Perspectives of Colorectal Cancer Risk and Screening Among Dominicans and Puerto Ricans: Stigma and Misperceptions

The Harvard community has made this article openly available. Please share how this access benefits you. Your story matters

Citation

Published Version
doi:10.1177/1049732309349359

Citable link
http://nrs.harvard.edu/urn-3:HUL.InstRepos:32294117

Terms of Use
This article was downloaded from Harvard University’s DASH repository, and is made available under the terms and conditions applicable to Other Posted Material, as set forth at http://nrs.harvard.edu/urn-3:HUL.InstRepos:dash.current.terms-of-use#LAA
Perspectives of Colorectal Cancer Risk and Screening among Dominicans and Puerto Ricans: Stigma and Misperceptions

Robert E. Goldman¹, Joseph A. Diaz¹, and Ivone Kim²
¹Brown University, Pawtucket, Rhode Island, USA
²University of Pittsburgh, Pittsburgh, Pennsylvania, USA

Abstract

Colorectal cancer is the second most common cancer among Latinos, but a lower percentage of Latinos are screened than Whites and Blacks. Along with recognized economic barriers, differences in knowledge and perceptions might impede colorectal screening among Latinos. We conducted 147 individual, qualitative interviews with Dominicans and Puerto Ricans in the northeastern United States to explore their explanatory models for colorectal cancer and screening barriers. Many participants had not previously heard of colorectal cancer. The most commonly mentioned cause of colorectal cancer was anal sex. Also considered risks were “bad food,” digestion leading to constipation, and strained bowel movements. Screening barriers included stigma, misperceptions, embarrassment, and machismo. Progress toward increasing colorectal cancer screening requires normalization of this screening among Latinos. Higher patient familiarity, along with improved physician counseling and referral, might contribute to reducing stigma and other barriers, and to enhancing knowledge and Latino community support of colorectal cancer screening.

Keywords
cancer, screening; Caribbean people; communication, doctor-patient; ethnicity; health behavior; immigrants; interviews, semistructured; Latino/Hispanic people; lay concepts and practices; risk, perceptions

For many types of cancer, Latinos living in the United States have higher mortality-to-incidence ratios and later-stage diagnoses than the general population (O’Malley, Gonzalez, Sheppard, Huerta, & Mandelblatt, 2003). Although colorectal cancer is the second most commonly diagnosed cancer among Latinos, studies repeatedly find that Latinos are less likely to obtain cancer screening tests (Felix-Aaron et al., 2005; Gorin, 2005; Gorin & Heck, 2004; Pollack, Blackman, Wilson, Seeff, & Nadel, 2006; Shah, Zhu, & Potter, 2006; Thompson et al., 2002). Recent data show that Latinos might also present at an earlier age with later-stage colorectal cancer (Stefanidis et al., 2006).

Differences in knowledge, attitudes, and beliefs might create barriers to colorectal cancer screening among Latinos. Previous study findings suggest that a higher proportion of Latinos have erroneous understandings of cancer (Tortolero-Luna, Glober, Villarreal, Palos, & Linares, 1995), and many have misperceptions about cancer that can impact their

Corresponding Author: Roberta E. Goldman, Center for Primary Care and Prevention, Memorial Hospital of Rhode Island, 111 Brewster St., Pawtucket, RI 02860, USA roberta_goldman@mhri.org.

Declaration of Conflicting Interests
The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.
preventive behavior (Morgan, Park, & Cortes, 1995). For example, Latina women are more likely to have fatalistic attitudes toward disease, a significant factor because fatalism might be a powerful correlate to lower rates of colorectal cancer screening (Gorin 2005; Huerta & Macario, 1999). Fewer Latinos had heard of colorectal polyps than non-Hispanic Whites (50% vs. 90%); more Latinos found performing fecal occult blood testing (FOBT) embarrassing (21% vs. 8% Whites); and Latinos were less likely than Whites to feel they needed to be screened even if they felt healthy (Walsh et al., 2004). Lack of health insurance and lack of sources of regular health care are known barriers to preventive health care and cancer screening among Hispanics and non-Hispanics alike (American Cancer Society, 2007; Shih, Zhao, & Elting, 2006). However, independent of socioeconomic factors, the use of colorectal cancer screening tests is consistently more prevalent among non-Hispanics (Meissner, Breen, Klabunde, & Vernon, 2006).

The purpose of this article is to address a gap in the literature regarding the social contexts of two specific U.S.-dwelling Latino groups that might impact their colorectal cancer screening behaviors. Specifically, we report findings regarding their explanatory models of colorectal cancer, perceived barriers to colorectal cancer screening, and uptake of colorectal cancer screening tests.

Methods

Theoretical Approach

The theoretical framework used in this study was based on a fields-of-interaction approach (Bourdieu, 1985; Thompson, 1990). Within each field there are specific social, economic, and cultural mores that serve as reference and informational sources for an individual. The sphere of interaction for the individual can extend beyond the identified domain, but frequently the scope of daily activity is confined by the parameters of the referential field. Our objective with this study was to identify how factors in the social domains of Dominicans and Puerto Ricans (two distinct Latino ethnic groups living in Rhode Island, with similar geographic origins but different legal status with regard to immigration) influenced perspectives about various cancers and cancer screening—including colorectal cancer, which is the focus of this article. A more detailed explication of the choice of Dominicans and Puerto Ricans for this study has been published elsewhere (Goldman & Ristica, 2004).

Research Design, Sampling, and Participants

For this qualitative study, semistructured interviews using open-ended questions were conducted in person with a total of 147 immigrant adults living in Rhode Island who self-identified as being of either Dominican or Puerto Rican ethnicity. The fields of interaction theoretical framework guided our selection of a purposive, stratified sample (Devers, 1999; Grbich, 1999; Kuzel, 1999; Marshall, 1996). The sample included the two ethnic groups, both genders, having or not having a spouse/intimate partner, and ages 18 and over, with an oversampling of people over age 40. We ensured that there was representation of people who had lived on the U.S. mainland for varying lengths of time, people living with and without children, and people who were employed and unemployed. Recruitment sites included varied community venues such as supermarkets, Latino social service and temporary employment agencies, community health fairs, Spanish-language radio, and Latino neighborhood streets. We excluded health care facilities to avoid biasing the sample toward individuals who had an existing relationship with a health care site (Bolen, Rhodes, Powell-Griner, Bland, & Holtzman, 2000). We believed we had achieved data saturation prior to concluding the 147th interview, but decided to continue through that point to ensure that the sample was balanced in terms of desired participant characteristics.
Participant Demographics

Participants included 74 women (49% Dominican; 51% Puerto Rican) and 73 men (52% Dominican; 48% Puerto Rican). Fifty-seven percent of the women and 63% of the men were at least 40 years old. More men (31%) than women (16%) were recent immigrants, having been living on the U.S. mainland for less than 5 years. The largest group (38% of women; 40% of men) had been living on the U.S. mainland for 5 to 15 years; 22% of the women had lived there for 16 to 25 years, and about a quarter of the participants had lived there for more than 25 years. The overwhelming majority of participants (89% of women; 95% of men) spoke Spanish as their main language at home, though two thirds of the women and about half of the men claimed to speak enough English “to get by.” More of the male participants were married (49% of men vs. 32% of women), in a consensual union (15% vs. 12%), or had a novia/novio (special girlfriend/boyfriend; 7% vs. 1%). Thirty-two percent of the women were single, compared to 10% of the men.

Women had somewhat higher education levels than did men, with the largest group having 7 to 12 years of schooling (63% of women; 58% of men). Eighteen percent of the women had less than 7 years of school vs. 29% of the men; and 19% of the women had more than 12 years of education vs. 14% of the men. More men than women were employed at the time of interview (50% vs. 24%), had health insurance (78% vs. 69%), and considered themselves to be healthy (74% vs. 61%). Regarding income security, 56% of the men stated that they had sufficient income for weekly basics, compared to 40% of the women. Of those who had sufficient income for basics, 54% of the women and 44% of the men stated that it was difficult for them to support their family/household.

Preparation for Interviewing and Familiarization With the Research Communities

Prior to developing the interview scripts, we spent a year conducting participant observation to increase our familiarity with the Rhode Island Latino communities (Goldman & Risica, 2004; Higgins et al., 1996). During this period we also met with 25 community leaders and professionals and formed the project advisory committee. Using an approach associated with community-based participatory research (Israel, Schulz, Parker, & Becker, 1998; Wallerstein & Duran, 2003), these individuals were involved in identifying and developing study questions, assisted with recruitment, and later participated in interpretation of the findings.

Data Collection

The overall interview script was designed to elicit participants’ perceptions of, attitudes toward, beliefs about, and experiences with health care and self-care, cancer, cancer prevention, and cancer screening. Colorectal cancer was one of four cancers addressed in the interviews; results regarding other cancers are presented elsewhere (Goldman & Risica, 2004). Questions were developed simultaneously in English and Spanish to enhance the appropriateness of Spanish phrasing. The complete interview guide is available from the corresponding author on request.

Interviews were conducted between October, 1998 and September, 1999 by gender-matched Latino interviewers. The 2-hour interviews were held in participants’ homes or in another community setting that afforded privacy. Interviews were offered in Spanish and English, but all participants, including those who said they were bilingual, chose Spanish. The hospital’s human subjects review board approved the study, and signed informed consent was obtained from each participant. Participants were given a $25 cash honorarium. Interviews were audiotaped and professionally transcribed.

Qual Health Res. Author manuscript; available in PMC 2013 February 28.
Analysis

All stages of data analysis were conducted with the original Spanish transcripts. Transcripts were read to acquire general familiarity with content and to isolate broad themes (Emerson, Fretz, & Shaw, 1995). Atlas.ti qualitative data management computer software was used for line-by-line coding (Richards & Richards, 1998). An initial, theory-driven topical code list was developed based on our preliminary knowledge of likely social field elements, our initial reading of the transcripts to identify broad themes, and our formative participant observation data analyses. The coding scheme, once designed, was formed along a number of topical cluster categories, yet remained flexible to accommodate new codes. Many sections of text were designated with multiple codes because the interview data in those areas of text were applicable to more than one social field.

Specifically, we were interested in noting the events and exposures from the multiple fields of interaction of participants’ lives (both past and present circumstances) that might contribute to their (then) current perspectives on health, illness, cancer and cancer prevention, and specifically, colorectal cancer and screening. For example, we used codes such as U.S. life, past, and legal to capture data about influences prior to immigration to, and during their life in, the United States. We used codes such as cancer opinion, cancer talk, cancer story, advice, and cancer hide to identify interview text addressing how participants formed their opinions about cancer, and where influences on these opinions were generated. Codes including gender, spend on health care, men, women, machismo, embarrass, and sex provided text segments for analysis regarding the influences of participants’ perceptions of appropriate and typical roles and behaviors of men and women. Codes regarding perceptions of disease risk and control drew from many areas of the interview, and included spirituality, supernatural, fatalism, control, fear, cancer inherit, cancer risk, sex, confusion, weak, food bad, food good, and environment. Comments regarding beliefs about disease and cancer prevention and the value of screening applied to a variety of codes as well as those specific to all the elements and types of colorectal cancer screening. Issues specific to screening logistics (ideological, logistical, economic, and so forth) were captured in codes such as screen—male barriers, screen—female barriers, facilitators—male barriers, facilitators—female barriers, and CRC screen.

The two coders (both Latinas) were extensively trained in the background and theoretical framework of the study, the coding process, and code definitions. Each coded the same subset of transcripts during training to ensure mutual understanding of codes and concordance in coding procedures. The principal investigator (the first author) supervised the coding process, met with the coders biweekly to review coded transcripts, and independently spot-checked coded transcripts for accuracy. Approximately 8,800 pages of typed transcript text were generated from the taped recordings. For organization and analysis we used an anthropological approach whereby the coding process was not intended to be an end result in itself; rather, it was only one logistical and preparatory stage of analysis that led to further analysis activities. The authors used the codes as data management and indexing devices to facilitate the retrieval of data on desired topics (Bernard, 2002). Subsequent examination of text that had been labeled with each code allowed intensive analysis on specific topics, which was informed by the broader, contextual perspective that had been gained from previous reading of the raw transcript data. Searches for alternative interpretations were conducted by additional review of the data, and discussed before final decisions were made about how to report and discuss the findings in the article.
Results

Overview of Findings

Following is the subset of findings from the large qualitative dataset specifically related to factors that appear to impact Dominican and Puerto Rican adults’ explanatory models for colorectal cancer, impediments to obtaining screening, and actual uptake of screening tests. It is notable that men and women of all ages offered similar perspectives about this little-known cancer, though for some factors and important themes there were differences by gender or age (younger or older than 40) regarding the level of familiarity with colorectal cancer, and the intensity or pervasiveness of certain opinions.

Explanatory Models of Colorectal Cancer

We asked participants: Are there things that happen to people, or things that people do that make it more likely that they will develop colorectal cancer? Many participants simply had no idea about this, having heard little if anything about this cancer. As a 39-year-old Dominican woman stated, “I couldn’t tell you what could cause colon cancer because they don’t talk much about this subject. Talk about other types of cancer is more common.”

Men and women over age 40 had more to say about what might cause colorectal cancer than did younger men and women. The most commonly identified explanatory category—sexual practices—was mentioned by both older and younger participants. Some participants cited sexual activity in general, with some clarifying that having too much sex leads to colorectal cancer. Others believed that colorectal cancer is contagious, claiming women get it from infected men or that men get it from prostitutes or “in the street.”

Likely because of the word rectal (or rectum) in the disease name, almost all participants who cited sex as implicated in colorectal cancer referred to anal sex, usually between men, but sometimes between men and women. Many participants who believed in sex-related causes used words that demonstrated their discomfort in discussing the topic. This was particularly true among women who believed that colorectal cancer risk was greatest with homosexual behavior. These women hinted around the subject before clearly stating their beliefs at the request of the interviewer. A 64-year-old Dominican woman noted, “I’m too embarrassed to say. Well, you know that now they use many ways to have sex; maybe I’m old-fashioned, but there are people who have sex back there, and it seems to me that that can be dangerous. I don’t know if I’m wrong.”

A 69-year-old Puerto Rican man explained, “You know how it is, you can imagine it. I’m not going to say it to you because my wife is over there, but there are men who like, oh, oh, to do it from behind.” Participants stated that from a moral and religious perspective anal sex is unnatural and should not be performed. They explained that the anus is not meant for sexual function and therefore anosexual acts lead to malignancy through a mechanism of anal injury and wounds that become infected, leading to colorectal cancer. A 37-year-old Dominican woman said, “Rectal sex—this is a risk because your behind part is made for leaving, not entering. So the vagina has the property to protect when the semen enters, but the anus no.”

Food was the next most commonly mentioned category of potential causes of colorectal cancer. There was a general notion of “bad food” among study participants, but many were not aware of specific food properties that contribute to colorectal cancer risk. Some participants stated that foods high in fat or hot spices might lead to colorectal cancer, and others mentioned alcohol, salt, low fiber, and coffee. A 71-year-old Puerto Rican man summed up this view: “We Hispanics eat bad foods.”
Women over age 40, some younger women, and men of all ages asserted that poor digestion leading to constipation and straining during bowel movements can cause colorectal cancer. The perceived mechanisms for this included that straining because of constipation results in cancer; that constipation and straining cause hemorrhoids, resulting in cancer; and that constipation causes feces to be retained in the body, leading to sickness and cancer. A 66-year-old Dominican woman explained, “The feces go from one day to two, and then it poisons the blood. Everything you eat—when all this is retained it contaminates the blood and from there comes the problem of cancer.” Finally, a few participants noted that people’s reluctance to go to the doctor to “get checked” puts them at risk for this cancer.

Perceived Barriers to Colorectal Cancer Screening

Participants’ discussion of colorectal cancer screening barriers was couched within a broader discussion of cancer screening, as participants’ familiarity with colorectal cancer screening modalities was minimal. Fear was the single most common category of screening barriers mentioned by men and women, regarding both their own sex and the opposite sex. Many female participants labeled men as cowards, claiming that men are far more fearful than women are, and this prevents men from seeking screening. Yet when female participants were asked what keeps women from procuring cancer screening tests, they mentioned fear even more frequently than they did when discussing men’s barriers. Male participants, for their part, stated that fear keeps women from screening, but their statements were more observational and less judgmental than were the women’s comments. The most common fear mentioned by either sex was that of finding out one has cancer, with the associated apprehension that a cancer diagnosis brings terrible physical pain and the end of one’s life. Some mentioned fear of the tests themselves. For men, fear and suspicion of the stigma and discomfort of the digital rectal exam (DRE) was specifically mentioned, as this is the exam most had experienced, often without forewarning from the physician. A 36-year-old Dominican man explained that many men are shy about having intimate medical exams, and that it would be helpful to them if they knew in advance what the physician planned to do and what the examination would assess:

It depends on the familiarity that one has with cancer. You see? If I don’t know that this exam exists and that this exam is done by this method of inserting a finger, well, if you just go to a doctor and the doctor says, “Eh, get yourself in position . . .” it’s a problem.

*Machismo*, defined for our purposes as the social construction of attitudes and traits recognized by members of a community as characteristic of men (Ramirez, 1999), was cited by both men and women as an influential factor in Latino men’s reluctance to undergo exams involving the rectum. Men were described by women of all ages as feeling invulnerable to illness, unwilling to get a test to see if they are sick, unwilling to see a doctor unless they have symptoms of sickness, and often disinclined to seek care even when they have symptoms. A 75-year-old Dominican woman explained:

*Machismo* is what impedes men from getting cancer tests. They don’t like to go to the doctor, or don’t have time for it. If you tell them to go they say, “Ay, what would I go there for?” You can see how the man acts: “No, I’m healthy and I don’t have to go to any doctor.”

A 37-year-old Dominican woman claimed that men avoid cancer screening because “It could be that it’s part of their culture: they are men, and maybe they just don’t think they get sick.” A 70-year-old Puerto Rican woman said, “It’s the machismo of the man that he doesn’t want to know if he’s sick.”
Many male participants’ opinions of other men supported the women’s comments. Men had additional explanations for how machismo diminishes their willingness to undergo rectal exams. Verguenza, or embarrassment connoting a sense of dignity mixed with shame (Diaz, 2001), was frequently acknowledged as a reason men would avoid a rectal exam, and a number of men said that to have such an exam would just be loco, or crazy. Some men explicitly associated the DRE with homosexuality. These participants were unwilling to undergo the exam because of fear of what it would mean for their masculinity if they had a DRE, and the associated stigma of the exam should anyone find out they had this exam. One 69-year-old Puerto Rican man who had been living on the U.S. mainland for more than 15 years explained how he has struggled with his attitude toward the DRE:

I’m not going to be macho like I used to be. I had the test two times and I haven’t changed. There are guys who are afraid of the finger, but nothing gives me fear. Those who are taken with fear have a complex. If one is a real man, you can have the finger inserted and still be the same afterward.

Verguenza was also the second most common reason that men and women indicated women were deterred from undergoing cancer screening. For women, verguenza revolved around exposing their naked bodies to the physician’s view and touch. For some older participants, verguenza diminished as they aged, although others claimed that being undressed in front of a doctor causes them more embarrassment as they get older. Some stated they would change doctors if asked to undergo an embarrassing test or exam. But despite the various discussions of verguenza, almost all participants said they would get a recommended medical test even if it disturbed them to do it. This stemmed from their prevailing views that although some tests were embarrassing, they were necessary for one’s health; procedures must not be regarded as embarrassing or humiliating if they are medical in nature. A 56-year-old Puerto Rican man believed that it would be “courting death itself” to neglect screening tests, and that many Latino men and women are in this situation. A 26-year-old Puerto Rican man stated flatly, “If [the test] is for me, sincerely if it is for my wellness, I’m interested because it’s for my health. Because God lost more than this, and God is not embarrassed.”

Both men and women also offered ignorance as a reason for not undergoing screening. For some, ignorance meant lack of knowledge, but for others it meant neglecting one’s health. This notion of neglect encompassed not worrying about one’s health, disliking medical visits and so avoiding them, assuming one will not get cancer, and women’s inattention to seeking care after their childbearing years. A 64-year-old Dominican woman said with disdain, “It’s gente bruta [thick-headed people]. The gente bruta that no more than think they can put a dab of menthol and ‘Ya, I’m all better,’ and a Tylenol, and keep on walking.”

Many participants confused testing based on symptoms (diagnostic testing) with screening for cancer, and considered it neglectful to avoid seeking care in the presence of symptoms. For some women, reluctance to be screened for cancer was a reflection of women’s priorities. They noted that whether it be because of verguenza or the busyness of their lives, women allow themselves to be “negligent,” “slovenly,” and “lazy” about their health and health care. A 24-year-old Puerto Rican woman explained that among the multiple reasons that impede a woman from getting health tests, “There are many women who are a little negligent. They don’t go to get themselves checked, and then when we do go and get tests, it’s very late.” A 51-year-old woman recounted,

There are conversations that I’ve heard. Some are embarrassed that [physicians will] see their parts. For some it’s that they’re tired; they’re just tired of going to the doctor and, I’m going to use the words that they use, to put in the finger.
Lack of health insurance and/or money was also recognized as a barrier to care, but this was not among the most frequently mentioned obstacles even though many participants lacked insurance and most had low household incomes. Faith healing and herbal healing were not mentioned by many participants, although there are a variety of such establishments in Rhode Island that are commonly frequented. As a 72-year-old Dominican woman explained,

It’s the ignorance that gets in the way because if you feel bad you have to go to the doctor. What will be, will be, but you have to go because the doctor is the only one who can make a person better. There are people who feel bad and they go to places with curanderos [faith healers] and such, and when you come to look at it [by a doctor] they’re already damaged.

Finally, some men and women were adamant that there are no good reasons for people to avoid getting screened. They explained that the problems of fear, machismo, and verguenza were issues that other people had but they themselves had overcome for their “own good” and for the sake of their health.

Colorectal Cancer Screening Uptake

The vast majority of participants had no experience with colorectal cancer screening, and few claimed to have had colonoscopy or flexible sigmoidoscopy. Many thought they recognized the interviewers’ description of the fecal occult blood test stool cards, but the majority said it was a test the doctor did in the office rather than one they did at home. Many men and women had received a DRE at least once in their life, although it was not their choice to undergo the test but rather an exam the doctor performed before the patients knew what was happening. A 70-year-old Dominican man explained, “Doctors have done this to me. Naked they placed me there to examine everything because this is included in the physical exam.” Some of the men associated the DRE with prostate cancer screening rather than colorectal cancer screening; however, most offered this as a form of colorectal screening that they had undergone.

Discussion

Colorectal cancer knowledge and screening rates in the United States are low across racial, ethnic, and economic groups, and particularly in the Latino population (Etzioni et al., 2004; Gorin, 2005; Ioannou, Chapko, & Dominitz, 2003; Shah et al., 2006; Shokar, Vernon, & Weller, 2005; Walsh et al., 2004). Codori, Petersen, Miglioretti, and Boyd (2001) found that believing that colorectal cancer can be prevented, and having a higher perceived risk, were associated with greater odds of screening. However, embracing these beliefs such that they override locally held explanatory models (Kleinman, 1981) or lay health theories (Shaw-Hughner & Schultz-Kleine, 2008) requires familiarity with the subject of colorectal cancer (Gorin, 2005), and colorectal cancer awareness among Latinos is minimal and fraught with misperceptions (Goodman, Ogdie, Kanamori, Canar, & O’Malley, 2006; Perez-Stable, Otero-Sabogal, Sabogal, McPhee, & Hiatt, 1994; Shokar et al., 2005).

Our results indicate that there are ideological and logistical challenges to overcome for colorectal screening rates to increase among Latinos, and that association with sexual stigma is paramount. Embarrassment is high for Latinos, particularly for men who feel that it threatens their sense of machismo. The impact of humiliating or embarrassing intimate exams on men’s sense of their masculinity has also been noted in other populations (Beeker, Kraft, Southwell, & Jorgensen, 2000; Kelly, 2009; Morman, 2000). This factor might be mitigated through increased understanding of the actual risks associated with this disease, and recognition that prevention is possible through screening (Gorin, 2005).
Latina women have seen improved rates of women’s cancer screening. The Papanicolaou test (Pap) has become normalized as an exam that most women know about and receive, and multiple entities focus on mammography awareness and outreach among minority women. It is unlikely that colorectal cancer screening rates will experience similar increases unless colorectal cancer testing becomes similarly normalized. Normalization in this sense would mean that even individuals who have not yet gotten the exam are familiar with what it is, know others who have been tested, and do not associate the need for testing with stigmatic behaviors. Physician referral for mammography (Bazargan, Bazargan, Calderon, Husaini, & Baker, 2003; Garbers & Chiasson, 2006) has repeatedly been shown to facilitate screening, and recently has also been shown for endoscopic examination of the colon (Christie et al., 2006). Because Latinos and other minorities are less likely to report having received a recommendation for colon endoscopy (Coughlin & Thompson, 2005), normalization for colorectal cancer screening might require establishing more routine referral mechanisms in primary care offices. This could include physician counseling tailored to addressing the concerns and risk perceptions of local patient populations (Hay, Coups, & Ford, 2006). Public media campaigns that address different populations’ risk perceptions can also contribute to enhancing screening for this cancer.

Increasing colorectal cancer screening among Latinos might pose greater challenges for physicians and public health campaigns than did screening for breast and cervical cancer. In addition to the barriers of cost, lack of insurance, and limited access to care demonstrated in other studies (Cristancho, Garces, Peters, & Mueller, 2008; Goodman et al., 2006; Shih et al., 2006), our research findings point to particular attitudes pervasive in Dominican and Puerto Rican communities, at least in Rhode Island. In this population, significant stigma is attached to colorectal cancer, and by extension, to colorectal cancer screening. Associations between colorectal cancer risk and anal sex were made pejoratively by younger and older participants of both genders. These associations have not been reported in the literature for populations other than Latinos, and even for Latinos, few studies have had this finding. Yepes-Rios, Reimann, Talavera, Ruiz de Esparza, and Talavera (2006) found that Mexican Americans perceived “male homosexual behaviors” to cause colorectal cancer, and Fernandez and colleagues (2008) noted that one participant claimed having sex in the “wrong way” could lead to developing this cancer. In addition, a study underway in Rhode Island with a population similar to ours found that in focus groups with Latinos, but not with non-Latinos, participants listed anal sex as a risk factor for colorectal cancer (Diaz, 2008). Maintaining this belief might lead Latinos to assume that if one does not engage in anal sex then one is not at risk for colorectal cancer, and thus does not need screening. Patients might be reluctant to follow physicians’ recommendations to get screened out of fear of how others might interpret the testing and judge them if it became known that they underwent the exams. For these reasons, even patients who choose to get screened might hide the fact from others, and in this way impede progress toward normalization of screening for colorectal cancer.

Social support and social ties have long been shown to be associated with Latina and other women getting Pap tests or mammograms (Fernandez, Palmer, & Leong-Wu, 2005; Larkey, 2006; Suarez et al., 2000), and have more recently been linked with non-Hispanics participating in colorectal cancer screening (Honda & Gorin, 2005; Kinney, Bloor, Martin, & Sandler, 2005; Wardle, McCaffery, Nadel, & Atkin, 2004). However, Larkey (2006) found that among previously nonadherent Latina women, an intervention with enhanced social support increased Pap screening and mammography, but it had no effect on colorectal cancer screening. Our findings among Dominicans and Puerto Ricans in Rhode Island indicate that until colorectal cancer screening becomes more common within Latino societies, the stigma associated with colorectal cancer might serve to diminish the positive effect social support would otherwise have.
Mainstream American public figures such as popular television talk show host Katie Couric, who televised her own colonoscopy in 2000 after her husband died at a relatively young age from colorectal cancer, and George W. Bush, who announced in 2002 that he underwent a colonoscopy to underscore the importance after age 50 of having the test, have contributed to public awareness about colorectal cancer screening. In the case of Couric, a study showed that her actions led to at least temporarily increased numbers of those getting screened (Cram et al., 2003). Similar public champions are needed for Latino and other ethnic minority, linguistically isolated communities.

Most of our participants claimed that despite anticipated embarrassment or discomfort, people should endure medical tests that are beneficial to their health. However, few had in fact undergone colorectal cancer screening. Recognizing and building on this prevailing attitude about medical care in Dominican and Puerto Rican communities might be a useful approach when educating Latinos about colorectal cancer screening.

The DRE is not an efficacious screening test for colorectal cancer, however physicians might still be using it as such, either in and of itself, or as a means to extract a stool sample for another suboptimal screening measure—the one-time, office-based FOBT (Collins, Lieberman, Durbin, & Weiss, 2005; Nadel et al., 2005). This could explain, in part, why many of our study participants had had a DRE. Latinos’ familiarity with this exam, therefore, could be used during screening counseling to serve as a stepping stone to facilitate counseling about receiving more effective colorectal screening measures. For Latina women, it might be useful to refer to their current understanding of the need for regular mammography and Pap testing when advising them to include another essential cancer screening for women of appropriate age.

A limitation of this study might also contribute to the study’s strengths: that is, that the study was conducted with individuals of Caribbean origin living in Rhode Island who self-identified as being from either of two specific Latino groups, Dominican or Puerto Rican. We purposively limited our population to these groups to avoid the error of combining the experiences of Latinos from widely diverse national backgrounds. However, because of this, the findings might not be applicable to people from other Latino groups, 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. However, as is appropriate for qualitative research design, the purposive stratified sample, recruited from a wide variety of public venues, ensured inclusion of individuals with the range of demographic characteristics relevant to this study.

In summary, there is much need of improvement in colorectal cancer screening rates in the United States, particularly among Latinos and other minority groups for whom rates continue to lag behind those of non-Hispanic Whites (Ata et al., 2006; Meissner et al., 2006; Walsh et al., 2004). Further research is needed to develop public awareness campaigns and individual counseling strategies that address the barriers to screening found within different population groups. At the same time, interventions to enhance physician referral in all underserved groups must also be developed as we work toward a comprehensive approach to normalizing colorectal cancer screening among Latinos and other minorities.

Acknowledgments

We thank the members of the community advisory board for their involvement in this project, and acknowledge the qualitative interviewers for the study: Pedro Baez, Raul Fortunet, Carolina Pichardo, and Lucia Tono. We also thank Pedro Pichardo for his expert transcription of the interview tapes in Spanish.

Funding
The authors disclosed receipt of the following financial support for the research and/or authorship of this article: This work was supported by a cooperative agreement granted by the U.S. Centers for Disease Control through the Association of Teachers of Preventive Medicine. Dr. Diaz is supported by a grant from the NIH/National Cancer Institute (KO7CA106780).

References


Devers KJ. How will we know “good” qualitative research when we see it? Beginning the dialogue in health services research. Health Services Research. 1999; 34(5 Pt 2):1153–1188. [PubMed: 10591278]


Diaz JA. Latino patients’ knowledge, attitudes, and beliefs about colorectal cancer. 2008 Unpublished raw data.


