

Barriers and Facilitators for Colorectal Cancer Screening Practices in the Latino Community: Perspectives From Community Leaders

Ana Natale-Pereira MD, MPH

Jonnie Marks PhD

Marielos Vega RN, BSN

Dawne Mouzon MPH

Shawna V. Hudson PhD

See next page for additional authors

Follow this and additional works at: <https://scholarlyworks.lvhn.org/medicine>



Part of the [Health Communication Commons](#), [Latin American Languages and Societies Commons](#), [Medical Sciences Commons](#), [Oncology Commons](#), and the [Race and Ethnicity Commons](#)

Published In/Presented At

Natale-Pereira, A., Marks, J., Vega, M., Mouzon, D., Hudson, S., & Salas-Lopez, D. (2008). Barriers and facilitators for colorectal cancer screening practices in the Latino community: perspectives from community leaders. *Cancer Control: Journal Of The Moffitt Cancer Center*, 15(2), 157-165.

This Article is brought to you for free and open access by LVHN Scholarly Works. It has been accepted for inclusion in LVHN Scholarly Works by an authorized administrator. For more information, please contact LibraryServices@lvhn.org.

Authors

Ana Natale-Pereira MD, MPH; Jonnie Marks PhD; Marielos Vega RN, BSN; Dawne Mouzon MPH; Shawna V. Hudson PhD; and Debbie Salas-Lopez MD, MPH



Barriers and Facilitators for Colorectal Cancer Screening Practices in the Latino Community: Perspectives From Community Leaders

Ana Natale-Pereira, MD, MPH, Jonnie Marks, PhD, Marielos Vega, RN, BSN, Dawne Mouzon, MPH, Shawna V. Hudson, PhD, and Debbie Salas-Lopez, MD, MPH

Background: Colorectal cancer (CRC) is the second-leading cause of cancer-related death in the United States and the third most commonly diagnosed cancer among Latinos. While Latinos represent one of the fastest-growing ethnic groups in the United States, their participation in cancer prevention and treatment trials is low.

Methods: Thirty-six Latino community leaders participated in five focus groups that examined factors affecting CRC screening practices among Latinos.

Results: The top four barriers identified were low knowledge and awareness of CRC, language barriers, lack of insurance, and undocumented legal status. Additional barriers included seeking health care only when sick, fatalism, fear, denial that CRC can occur, other needs more pressing than preventive care, and use of home remedies rather than biomedical care. Participants also described strategies that could be used to increase screening rates including mass media, screening reminders, educational programs using visual tools, and interventions tailored to various literacy levels.

Conclusions: To ensure that the specific needs and health beliefs of the Latino community are addressed, future research should incorporate community input to create more tailored and effective cancer educational programs for Latinos.

Introduction

Hispanics/Latinos represent one of the fastest-growing ethnic groups in the United States. In 2000, there were 35.3 million Latinos living in the United States, comprising 12.5% of the total population.¹ By 2050, this number is expected to grow to 102.6 million, or 25% of the population.² Like other minorities in the United States, Latinos experience poor health outcomes and are disproportionately affected by disparities in access to health care.³

From the Departments of Medicine (AN-P, DM, DS-L) and Family Medicine (MV, SVH) at the University of Medicine and Dentistry of New Jersey, New Jersey Medical School, Newark, NJ, and Public Health Productions, Cleveland, Ohio (JM). Submitted December 13, 2006; accepted June 14, 2007.

Address correspondence to Ana Natale-Pereira, MD, MPH, Division of Academic Medicine, Geriatrics, and Community Programs, Department of Medicine, University of Medicine and Dentistry of New Jersey-New Jersey Medical School, 30 Bergen Street, ADMC 614, Newark, NJ 07103. E-mail: natalean@umdnj.edu

Abbreviations used in this paper: CRC = colorectal cancer, CBO = community-based organization.

Colorectal cancer (CRC) is the second-leading cause of cancer-related death in the United States.⁴ Among Latino men and women, CRC is the third most commonly diagnosed cancer.⁵ It is also the second- and third-leading cause of cancer death among Latino men and women, respectively.⁵ Latinos in the United States have the lowest rate of fecal occult blood tests (FOBTs) (11.9% compared to 16.3% of whites and 16.4% of African Americans) and combined endoscopy/FOBT (29.9% compared to 44.2% of whites and 38.9% of African Americans).⁶ Although Latinos have lower rates of cancer incidence and mortality than other major ethnic groups,⁷ they tend to be diagnosed at later stages of disease, particularly for cervical, breast, and colon cancer.⁸

Given the disparities in screening and diagnosis, it is important to identify the factors that affect cancer screening rates in the Latino community. A recent study found that cancer screening rates are lowest among individuals who are

members of a minority group, have a low income level, have a low education level, and lack a usual source of care.⁹ Lack of insurance has also been found to be associated with lower cancer screening rates.¹⁰ Acculturation adds another layer of complexity: US residents born in another country often have the lowest rates of cancer screening.^{11,12}

Previous studies examining CRC screening have identified the following barriers that are common among all racial/ethnic groups: lack of awareness,¹³⁻¹⁷ lack of provider recommendation or information,¹⁸⁻²⁰ anticipation of pain,¹⁶ cost,^{17,19,21} fear,^{21,22} and embarrassment.^{17,19,21} However, barriers associated with CRC screening among Latinos is less commonly studied. Although this field is relatively new, research on other cancers has identified language barriers,^{17,23} fatalism,²⁴ and a fear of being seen as sick or weak²⁵ as barriers to cancer screening that are unique to the Latino population.

Because of the documented screening disparities among Latinos, the present study used focus groups to identify both the barriers and facilitators of CRC screening among Latinos, specifically as they relate to knowledge, level of awareness, culture, and health beliefs. This study represents phase I (needs assessment) of an intervention study to increase CRC screening rates among Latinos. Community leaders were targeted for this phase because of the large number of Latino clients they serve on a daily basis. Because of their contact with a wide range of Latino subgroups, we believed this would be an effective method of ascertaining the factors that affect CRC screening among the larger Latino population. The findings from this phase represent part of formative research to develop a culturally and linguistically appropriate multicomponent educational module about CRC for Latinos, which was subsequently implemented at each community site.

Methods

Five focus groups, each meeting for approximately 1 hour, were conducted to determine the factors that affect CRC screening practices among Latinos. A total of 36 Latino staff members from five community-based organizations (CBOs) in Newark, New Jersey, a predominantly urban community, participated in the focus groups. One focus group was conducted per CBO. All participants gave written informed consent to participate in the focus groups.

The participating CBOs have predominantly served the social needs of the local Latino community. Health care is only minimally delivered at these centers, primarily through the use of health fairs and basic prevention programs through the local health department. However, these sites are often the first stop for clients seeking health information and advice on health-related issues, and as such, they often become the gauge of health-related problems affecting the community.

These organizations address the social, behavioral, cultural, and spiritual needs of the Hispanic population and have meaningful insight into the needs of this population. Focus group participants were recruited from the leadership and workforce of each CBO, and they included community organization leaders, educators, case managers, social workers, and other employees. The majority of focus group participants were women (77.8%). Additional demographic information about the sample is shown in Table 1.

All focus groups were led by a bilingual Latina nurse facilitator. The group comments were audiotaped, transcribed verbatim, and translated into English by a professional translator. All focus group data were analyzed by an independent analyst. After several readings of the verbatim transcripts of the audiotaped groups, the analyst reduced the data by eliminating all material that did not address the research question. The data were then entered into NVivo (QSR International, Melbourne, Australia), a qualitative data analysis software package that supports a “grounded theory” approach. The analyst developed a coding scheme by extracting major themes expressed by the focus group participants and then coded each sentence according to this theme several times. Themes and conclusions were reviewed by the focus group moderator to ensure that they accurately reflected the data. This study was approved under expedited review by the Institutional Review Board at the University of Medicine and Dentistry of New Jersey-New Jersey Medical School.

Table 1. — Description of 36 Latino Community Leaders Participating in Focus Groups

	No. of Participants	%
Men	8	22.2
Women	28	77.8
Country of Origin		
Puerto Rico	13	36.1
United States	6	16.7
Ecuador	5	13.9
Brazil	4	11.1
Other	8	22.2
Education		
8 yrs or less	1	2.8
9–11 yrs	0	0.0
High school graduate	11	30.5
Some college or higher	24	66.7
Know someone with CRC		
Yes	8	22.2
No	28	77.8
# of Yrs Living in United States		
Mean	25.1	N/A
SD	13.0	
Range	11-65	
Age (yrs)		
Mean	40.9	N/A
SD	11.1	
Range	23-67	

Results

Demographic Profile of Community Clients

According to participants, their clients originate from several Spanish- and Portuguese-speaking areas including Puerto Rico, the Dominican Republic, Ecuador, Mexico, Colombia, Portugal, and Brazil. The CBOs serve people of all ages; however, staff members from two CBOs stated that at least half of their clients are over 50 years of age. Although the educational levels of the clients vary, participants agreed that the levels are often low and many clients can neither read nor write. Clients are usually employed in lower working class jobs such as cleaning or restaurant work. Many women care for their children at home while their husbands work outside the home. As one staff member summarized, “Economically, many of them have very insecure jobs. Many of them are undocumented and work on a per-diem basis.” Another describes clients’ socioeconomic status as “uninsured or undocumented (illegal) immigrants who are in constant fear of being deported from the United States.”

Participants asserted that most of their clients who have migrated to this area maintain customary practices, such as their diet and language. One participant said, “Most of them also want to preserve their culture when they come here, so it is a struggle for them because they want their children to grown up with American traditions but also not to forget their heritage. It is not easy for them.”

Barriers to CRC Screening

Participants identified many barriers to CRC screening in the Latino community. Table 2 presents these barriers and a quotation that illustrates a major theme associated with each barrier. The first four barriers — language, lack of health insurance, undocumented status, and little knowledge of CRC — were mentioned in all five groups and agreed on by many participants. Individuals in three of the five focus group identified additional barriers: (1) the idea that people don’t talk about CRC, (2) the low-perceived risk of CRC, (3) the low priority for CRC

Table 2. — Barriers to CRC Screening

Barrier	Illustrative Quote
Language	“Language is...a barrier because many times, when even we go into the hospital, you can see some people are very afraid because they cannot understand what is being said to them.”
Lack of health insurance	“I agree that, for most people here, the most significant barrier is the lack of insurance. People who live in this area are working to support families and usually don’t get health benefits, so anything related to prevention is just not a priority.”
Undocumented status	“I think that people know where they can go to get medical attention, but many are afraid, you know, because they may be illegal in this country. They are afraid to be deported.”
Little knowledge about CRC	“I would say that in the Hispanic community, especially for those who are new immigrants and who have lived most of their lives in a Hispanic country, they probably haven’t heard a lot about cancer of the colon.”
Don’t talk about CRC	“So, it is not something that you talk about all of the time. Something common as a heart attack, diabetes or something that we all are commonly aware of it.”
Low perceived risk of CRC	“...if you don’t know about something, you don’t think about the risk.”
Low priority of CRC	“You know, people have to deal every day with other things, and things that don’t put them at immediate risk are not a priority.”
Other health concerns	“Cholesterol, heart disease, asthma, but not that cancer.”
Seeking health care only if sick	“It is why many people, when they go to a doctor, it is already too late. They wait until they can’t stand the pain anymore.”
Fear	“You know the word itself [cancer] is very scary.”
Denial	“You know, that even if they know this disease, they would think that it would not happen to me.”
Fatalism	“...but they believe that if God is willing, things are going to happen and things will get better, thanks to God. If this is what God wants to happen, this is what happens.”
Low priority of biomedical health care	“We provide a lot of workshops, services, and things that help them, but they are living day by day, trying to survive, and even if they are not in that situation, they stay thinking that way. Even when they get or have a job, they still have the sense that maybe tomorrow I [they] won’t have the job, so they do not give the time to take care of themselves.”
No regular health care	“Yes, many of the people who come here do not have a doctor and do not know where to go to get these tests done.”
Instructions not clear	“Even for people who go to the doctor, they many times are not explained how to do things. They just have 3 seconds to be with the doctor and then they give you something and say ‘just do it at home and I’ll see you in the next visit,’ but you have no clue how to do it.”
Use of alternative health care	“In my culture, there are certain things that you just would not go to the doctor for, you know. They would use home remedies, you know.”

screening, (4) other health concerns, (5) fear, (6) unclear instructions from the doctor, and (7) use of alternative health care. The remaining barriers were mentioned less frequently, but participants did not disagree with them when they were cited.

Language: Language was the most prominent barrier mentioned in all focus groups. Participants noted several ways in which the health care system's failure to serve non-English speakers interferes with Latinos' seeking and obtaining health care, including CRC screening.

First, health care providers usually do not speak their patients' languages, and interpreters and translators are usually not available when such patients access care. As one participant said, "Sometimes they [Latinos] go to the hospital and they get very confused because they are asked questions in English and don't know how to answer them." Another complained, "I could not believe when my grandfather was for a few days hospitalized, we had to leave someone with him day and night because there was not one [doctor/nurse] who spoke Spanish to him." According to participants, at times, anyone in the vicinity who speaks Spanish is pressed into serving as an ad hoc interpreter, even though such practices violate patient confidentiality. For example, a participant related, "I went to the hospital about a year ago and had to help to translate something for a nurse. I just was sitting waiting to see the doctor and was asked if I could help to translate something for a patient. The nurse had heard us speaking in Spanish, so she didn't hesitate to ask me." Additionally, according to one participant, health care providers do not take the time to make sure their patients understand what has been said to them.

Second, information about diseases (including CRC) that is disseminated to the public through advertisements, billboards, posters, mass media, and public service announcements is usually in English. Thus, non-English speakers cannot act on this information and seek CRC screening. Furthermore, the instructions for screening tests are usually in English. For example, the fecal occult blood test (FOBT), a screening tool for CRC, is performed at home and requires one to avoid certain foods for several days and to obtain stool samples several times in a particular way. Such instructions can be complicated for fluent English speakers; for non-English speakers who have not been thoroughly instructed in the test by their health care providers, they may be impossible to follow. Furthermore, in another instance of the health care system's reliance on community volunteers to provide interpretive services, when CBOs offer health screenings, clients sometimes call the CBOs for help in understanding test instructions. According to one participant, "This can overwhelm us."

In response to the barrier presented by language, one participant said, "People or agencies who provide or offer services in general to the community should be

held accountable [responsible] to make it linguistically and developmentally appropriate so that the community can have access to it and understand it. Many times, the information is out there, but they do not understand it." The participant also emphasized the importance of tailoring information specifically to the intended audience. "Even when the information is in Spanish, sometimes it is in a Spanish that is very refined, and many of the clients do not understand it because they only know basic Spanish."

Lack of Health Insurance: Another common barrier noted by participants is lack of any or adequate health insurance. As one participant said, "I think that not having insurance is a big obstacle for them [the community] getting screened. People are also afraid of how much it will cost to get things done when they get sick. We have people who come here looking for help because they get big bills from the hospital and they cannot pay for it. We don't know how to help them at that point so they get discouraged about going to look for health care." These findings suggest that people will not be screened if the cost of the test (and the necessary treatment if a positive diagnosis is made) is beyond their means.

Undocumented Status: Participants told stories about how afraid undocumented Latinos are to put themselves in any situation that may expose their status. This poses a major barrier to screenings conducted in places and by people they do not trust. As one said, "They do come when we offer the services here. Women come to get their mammograms and Pap smears when the [mobile] van comes here, but that is because they know us and feel secure. Even if they are assured that in the hospital, they would not check their immigration papers, they just don't feel secure." Another reported that, "Even in the hospital where they said that by law they need to see you, the first thing that they ask you for is an ID and Social Security number." This fear can be crippling for many undocumented Latinos and is a major barrier to seeking health care.

Little Knowledge About CRC: According to focus group participants, most Latinos do not know much about CRC. As one participant said, "No, most people are very aware of other types of cancer, such as breast and lung cancer, because you hear a lot about them all the time. But cancer of the colon, you do not hear anyone talking about it." Several thought the only way people would know about CRC is if they knew someone who had it, or, according to one participant, "When they learn about it is when the doctor sends them to get a test done and then they appear with that [cancer]." Participants agreed that few community members have detailed information about CRC such as its rate of occurrence, risk factors, symptoms, and screening recommendations. Several pointed out that if the staff members themselves did not have much CRC information, it was

extremely unlikely that community members would know much. As one said, "If we [staff] don't know a lot, they probably know less."

Consequent to low levels of knowledge of CRC, participants stated that their clients do not talk about CRC and do not perceive themselves to be at high risk of developing this disease. According to participants, people do not talk about CRC because there is not as much information about it available in the Latino public sector (eg, on television) compared with other health problems. One participant mentioned another possible reason for not talking about CRC when discussing appropriate brochures: "Over here, where it says, 'Rompanos el silencio ('Break the silence'); it is very good because I noticed that in our culture, talking about defecation is very personal." Apparently, since CRC affects parts of the body and functions that are considered private, it is not discussed in this community.

Two participants attributed perceptions of low risk to lack of knowledge: "Well, if they do not know about it, they would not think that they are at risk." "[Participant] is right about that. I agree with this too. They have to be told and then they might think that they are at risk." Another added, "People also don't pay attention if they don't have any symptoms. If there are no changes in bowel movements, people are not going to get concerned." Additionally, one participant believed "that people sometimes think that if it doesn't run in their families, it is not going to happen to them. They don't think that 'I' can be the first one to develop it. They should be more educated." Participants continued by asserting that if people do not consider themselves at risk of developing CRC, they are unlikely to try to prevent or detect the disease.

Finally, participants expressed that CRC screening has a low priority among their Latino clients compared with other health concerns they face (eg, heart disease, diabetes, asthma). In addition, these conditions are more visible in the community and are therefore most likely to receive attention from community members.

Seeking Health Care Only If Sick: The focus groups also revealed that seeking preventive health care such as cancer screening is not a customary behavior for most Latinos. As one said, "I think that, a lot of times with a lot of our clients, especially among Latinos, we don't go to the doctor unless we are sick. We don't get tested unless we feel pain." According to another, "If you think about when people come here, many don't have health insurance so screening is not something that they would think about. Screening — you do it when you are feeling well and not sick." As a result, cancer can be advanced before health care is sought. One participant related her personal experience: "My mother didn't have any signs so she didn't go to see a doctor until it was [too] late." The complexities in their lives, with usually multiple jobs and no time to address dis-

ease prevention, along with limited knowledge of CRC, create additional barriers that are difficult to overcome.

Fear, Denial, and "Fatalism": Participants reported several attitudes common to their Latino clients that serve as barriers to screening. Participants mentioned four types of fear: fear of cancer itself and its diagnosis, fear of the consequences of cancer, fear of hospitals, and fear of medical mistakes. Any type of cancer diagnosis is feared. As one said, "People are afraid when they go to the hospital to get screened because they are afraid that they would be diagnosed with cancer." Experiences of others' suffering from cancer can also induce fear. For example, as one participant related, "My uncle got diagnosed with colorectal cancer and so all of us learned from what happened to him. He is very depressed; he gave up everything, even driving." Another participant cited a general fear of hospitals: "The other thing that I want to mention in terms of education is that sometimes, a lot of people fear the hospital, so for them, getting the information from the hospital is difficult because they do not associate themselves with the hospital." Finally, one participant mentioned that clients might be afraid of group screenings because people will worry that their tests have been "mixed up with someone else's test."

Another attitude — denial — was evident in the quote reported above that people do not think "it" can happen to them if CRC has not occurred previously in a relative. Additionally, Latinos' strong faith in God was emphasized by many participants. One aspect of this faith is often called "fatalism" in that people may believe that if God wants something such as CRC to happen, there is nothing one can do about it. Although such fatalism can be a barrier to screening, results presented in the "Facilitators" section suggest a more dynamic process.

Use of Alternative Health Care: According to participants, Latinos, particularly elders or those with elders in the home, are more likely to use home remedies rather than traditional biomedicine to treat illnesses. As one participant related, "My grandma said that she would pick up things such as plantain leaves and create something and it will work, so home is where people in some of our countries would find their healing instead of going to a medical facility. You would take care of what is happening to you. I don't say that it is all related to culture, but I think that it plays a part in how people make decisions about their health care."

Other Barriers: The relatively low priority for health care and difficulty accessing this care were also cited as barriers to screening. Participants maintained that clients have so many other issues in their lives that health care is not a priority, and many have no regular doctor or access to public clinics. One participant described clients' lives by saying, "Also, people have to work, and getting time off from work to go and get the

Table 3. — Facilitators of CRC Screening

Facilitator	Illustrative Quote
Desire for information and health services	"I agree, it is good to hear that you will be bringing this program to our community. I believe that if you tell people about colorectal cancer and give them all of the information that they need, they would get the test done."
Recommendations from health care providers	"You hear people always saying, 'the doctor said,' so that means that people do listen to their doctors, you know what I mean. Even if I tell them to do something, they would tell me, 'but my doctor said this is...'"
Multiple sources of trusted health information	"Where do you think that most people who come here get their health care information?" (Facilitator) "Wherever they can." (Participant)
Active role in health	"She always thinks that when you get sick, if you pray enough, God will listen and then will heal you."
Feasibility of FOBT	"I think that this can be easily disseminated by giving a clear explanation and telling them, you take it home, you do this, and then you throw it in the mail. It is not so bad. Who couldn't do that?"

tests done is not easy. They are afraid of losing their jobs. The jobs that they do are those in which they get paid by the hour. If they are not there, they do not get paid." Furthermore, even when health care is important to clients and they want to obtain services, barriers such as lack of transportation can impede them. People have to take two or three buses at times to get to an area of health care service. In addition, characteristics of the US health care system or of individual providers, such as the limited amount of time providers spend with patients to explain things to them, frustrate attempts to obtain health care.

Facilitators of CRC Screening

In addition to examining barriers to CRC screening, focus groups also discussed potential ways in which screening could be improved. A list of facilitators or factors that could be adapted and utilized to increase screening rates became evident from the discussion. Table 3 includes some facilitators and quotations from participants that express a dominant theme for each. The idea that their clients receive health information from multiple sources was mentioned in all five focus groups, and data from two focus groups indicate that Latinos also report receiving information from their health care providers.

Desire for Information and Health Services:

Focus group participants asked questions about CRC to the group moderator, who was a nurse. Among other things, they asked about screening recommendations, epidemiology, causes, risk factors, and symptoms, and they requested formal trainings on CRC. As one said, "We also need to get educated about it. We need to learn the same way our clients need to learn about it." This desire for information, though expressed by relatively "elite" members of the Latino community, was assumed to be present among the clients as well. A quote in Table 3 attests participants believed that the community would obtain screening if they were given appropriate information.

Recommendations From Health Care Providers: Participants maintained that their clients listen to their doctors and, if they take time to explain screening tests carefully and make sure patients understand, patients will follow through. Therefore, relationships with providers (and providers' recommendations for screening) are important facilitators of screening.

Multiple Sources of Trusted Health Information: According to participants, clients have many sources of health information they trust including mass media, religious leaders, health professionals, health fairs, CBOs, and, importantly, members of their social networks. As one participant stated, "When people know about something, they go and tell someone else and then that person will tell someone else." Media such as Spanish television, including "novelas" (soap operas), provide much biomedical information, though one participant said she had not seen anything dealing with CRC. Several participants mentioned that clients often ask their priests for information even before going to a doctor, although the reasons for this were not explained. One participant who is a priest said he felt equipped to provide health information, often referring his parishioner to a health care professional if necessary. In short, many trusted information avenues are available to Latinos, and the challenge is to exploit all available channels to deliver correct and compelling information about CRC.

Active Role in Health: Although health care practitioners and researchers often refer to "fatalism" or "external locus of control" to describe passive attitudes regarding one's ability to change fate (or God's will) in matters of health, this depiction might reflect a misunderstanding of how this actually operates in Latinos' lives. As noted above, one participant's comment about her personal experience revealed an active rather than passive role for individuals in their relationship to God: "My mother, when my father got very sick and he had to go to get a lot tests done, all she could do was to pray and pray. She always thinks that when you get sick, if

you pray enough, God will listen and then will heal you.” In other words, if a person prays hard, their actions might change God’s mind. This does not indicate passivity; rather it suggests that taking an active role to change one’s fate is possible and might be a highly valued behavior.

Feasibility of FOBT: Finally, one participant remarked that most clients were capable of using the FOBT if it was explained clearly, which is a necessary condition for completing the test.

Strategies to Increase Screening

The focus groups also spent time discussing different approaches to improve the screening efforts. Many strategies for overcoming barriers and supporting facilitators emerged from the discussions. Using CBOs was explicitly mentioned in all five groups, and affordable tests were mentioned in four groups. Strategies involving outreach, secure settings, and multiple teaching methods were noted in three groups. Table 4 lists these strategies and illustrative quotations.

Outreach: Given that there is little information in the media or in the Latino community about CRC, participants stressed that community outreach is critical so that patients begin to think about the disease. They suggested using mass media and placing brochures and flyers where people can pick them up. One participant said, “Let people know things such as

that colorectal cancer is the second-leading cause of cancer deaths. I didn’t know that and I would think that this is a strong statement. It will make people think about it.” Another said, “More advertisement will be helpful. You know, like what we see on television about breast cancer. More brochures or educational materials that we can give to the people who come here would at least start to get the information into the hands of the community.” Another offered, “Especially in the Spanish radio and television stations. Hispanics watch television here more than back home. I believe that it is a good way to make them aware of things such as colorectal cancer.”

One participant suggested using the newspaper to tell people about any educational programs for CRC. She said, “It is also important to let people know what is available to them. I mean, we advertised in the newspaper when the mammography van is coming. They do it for free. A lot people learn about it through the newspaper.” Flyers are also useful to tell people about programs and services. One participant said that they obtain good results by announcing new programs or services to clients when they go to the CBO for other programs.

Community-Based Organizations: Many participants stated that the best way to educate the community is through the CBOs rather than in the hospitals. The CBOs are known and trusted within the Latino

Table 4. — Recommendations to Increase CRC Screening Rates Among Latinos

Strategy	Illustrative Quote
Outreach	“There has to be better outreach to let people know about the things that you are talking [about] with us.”
CBOs	“...using community-based organizations or community agencies will serve as a ‘via’ [bridge], as a way to get the information out to the community more effectively, than if it comes directly from the hospital...”
Secure settings	“We cannot wait for them to go and get the tests done. It will not happen. We have to find a way for them to feel secure and bring the tests to places where they feel comfortable.”
Convenience	“It has to happen also during the times that they can come. I mean, if they work during the day, you have to offer programs during the night.”
Incorporate CRC into other CBO programs	“When we do the parents’ workshop, it will be good for us to incorporate 15 minutes to talk about colorectal cancer and, in that way, getting people to learn about it.”
Affordable tests	“Are these tests expensive? If they have to pay for them, they will not get them done. I guess that this is related to not having insurance, as we were talking before.”
Conduct formative research with community members	“They should use the community people to do focus groups like this one to get the information together and get them to give feedback on the information that it going to be put out in the community.”
Appropriate languages	“Do you have it in Spanish? If they cannot understand and cannot read in English, you can’t expect them to get it done.”
Tailored information	“I think both populations [educated and without education] need to be considered.”
Multiple teaching methods	“There are people who learn better listening, and there are others who learn better with visuals.”
Adequate information	“People need to know who provides the test, where do the results go. If you don’t have money to pay, where is the money coming from, and things like that!”
Ways to help people remember to do the test	“Yes, that can be a problem because you need to take three different samples in three different days. We need to find a way to help people not to forget.”

community. As one participant said, “We can help facilitate the process.” Referring to the priest at a church, she continued, “The parishioners believe in him. He can sell your product for you.” Other advantages of CBOs are that undocumented people feel secure at these facilities, and these organizations can offer educational programs at times that are convenient to their clients. Others suggested that incorporating CRC education into existing programs, such as parenting classes, might be a successful strategy since people may be less likely to attend programs devoted to CRC if they do not understand its importance. This strategy will allow clients to receive educational information about CRC before they are aware of its importance while attending a program on a topic that is a priority to them. Another participant indicated that CBO staff members could continue to educate the community if they were trained themselves. “I think that what they [researchers] need is to have workshops to teach them how to use the test, what you do, what are the symptoms, including training us to be able to provide them with information after those programs are gone, so we can continue having the workshops.”

Affordable Tests: As discussed above, people will not undergo screening if the test is not affordable, so it is critical to provide tests free of charge or at low cost. People must also know how to access affordable treatment if they receive a positive result.

Other Facilitators: Participants suggested that community members provide input into any educational programs so that they respond to their needs. In addition to having educational materials available in the languages that people actually use, participants emphasized that these materials must incorporate terms that “may not be nice,” but that are the terms that people from different areas use and understand. (Examples of appropriate terminology related to CRC were “excreta,” “defecación,” and “pupu” for stool, and “intestino grueso” and “tripas” for large intestine.) In the same vein, another stressed that merely translating materials correctly was not enough. According to her, “You should present the information in very simple terms so that they can understand the concepts. It is not just about translating something.”

Another participant pointed out that there is diversity within the community and that educational materials and methods need to be tailored to meet diverse needs. One participant said, “When people are waiting to see a doctor or to see us here, they should be shown a video that talks about cancer and why [it] is important to get tested. Some people cannot read or write, so they need to see something visually.” Another said, “For example, the people that I work with are more educated, so it will be great for them to learn about the anatomy and all that, but in terms of the people almost without any education, things have to be presented in very simple terms. They might not need to know about

the anatomy — just how to do the test and why it is so important to get it done.”

Discussion

Many of the barriers cited by focus group participants overlap and are consequences of a variety of underlying factors: clients’ minority, migrant, and/or undocumented status, in addition to their relatively low levels of education, employment, and economic resources. These are important social determinants of health affecting the community. Though addressing these society-level, structural issues is beyond the scope of this project, participants were optimistic about community strengths that could be leveraged, and they offered many strategies to overcome the seemingly daunting barriers.

The results observed in this qualitative study are important. First, they support the notion of perceived risk of CRC as a major barrier to screening, a finding that has been documented elsewhere.²⁶⁻²⁸ Our results are consistent with past research identifying lack of awareness,¹³⁻¹⁷ cost,^{17,19,21} and fear^{21,22} as common barriers to CRC screening among all racial/ethnic groups. However, this study extends beyond research by also identifying factors such as undocumented status, low priority of CRC screening (especially given other health concerns), the tendency to seek health care only when sick, and use of alternative health care as potential barriers to CRC among Latinos. Secondly, the findings suggest that religion and spirituality play important roles in transforming fatalism from a passive to an active process. The findings are also consistent with past research demonstrating the effectiveness of physician recommendation in the completion of CRC screening,²⁹ even among populations with low literacy rates.³⁰ Finally, this study emphasizes the active role that community organizations can play in the effort to reduce cancer health disparities through establishing and strengthening community academic partnerships.

This study has important limitations. First, the use of focus group methodology limits the generalizability of the findings. Focus groups are limited in time and scope. They limit the ability of researchers to keep responses confidential. As well, the social dynamics promote an atmosphere where socially desirable responses may be rewarded. Second, our focus group participants were leaders of community organizations who spoke on behalf of the larger community. Therefore, they were a level removed from the patients and community members whom we want to be involved in CRC screening. While this recruitment strategy deviates from the traditional method of focus group participant selection and might bias the reproducibility of the information, it yielded valuable discussion. Our focus was to understand the perspective of those who not only are members of the Newark community but also have direct con-

tact and are trusted agents of the larger population. Many people in the community go to these leaders for information and confide in them before they talk to anyone in the health care system. Therefore, their perspectives as opinion leaders are important.

Future research is needed in the following areas: (1) expanding our information about appropriate terminology, metaphors, and analogies to use when educating Latinos about CRC, (2) understanding ethnomedical ideas among Latinos about cancer causation, prevention, cancer treatment, and health and disease in general, (3) recognizing how Latino people combine traditional and home healing with biomedicine (medical pluralism), (4) studying religious ideas related to health and illness, (5) determining whether the observed differences in cancer beliefs vary across ethnic groups within the Latino population, and (6) evaluating the effectiveness of cancer control intervention programs for Latinos.³¹

Educational programs aimed at increasing CRC awareness and screening in this population will be successful only if the specific barriers and health beliefs of the Latino community are addressed. Results from qualitative studies such as these can be used to develop interventions to increase knowledge and awareness about the importance of CRC screening, in addition to the rate of screening and early detection among Latinos.

Disclosures

The project described was supported by Grant Number #5U01 CA86117-05 to Redes En Acción from the National Cancer Institute Special Populations Network. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Cancer Institute.

No significant relationship exists between the authors and the companies/organizations whose products or services may be referenced in this article.

The editor of Cancer Control, John Horton, MB, CbB, FACP, has nothing to disclose.

References

1. US Census Bureau. *The Hispanic Population: Census 2000 Brief*. Washington, DC: US Census Bureau; 2001.
2. US Census Bureau. *US Interim Projections by Age, Sex, Race, and Hispanic Origin*. Washington, DC: US Census Bureau; 2004. <http://www.census.gov/ipc/www/usinterimproj/>. Accessed October 3, 2007.
3. Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academy Press; 2002.
4. American Cancer Society. *Cancer Facts & Figures, 2006*. Atlanta, GA: American Cancer Society; 2006.
5. American Cancer Society. *Cancer Facts & Figures for Hispanics/Latinos, 2003-2005*. Atlanta, GA: American Cancer Society; 2005.
6. American Cancer Society. *Cancer Prevention and Early Detection: Facts & Figures, 2006*. Atlanta, GA: American Cancer Society; 2005.
7. Ries LAG, Eisner MP, Kosary CL, et al. SEER Cancer Statistics Review, 1975-2002. Bethesda, MD: National Cancer Institute; 2005. http://seer.cancer.gov/csr/1975_2002/. Accessed October 3, 2007.
8. Singh GK, Miller BA, Hankey BF, et al. *Area Socioeconomic Variations in US Cancer Incidence, Mortality, Stage, Treatment, and Survival, 1975-1999*. NCI Cancer Surveillance Monograph Series, No 4. Bethesda, MD: National Cancer Institute; 2003.
9. Swan J, Breen N, Coates RJ, et al. Progress in cancer screening practices in the United States: results from the 2000 National Health Interview Survey. *Cancer*. 2003;97:1528-1540.

10. Institute of Medicine. *Care without Coverage: Too Little, Too Late*. Washington, DC: National Academy Press; 2002.

11. Goel MS, Wee CC, McCarthy EP, et al. Racial and ethnic disparities in cancer screening: the importance of foreign birth as a barrier to care. *J Gen Intern Med*. 2003;18:1028-1035.

12. De Alba I, Hubbell FA, McMullin JM, et al. Impact of U.S. citizenship status on cancer screening among immigrant women. *J Gen Intern Med*. 2005;20:290-296.

13. Klabunde CN, Schenck AP, Davis WW. Barriers to colorectal cancer screening among Medicare consumers. *Am J Prev Med*. 2006;30:313-319.

14. Klabunde CN, Vernon SW, Nadel MR, et al. Barriers to colorectal screening: a comparison of reports from primary care physicians and average-risk adults. *Med Care*. 2005;43:939-944.

15. Shokar NK, Vernon SW, Weller SC. Cancer and colorectal cancer: knowledge, beliefs, and screening preferences of a diverse patient population. *Fam Med*. 2005;37:341-347.

16. Brouse CH, Basch CE, Wolf RL, et al. Barriers to colorectal cancer screening: an educational diagnosis. *J Cancer Educ*. 2004;19:170-173.

17. Goodman MJ, Ogdie A, Kanamori MA, et al. Barriers and facilitators of colorectal cancer screening among mid-Atlantic Latinos: focus group findings. *Ethn Dis*. 2006;16:255-261.

18. Gorin SS. Correlates of colorectal cancer screening compliance among urban Hispanics. *J Behav Med*. 2005;28:125-137.

19. Marks JP, Reed W, Colby K, et al. A culturally competent approach to cancer news and education in an inner-city community: focus group findings. *J Health Commun*. 2004;9:143-157.

20. Coughlin SS, Thompson T. Physician recommendation for colorectal cancer screening by race, ethnicity, and health insurance status among men and women in the United States, 2000. *Health Prom Pract*. 2005;6:369-378.

21. Beeker C, Kraft JM, Southwell BG, et al. Colorectal cancer screening in older men and women: qualitative research findings and implications for intervention. *J Commun Health*. 2000;25:263-278.

22. Li T, Nakama H, Wei N. Reasons for non-compliance in colorectal cancer screening with fecal occult blood test. *Eur J Med Res*. 1998;3:397-400.

23. del Carmen M, Findley M, Muzikansky A, et al. Demographic, risk factor, and knowledge differences between Latinas and non-Latinas referred to colonoscopy. *Gynecol Oncol*. 2007;104:70-76.

24. O'Malley AS, Renteria-Weitzman R, Huerta EE, et al. Patient and provider priorities for cancer prevention and control: a qualitative study in mid-Atlantic Latinos. *Ethn Dis*. 2002;12:383-391.

25. Bastani R, Gallardo NV, Maxwell AE, et al. Psychosocial factors that influence participation in colorectal cancer screening. *J Psychosoc Oncol*. 2001;19:65-84.

26. Codori AM, Petersen GM, Miglioretti DL, et al. Health beliefs and endoscopic screening for colorectal cancer: potential for cancer prevention. *Prev Med*. 2001;33:128-136.

27. Kremers SP, Mesters I, Pladdet IE, et al. Participation in a sigmoidoscopic colorectal cancer screening program: a pilot study. *Cancer Epidemiol Biomarkers Prev*. 2000;9:1127-1130.

28. Janz NK, Wren PA, Schottenfeld D, et al. Colorectal cancer screening attitudes and behavior: a population-based study. *Prev Med*. 2003;37:627-634.

29. Klabunde CN, Vernon SW, Nadel MR, et al. Barriers to colorectal cancer screening: a comparison of reports from primary care physicians and average-risk adults. *Med Care*. 2005;43:939-944.

30. Guerra CE, Dominguez F, Shea JA. Literacy and knowledge, attitudes, and behavior about colorectal cancer screening. *J Health Commun*. 2005;10:651-663.

31. O'Malley AS, Gonzalez RM, Sheppard VB, et al. Primary care cancer control interventions including Latinos: a review. *Am J Prev Med*. 2003;25:264-271.