domain include informational knowledge and the type of communication that occurs between the healthcare providers and patients. The findings indicate that many patients perceive the healthcare setting as a context where relationships are asymmetrical; language difficulties abound, and these are at times compounded by a communication style that is rushed and

Table 3. Perceptions of cervical cancer risk: themes and subthemes, by gender, age, and order of frequency mentioned

Rank Order	Women Under Age 40	Women Age 40 and Older	Men Under Age 40	Men Age 40 and Older
1.	Careless about health care —Not getting checkups —Not going to doctor when have symptoms	Careless about health care —Not getting checkups —Not going to doctor when have symptoms	Careless about health care —Not getting checkups	Careless about health care —Not getting checkups
2.	Sexual relations/being careless about sexual relations —Woman has too many sexual partners —Sex too frequently —Sex during menstruation	Sexual relations/being careless about sexual relations —Woman has too many sexual partners —Male partner has too many sexual partners —Inflammation, infection, or venereal disease —Using condoms —Having sex too soon after childbirth	Careless about hygiene	Sexual relations/being careless about sexual relations —Getting venereal disease/other infection from a man —Woman has too many sexual partners —Too much friction in intercourse
3.	Careless about hygiene	Heredity	Sexual relations/being careless about sexual relations —Woman has too many sexual partners —Too much friction in intercourse —Getting infection from a man	Women are vulnerable —Risk of accumulation of menstrual blood
4.		Careless about hygiene	Women are vulnerable —Menstruation makes area of body delicate; decomposition of menstrual blood causes cell growth —Women are weaker/more susceptible to infections	Careless about hygiene, including during menstruation
5.			Pregnancy —Careless about resting after childbirth —Pregnant too often	Pregnancy —Not getting postpartum checkups —Pregnant too often —Getting pregnant too soon after giving birth
6.		Women's behaviors puts them at risk (though respondents could not list what these are)		

impersonal. Some participants felt that they needed to know more about cancer and screening, and contended that it was the physician's responsibility to inform the patient. A 48-year-old Dominican woman explained:

"Talking with your doctor is really important when a person has doubts because one feels much better if the doctor explains things to you. Not just diagnosing you and writing prescriptions. To really steep yourself more in things, in the health problem you have."

Other participants believed they had sufficient information, although this perception may not, in actuality, correspond to their having accurate and com-

plete knowledge about tests and screening guidelines.²⁷ Many participants, for example, underestimated the time interval for screening tests, assuming every 6 months was the most appropriate time frame for having mammography and Pap testing. In addition, participants seemed confused about the purpose of the tests in terms of screening, diagnosis, or prevention, questioning their need for screening when they were not experiencing overt pain or symptoms.

Although most women previously had Pap testing, many were unable to name or describe a test for cervical cancer; in fact, most had no idea what the Pap testing procedure tested for. Older

women particularly had little information, many feeling that these decisions were best left to the doctor. For example, a 66-year-old Dominican woman responded this way to a question about what test is used for cervical cancer: "Well, it's the doctors who do the tests." About half of the women over age 40 stated that Pap testing should be done yearly, and the others thought every 6 months was necessary. Younger female participants generally believed that every 6 months, or more often, was appropriate. Almost all of the women over age 40 felt that it was important to start doing Pap testing "early," and many defined early as age 35. Others believed

that women should start getting regular Pap tests when "they are married," which for most was a gloss for starting sexual relations. For women under age 40, this was the benchmark most commonly cited, though the explanation varied. Some believed that women were more at risk for disease after they start having sex, while others said that it was simply improper for a women who had never had sexual relations to get an intimate exam. A 49-year-old Puerto Rican woman explained:

"One must examine oneself as soon as one has sexual relations. Because I think that a girl who never had sexual relations shouldn't have tests of this nature. I am not going to permit it. They're not going to examine my daughter while she is still a *señorita*. I hope that after she is a woman she takes action, and they do the test."

The most widely shared belief about cervical cancer prevention, centered around having regular check-ups, though there was little understanding of how this procedure would be preventative. A 51-year-old woman of both Dominican and Puerto Rican background exclaimed: "I haven't heard much about this kind of (cervical) cancer, but it's good to protect oneself!"

In relation to breast cancer screening tests, most of the women in the study expressed confusion about the breast self exam (BSE), with some claiming to do it many times a week or every time they shower. A 34-year-old Puerto Rican woman explained her lack of confidence with the procedure:

"I believe that by palpating many people can discover something, but I don't believe in this much because . . . if I'm doing it myself, I may not do it well. Or maybe I'm doing it at times that I shouldn't, because they say before the period or after—I don't know how it is. So I believe more in the mammogram."

While most of the age-appropriate women in the study previously had at least one mammogram, the interviews revealed women's ambivalent attitudes regarding the benefits and efficacy of the

exam. In this study, participants were more familiar with breast cancer than the other cancers addressed in the interviews (cervical, colorectal, and prostate). Yet concerns about mammography remain due in part to repetition of personal experience stories, and lack of accurate information about the procedure. A 59-year-old Dominican woman exemplifies this situation:

"I really had a fright the last time I had a mammogram because my breasts hurt me for a month. There has got to be another method that is less painful to do this because in my understanding this can also cause damage. I will keep doing it, believing though that it won't help me but will make me worse, due to the pain and because you are bruised inside and this has got to be dangerous for you."

Conversely, some women did feel comfortable with mammography, as one 64-year-old Dominican explained:

"A bus came and stopped in front of the health clinic and I went in and they did the mammogram. People say that it hurts tremendously, but it didn't hurt me at all. I'll do it again."

Some participants expressed annoyance that they were not given sufficient information, especially about test results. As one women stated, "I'm tired of getting tests and not being told how they turned out." The Spanish word *confianza* (comfort, trust, or confidence) was used frequently to explain how participants felt about physician visits and screening tests. Women said that when the physician gives them explanations, their sense of *confianza* increases. Lack of *confianza* was associated with a variety of screening barriers that included an absence of confidence and trust in the physician, doubts about the reliability of tests, and the lack of comfort and familiarity with the physician, as well as other distancing behaviors which increase embarrassment. Feelings of shame and embarrassment were in a transitional state. Although women often talked about embarrassment in relation to the Pap test, embarrassment was not cited as a major barrier to actually getting a

Pap test. Views of the Pap test varied; some women said they had been more embarrassed in the past before they got used to it, and others said that the embarrassment became worse as they got older. Many felt that having *confianza* in the physician, and a physician's comforting communication style, could decrease their embarrassment about the tests. A 64-year-old Dominican woman gave the following example about how a doctor had helped her feel more at ease about having a Pap test:

"At one time it gave me much shame. In Santo Domingo when I was about 33, I had a lot of pain and I felt really bad, so my husband took me to a clinic. Ay, they put me in a position, and after when I sat in the office with that doctor, I had my head down, and the doctor said to me, 'Raise your eyes and look at me directly.' 'No, ay, no' I said. 'Doctor I'm full of shame about what you did to me.' So then he said to me, 'Well, look, I'm going to tell you something so that you don't feel ashamed: I did this very same test to a nun!' So I thought, if the nuns who don't have contact with men have this done, why would I feel shame? And I lifted my head to look at him."

Community/Individual Domain

The community/individual domain includes informational flows in the broader community and how they might influence an individual's personal perspective on cancer risk and screening. The comments from study participants about barriers to breast and cervical cancer screening included many that have also been found in previous studies: fear of the test or pain from the test; reluctance to visit a doctor; not believing one could get cancer, reluctance to find out one has cancer, and fear, shame or embarrassment about getting genital exams.

The word *descuido* (carelessness or negligence) was used by women and men to describe breast cancer risk behaviors. People's behaviors were thought to constitute carelessness when they failed to get check-ups or failed to get tested after finding a lump or feeling a

PERCEPTIONS OF BREAST AND CERVICAL CANCER - Goldman and Risica

pain, or habitually wore unsupportive bras or no bra at all. Issues around *descuido* commonly interfaced with economic and other barriers to explain why women do not get screening tests. As a 43-year-old Puerto Rican woman related:

"They're not worried, not thinking, they believe nothing's more important than the hairdresser, or than work. They don't take the time, because time is short for losing the opportunity to earn money in the factory. They have to lose a day to see about their health. For these reasons many women die—because they don't look into their health."

Carelessness was also commonly cited by women and men as a risk for cervical cancer, largely in relation to not getting medical checkups, and by women as not going to the doctor when one has pain. In addition, carelessness included maintaining poor hygiene, having too many sexual partners thus putting the woman at risk of catching an infection, and a variety of factors in relation to post-partum care.

Participants held some breast cancer risk beliefs that support results of other studies; these included blows to the breast both unintentional by children and intentional domestic violence, heredity, smoking, and breast reduction or enhancement.²¹ Participants in this study also held other beliefs about risk for breast cancer, such as expending too much physical force. A 48-year-old Dominican woman explained:

"We women have to take a lot of care with the things that one has to do because whatever *fuercita* (small force) that you exert might do damage to you."

A risk for breast cancer commonly cited by participants related to breastfeeding generally, or a complex of issues concerning breastfeeding practice and technique. These issues included: the baby biting the nipple or hitting the breast while feeding and causing a lump to form, variants of reasons for milk accumulation due to not breastfeeding at all, breast feeding too many babies, or

not emptying the breast entirely. A 78-year-old Dominican woman explained:

"They say that the people who are most sure to get breast cancer are those who give the breast. Because sometimes milk stays behind that they don't finish giving to the babies, and this starts accumulating and it builds up."

And a 75-year-old Dominican woman told this story:

"I knew a friend of mine who died. She didn't give breast milk to the baby right away when he was born because they did a cesarean. So what happened is that she couldn't maintain the milk after. She couldn't give the breast. And from this came a cancer."

The behavioral result of people perceiving breastfeeding as a cancer risk was summed up by a 56-year-old Puerto Rican man: "These days many women don't want to give the breast to their children due to the fear of it."

Both men and women perceived sexual relations to constitute an important category of risk for cervical cancer. While many of the beliefs reflected actual risks for cervical cancer, most participants had only vague notions about the relationship between behavior and risk. Specific risk behaviors frequently cited by women included: starting to have sex at a young age; having too many sexual partners; husband or boyfriend having too many sexual partners; infection caught from a sexual partner; and not getting checked. Other perceptions about cervical cancer risks included: that cervical cancer itself is an infection caught from a sexual partner; that it is caught from sitting on a public toilet or in other dirty places; that it results from venereal diseases (though no specific disease was mentioned and HIV/AIDS was never mentioned); having too much sex with one partner; having sex during menstruation; and having sex too soon after the birth of a baby. A 62-year-old Dominican woman explained how she followed cultural norms after childbirth:

"When I had my children, my husband

didn't touch me until after the 41 days. He was very aware. The woman has to guard her canal when she gives birth."

A younger Dominican woman, 37 years old, explained this concept in more detail:

"I remember my dear grandmother telling me that after you give birth you have to allow your vagina to return to its normal state. You have to be careful because it's a child, it's a head that goes out from there, and the organs are relaxed. You have to give time in your life before you have sexual relations because for a few seconds of gratification, you are going to mistreat your vagina."

Heredity was not often explicitly mentioned by either gender, but there was a sense among those who knew about cervical cancer that "women suffer from cervical cancer as men suffer from prostate cancer." A 59-year-old Dominican woman summed up the confusion expressed by many about the causes of cervical cancer:

"Ay, I'm not really sure. It could be the husband, or many women have different partners, and it could be that one partner has some kind of disease, and it could be that this causes the woman to get an inflammation, and this also causes it to turn into cancer . . ."

Some men believed that there was a relationship between cervical cancer risk and the vulnerability of women's bodies. Men expressed concern for women's vulnerability and "weakness" in the vaginal area, and the ease with which it can get diseased. Some of the men were concerned with women's need to observe restrictions on activity in the postpartum period. In addition, some men believed that the way men treat women during sexual relations could cause cancer, and an overly large penis put women at risk for cervical cancer. One 19-year-old Dominican man said that cervical cancer risk stemmed from using condoms during sex. Unlike the women who cited cancer risks related to having sex during menstruation, men's perceptions were that it is menstruation itself that makes women particularly susceptible. A 37-

year-old Puerto Rican man listed the concerns commonly expressed by men:

"Well, a lot of things enter there, and the situation with the woman in relation to menstruation can give cancer. Plus the infections. The woman is something very complicated in terms of her body and her system of operation."

The qualitative interviews allowed for an exploration of the multifaceted dimensions of fatalism among Puerto Ricans and Dominicans. A sense of resignation predominated among some participants, making them feel that there is only so much one can do to avoid sickness and death. Even if cancer is found early, a 59-year-old Puerto Rican woman said, "it will just give you a little more time between when you find out and when you die." And a 37-year-old Dominican woman explained, "Sure, taking care of yourself will help, but when cancer says 'I'm going over there' at that point there's no type of care because it's already inside." When discussing the possibility of cancer survivorship or mortality, Dominican male respondents often referred to the general inevitability of death. In this context, they used a colloquial expression ("*Nadie nació para semilla*") which does not translate directly, but essentially means "everyone will die at some time." However, these fatalistic expressions about the terminal nature of cancer had a positive counterpart. Both women and men frequently stated that people should be more vigilant about their health and take responsibility for getting check-ups, being tested regularly and avoiding carelessness (*descuido*).

DISCUSSION

A limitation of the study is that it included only individuals living in Rhode Island of Caribbean-origin who self-identified as either Dominican or Puerto Rican. Dominicans and Puerto Ricans, because of their similar geographic origin, share many characteristics that set them apart from other

Spanish speaking groups who are commonly collected under the umbrella of Hispanic. Study results, while avoiding the generalizations that occur when inappropriately combining the experiences of Hispanics from diverse national backgrounds, may not be applicable to people from other Hispanic groups.³⁹⁻⁴⁰ The findings may also not apply to Dominicans and Puerto Ricans living in other areas of the United States, or to those who would have chosen to do an interview in English rather than in Spanish. In addition, the qualitative sample was not chosen randomly. The purposive stratified sample that we did recruit from a wide variety of public venues, however, ensured inclusion of individuals with the range of demographic characteristics relevant to this study.

The findings from this qualitative study underscore the complexity of the issues concerning cancer perceptions and behaviors among Hispanics, and provide meaning and context that help explain some of the conflicting perceptions in this group. The literature contains many discussions of how shame, embarrassment, and fatalism impede screening among Hispanics. For the Caribbean-origin populations in this study, fatalism is not the one-dimensional concept often depicted among Hispanics. Findings show that a strong sense of fatalism and feelings of embarrassment coexist with firm beliefs about the importance of medical check-ups and screenings, and increasing normalization of at least the *idea* of Pap testing and mammography.

Overall in these qualitative interviews, Dominicans and Puerto Ricans expressed similar views regarding breast and cervical cancer risk and screening. However, Dominicans expressed a somewhat greater awareness of cancer screening and sense of individual responsibility to reduce risk than did Puerto Ricans. This notion is supported by a telephone survey that was also conducted by our research group in this

Findings show that a strong sense of fatalism and feelings of embarrassment coexist with firm beliefs about the importance of medical check-ups and screenings, and increasing normalization of at least the idea of Pap testing and mammography.

study population.⁵⁵ The telephone survey findings show that more Dominicans than Puerto Ricans reported agreeing that one can prevent some cancers, and that regular exercise and fruit and vegetable intake were associated with lower risk of cancer. However, Dominicans were more likely than Puerto Ricans to agree that they can do nothing if God gives them cancer. Thirty percent to 40% of both Dominicans and Puerto Ricans in the survey agreed that praying regularly lowers chances of getting cancer. And about 35% of both Dominican and Puerto Rican survey respondents agreed that even if cancer is found early, they will still die from it.⁵⁵

The study found that it is important to distinguish between people's perceptions of having information about cancer and screening, and their actually having a level of knowledge about risks, tests, guidelines, and testing rationale—knowledge that can promote sustained, regular screening.²⁷ While most participants in the qualitative interviews claimed to believe frequent screening and early detection is important, and some did get screened at appropriate intervals, as has been found in other studies, many have not been screened according to guidelines.⁵⁶ Women often over-estimated the frequency with which screening is necessary, which may in fact decrease the efficacy of an exam

such as the breast self-exam (BSE). Overly frequent BSE, done too quickly each time with improper technique, may explain the high rate of performance of this self-exam found in the current study and those reported in the literature. And sufficient information about how to perform BSE is lacking, even when women say they have been taught the procedure. In one study of immigrant Hispanic women, 65% claimed to have been taught to do BSE by a health professional, although only 14% of that sample answered survey questions indicating that they understood correct BSE technique.⁵⁷ Over-estimations of the required frequency of exams such as mammography and the Pap test may also have the affect of impeding women's self-efficacy to engage in regular, periodic screening due to the perceived burden of getting such frequent testing. This situation may help explain why many women in this study who hold these beliefs actually get screened irregularly, and at intervals *greater* than those recommended. This finding is compounded by the higher Hispanic than non-Hispanic White rate of cervical cancer found nationally⁵⁸; SEER data for 1973–1999 found Hispanic women to have twice the incidence of invasive cervical cancer than non-Hispanic women.⁵⁹ Strategies for counseling about regular cancer screening and appropriate screening intervals therefore need to take into consideration the situation of each individual Hispanic patient. Counseling strategies need to address the complexity of the patient's perspective because these strategies may affect follow-through with these and other less familiar types of screening, such as for colorectal cancer.

The high level of familiarity study participants had with breast and cervical screening tests, despite confusion about the term "cervix," likely reflects improvements in patient education and other forms of health communication, including more translated materials, for Spanish speakers. However, health lit-

eracy and verbal communication barriers persist in Hispanic and other minority and low-income communities, impeding access to physician care and the uptake of regular screening.^{32,60} While 80.9% of Puerto Rican and 83.3% of Dominican survey respondents in this study claimed to know that the Pap tests were for cervical cancer (which were similar to the NHW response),⁵⁵ most participants in the qualitative interviews could not describe the purpose of the Pap test or relate it to cervical cancer screening. A potential danger may coincide with patients' increasing claims about knowledge of Pap testing and mammography. Improved rates in the category of "ever having been tested" reported in national statistics such as the Behavioral Risk Factor Surveillance System telephone survey,³ may be interpreted by health professionals as an indication that Hispanic women have adequately internalized the philosophy of screening and have the essential information to make informed decisions about preventive health.²⁹ As the data in the current study show, considerable misconceptions remain prevalent at the community level about what purpose these screening tests serve, the distinction between prevention and early detection, appropriate screening intervals, what early detection means for a woman's survival potential, what constitutes prevention, and what puts one at risk for these cancers.

A commonly mentioned cluster of risks for breast cancer in this study involved breastfeeding. The association of breastfeeding with a health risk to the mother is unfortunate given the many benefits to mother and baby from breastfeeding, and the potential, though yet unclear, association of lactation with reduced breast cancer risk.⁶¹ Behaviors associated with sexual relations were most frequently mentioned for cervical cancer risk. Some of the behaviors participants cited were accurate representations of risk. Other listed behaviors indicate participants' misconceptions in

this area; it was evident that many participants did not understand why or how certain sexual behaviors increase risk for cervical cancer. These risk perceptions may constitute screening barriers for those who do not feel that their own behaviors represent risks for breast or cervical cancer.

Trust and communication between healthcare providers and patients have been found to be influential in increasing uptake of cancer screening.^{62,63} For Spanish-speaking patients, the role of the physician in providing education about breast and cervical cancer is extremely important, and the ability to instill a sense of *confianza* (comfort, trust, confidence) is essential.^{64–65} The current situation of many group medical practices and community health centers in the United States is that continuity of care is not guaranteed; therefore, patients must see physicians according to their availability, particularly for acute visits. This trend presents a challenge to developing and maintaining *confianza* between physicians and patients. A plausible solution to this problem in some healthcare settings may be to place the responsibility for cancer prevention and screening communication with providers other than the physician. Nevertheless, for the participants in this study, getting information and explanations from "their doctor" was extremely important. For these participants, information constituted more than the essential facts that could be obtained through a patient education brochure, for example. Information was closely aligned with the communication processes between physicians and patients that play a significant role in participants' feelings of *confianza* in their doctor. *Confianza*, and their doctor's willingness to provide explanations and information, was seen as influential in decreasing participants' embarrassment and increasing their likelihood of getting screening tests.

Enhanced communication in the clinical setting can be promoted through understanding people's percep-

tions and expectations about their health conditions, and the contexts that influence these perceptions in which communication itself happens.^{21,66} Individuals' perceptions are formed and embedded within a complex of contextual factors in daily life. Providers must therefore be aware that when medical information and effective communication processes in the clinical setting are inadequate, non-biomedical sources will be relied on to understand and explain risk and illness. Family and prevalent community beliefs have considerable influence on how individuals perceive their health status, and on whether they follow-through with professional recommendations. Patient education strategies can therefore no longer conceptualize individual risk factors, behaviors, or treatment decisions in isolation from the life contexts in which they occur. New modalities are needed for physicians and other healthcare providers to facilitate culturally responsive communication in general, and for informational counseling about cancer prevention and screening with Hispanic patients who may be at great risk for late detection of cancer.

ACKNOWLEDGMENTS

This work was supported by a cooperative agreement granted by the US Centers for Disease Control through the Association of Teachers of Preventive Medicine. The authors would like to acknowledge the essential role of the qualitative interviewers for this project: Pedro Baez, Raul Fortunet, Carolina Pichardo, and Lucia Tono. We would also like to thank the many members of the Community Advisory Committee for their assistance throughout the project; Pedro Pichardo for his expert transcription of the interview tapes; and Ronald Harder for his insightful comments on drafts of this paper.

REFERENCES

1. US Census Bureau, US Department of Commerce. US Census 2000. Available at: www.census.gov.
2. Coughlin S, Uhler R. Breast and cervical cancer screening practices among Hispanic women in the United States and Puerto Rico, 1998–1999. *Prev Med.* 2002;34:242–251.
3. Blackman D, Bennett E, Miller D. Trends in self-reported use of mammograms (1989–1997) and Papanicolaou tests (1991–1997)—Behavioral Risk Factor Surveillance System. *MMWR.* 1999;48(SS-6):1–22.
4. May D, Lee N, Richardson L, Giustozzi A, Bobo J. Mammography and breast cancer detection by race and Hispanic ethnicity: results from a national program (United States). *Cancer Causes Control.* 2000;11:697–705.
5. Hubbell F, Chavez L, Mishra S, Magana J, Valdez R. From ethnography to intervention: developing a breast cancer control program for Latinas. *J Natl Cancer Inst Monogr.* 1995; 18:109–115.
6. Hubbell F, Chavez L, Mishra S, Valdez R. Differing beliefs about breast cancer among Latinas and Anglo women. *West J Med.* 1996; 164:405–409.
7. Facione N, Miaskowski C, Dodd M, Paul S. The self-reported likelihood of patient delay in breast cancer: new thoughts for early detection. *Prev Med.* 2002;34:397–407.
8. Hiatt R, Pasick R, Stewart S, et al. Community-based cancer screening for underserved women: design and baseline findings from the breast and cervical cancer intervention study. *Prev Med.* 2001;33:190–203.
9. Hedeon A, White E. Breast cancer size and stage in Hispanic American women, by birthplace: 1992–1995. *Am J Public Health.* 2001; 91(1):122–125.
10. Ruey-Jiuan Lee J, Vogel VG. Who uses screening mammography regularly? *Cancer Epidemiol Biomarkers Prev.* 1995;4:901–906.
11. Chen F, Trapido EJ, Davis K. Differences in stage at presentation of breast and gynecologic cancers among Whites, Blacks, and Hispanics. *Cancer.* 1994;73:2838–2842.
12. Miller B, Hankey B, Thomas T. Impact of sociodemographic factors, hormone receptor status, and tumor grade on ethnic differences in tumor stage and size for breast cancer in US women. *Am J Epidemiol.* 2002;155:534–545.
13. Zambrana R, Breen N, Fox S, Gutierrez Mohamed M. Use of cancer screening practices by Hispanic women: analyses by subgroup. *Prev Med.* 1999;29(6, pt 1):466–477.
14. Nápoles-Springer A, Pérez-Stable E, Washington E. Risk factors for invasive cervical cancer in Latino women. *J Med Syst.* 1996;20:277–293.
15. Boyer LE, Williams M, Clark Callister L, Marshall E. Hispanic women's perceptions regarding cervical cancer screening. *JOGNN.* 2001;30(2):240–245.
16. Borrayo E, Jenkins S. Feeling healthy: so why should Mexican-descent women screen for breast cancer? *Qual Health Res.* 2001;11(6): 812–823.
17. Peters RK, Bear MB, Thomas D. Barriers to screening for cancer of the cervix. *Prev Med.* 1989;18:133–146.
18. Morris DL, Lusero GT, Joyce EV, Hannigan EV, Tucker ER. Cervical cancer—a major killer of Hispanic women: implications for health education. *Health Educ.* 1989;20:23–28.
19. Laws M, Mayo S. The Latina Breast Cancer Control Study, year one: factors predicting screening mammography utilization by urban Latin women in Massachusetts. *J Community Health.* 1998;23(4):251–267.
20. Chavez L, Hubbell F, Mishra S, Valdez R. The influence of fatalism on self-reported use of Papanicolaou smears. *Am J Prev Med.* 1997;13(6):418–424.
21. Chavez LR, Hubbell FA, McMullin JM, Martinez RG, Mishra SI. Structure and meaning in models of breast and cervical cancer risk factors: a comparison of perceptions among Latinas, Anglo women, and physicians. *Med Anthropol Q.* 1995;9(1):40–74.
22. Smiley MR, McMillan S, Johnson S, Ojedda M. Comparison of Florida Hispanic and non-Hispanic Caucasian women in their health beliefs related to breast cancer and health locus of control. *Oncol Nurs Forum.* 2000; 27(6):975–984.
23. Suarez L. Pap smear and mammogram screening in Mexican-American women: the effects of acculturation. *Am J Public Health.* 1994; 84:742–746.
24. Bernstein J, Mutschler P, Bernstein E. Keeping mammography referral appointments: motivation, health beliefs, and access barriers experienced by older minority women. *J Midwifery Womens Health.* 2000;45:308–313.
25. Stoner T, Doward B, Carr W, Maldonado G, Church T, Mandel J. Do vouchers improve breast cancer screening rates? *Health Serv Res.* 1998;33:11–29.
26. Center on an Aging Society. *Data Profile 9: Older Hispanic Americans.* Washington, DC: Georgetown University; 2003.
27. Valdez A, Banerjee K, Ackerson L, Fernandez M, Otero-Sabogal R, Somkin C. Correlates of breast cancer screening among low-income, low-education Latinas. *Prev Med.* 2001;33: 495–502.
28. Metsch L, McCoy C, McCoy H, Pereyra M, Trapido E, Miles C. The role of the physician as an information source on mammography. *Cancer Pract.* 1998;6:229–236.
29. Wu Z, Black S, Markides K. Prevalence and associated factors of cancer screening: why are so many older Mexican-American women never screened? *Prev Med.* 2001;33:268–273.
30. Veit C. Motivating mammography adherence in elderly Latinas: a test of three mathematical models of decision making. *Med Decis Making.* 1999;19:448–465.
31. Randolph W, Freeman D, Freeman J. Pap smear use in a population of older Mexican-American women. *Women Health.* 2002; 36(1):21–31.
32. Lindau S, Tomori B, McCarville M, Bennett C. Improving rates of cervical cancer screening and Pap smear follow-up for low-income

PERCEPTIONS OF BREAST AND CERVICAL CANCER - Goldman and Risica

- women with limited health literacy. *Cancer Invest.* 2001;19(3):316-323.
33. Buller D, Modiano M, Guernsey de Zapien J, Meister J, Saltzman S, Hunsaker F. Predictors of cervical cancer screening in Mexican-American women of reproductive age. *J Health Care Poor Underserved.* 1998;9:76-95.
 34. Roetzheim R, Van Durme D, Brownlee J, Herold A, Woodard L, Blair C. Barriers to screening among participants of a media-promoted breast cancer screening project. *Cancer Detect Prev.* 1993;17:367-377.
 35. Lobell M, Bay R, Kelton V, Rhoads M, Keske B. Barriers to cancer screening in Mexican-American women. *Mayo Clin Proc.* 1998;73:301-308.
 36. Paragallo N, Box P, Alba M. Breast care among Latino immigrant women in the U.S. *Healthcare Women Int.* 1998;19:165-172.
 37. Stein JA, Fox SA. Language preference as an indicator of mammography use among Hispanic women. *J Natl Cancer Inst.* 1990;32:1715-1716.
 38. Richardson JL, Marks G, Solis JM, Collins LM, Birba L, Hisserich JC. Frequency and adequacy of breast cancer screening among elderly Hispanic women. *Prev Med.* 1987;16:761-774.
 39. Ramirez A, Suarez L, Laufman L, Barroso C, Chalela P. Hispanic women's breast and cervical cancer knowledge, attitudes, and screening behaviors. *Am J Health Promot.* 2000;14(5):292-300.
 40. Ramirez A, Talavera G, Villarreal R, et al. Breast cancer screening in regional Hispanic populations. *Health Educ Res.* 2000;5:559-568.
 41. Oboler S. *Ethnic Labels, Latino Lives: Identity and the Politics of (Re)Presentation in the United States.* Minneapolis, Minn: University of Minnesota Press; 1995.
 42. Sontag S. *Illness as Metaphor.* New York, NY: Vintage; 1978.
 43. Molina C, Aguirre-Molina M. *Latino Health in the US: A Growing Challenge.* Washington, DC: American Public Health Association; 1994.
 44. Higgins D, O'Reilly K, Tashima N, et al. Using formative research to lay the foundation for community level HIV prevention efforts: an example from the AIDS Community Demonstration Projects. *Public Health Rep.* 1996;111(suppl 1):28-35.
 45. Grbich C. *Qualitative Research in Health.* Thousand Oaks, Calif: SAGE Publications; 1999.
 46. Marshall MN. Sampling for qualitative research. *Family Pract.* 1996;13(6):522-525.
 47. Kuzel A. Sampling in qualitative inquiry. In: Crabtree B, Miller W, eds. *Doing Qualitative Research: Research Methods for Primary Care.* Thousand Oaks, Calif: SAGE Publications; 1999:31-44.
 48. Devers KJ. How will we know "good" qualitative research when we see it? Beginning the dialogue in health services research. *Health Serv Res.* 1999;34:1153-1188.
 49. Frazier E, Jiles R, Mayberry R. Use of screening mammography and clinical breast examinations among Black, Hispanic, and White women. *Prev Med.* 1996;25:118-125.
 50. Qureshi M, Thacker H, Litaker D, Kippes C. Differences in breast cancer screening rates: an issue of ethnicity of socioeconomic? *J Womens Health Gender Based Med.* 2000;9(9):1025-1031.
 51. Bolen J, Rhodes L, Powell-Griner E, Bland S, Holtzman D. State-specific prevalence of selected health behaviors, by race and ethnicity—Behavioral Risk Factor Surveillance System, 1997. *MMWR.* 2000;49(SS-2):1-60.
 52. Emerson RM, Fretz RI, Shaw LL. *Writing Ethnographic Fieldnotes.* Chicago, Ill: University of Chicago Press; 1995.
 53. Richards T, Richards L. Using computers in qualitative research. In: Denzin N, Lincoln Y, eds. *Collecting and Interpreting Qualitative Materials.* Thousand Oaks, Calif: SAGE Publications; 1998.
 54. Bernard HR. *Research Methods in Anthropology: Qualitative and Quantitative Approaches.* Walnut Creek, Calif: Altamira Press; 2002.
 55. Risica P, Goldman R. Personal communication.
 56. Mandelblatt J, Gold K, O'Malley A, et al. Breast and cervix cancer screening among multiethnic women: role of age, health, and source of care. *Prev Med.* 1999;28:418-425.
 57. Peragallo N, Fox P, Alba M. Acculturation and breast self-examination among immigrant Latina women in the USA. *Int Nurs Rev.* 2000;47:38-45.
 58. Amaro H, de la Torre A. Public health needs and scientific opportunities in research on Latinas. *Am J Public Health.* 2002;92(4):525-529.
 59. MMWR. Invasive cervical cancer among Hispanic and non-Hispanic women—United States, 1992-1999. *MMWR.* 2002;51:1067-1070.
 60. Deroose K, Baker D. Limited English proficiency and Latinos' use of physician services. *Med Care Res Rev.* 2000;57:76-91.
 61. Newcomb P. Lactation and breast cancer risk. *J Mammary Gland Biol Neoplasia.* 1997;2:311-318.
 62. O'Malley A, Forrest C, Mandelblatt J. Adherence of low-income women to cancer screening recommendations: the roles of primary care, health insurance, and HMOs. *J Gen Intern Med.* 2002;17:144-154.
 63. Goldman R. Cultural issues in breast and cervical cancer screening. In: Dubé C, Rosen R, Toohey J, et al, eds. *Communication Skills for Breast and Cervical Cancer Screening.* Providence, RI: Brown University; 1998.
 64. Molina C, Zambrana R, Aguirre-Molina M. The influence of culture, class, and environment on health care. In: Molina C, Aguirre-Molina M, eds. *Latino Health in the US: A Growing Challenge.* Washington, DC: American Public Health Association; 1994:23-43.
 65. Larkey L, Hecht M, Miller K, Alatorre C. Hispanic cultural norms for health-seeking behaviors in the face of symptoms. *Health Educ Behav.* 2001;28:65-80.
 66. Puschel K, Thompson B, Coronado G, Lopez L, Kimball A. Factors related to cancer screening in Hispanics: a comparison of the perceptions of Hispanic community members, healthcare providers, and representatives of organizations that serve Hispanics. *Health Educ Behav.* 2001;28:573-590.

AUTHOR CONTRIBUTIONS

Design and concept of study: Goldman

Acquisition of data: Goldman

Data analysis and interpretation: Goldman, Risica

Manuscript draft: Goldman, Risica

Statistical expertise: Risica

Acquisition of funding: Goldman

Supervision: Goldman