BARRIERS AND FACILITATORS OF COLORECTAL CANCER SCREENING AMONG MID-ATLANTIC LATINOS: FOCUS GROUP FINDINGS

Objective: To examine patient and provider barriers and facilitators of colorectal cancer (CRC) screening among mid-Atlantic Latinos seeking care at urban primary care clinics and describe implications for the design of interventions in primary care.

Design and Method: Nine focus groups were conducted with 70 Latino patients and 27 primary care providers. Content analysis of focus group transcripts was performed using established qualitative techniques.

Results: Comments on CRC screening fell into 10 content areas: primary care site or provider characteristics (25% patient/21% provider comments); knowledge (18% patient/12% provider comments); cost/insurance coverage (10%/25%); attitudes (14%/7%); ordering of priorities (10%/11%); language (12%/7%); procedural issues regarding screenings (8%/10%); discrimination (2%/1%); and issues related to being a new immigrant (.2%/6%). Patient lack of understanding of the screening test procedures, inadequate knowledge about colorectal cancer, inadequate numbers of Spanish-speaking providers, and the cost of screening were most often cited as barriers by patients. Both providers and patients repeatedly mentioned the lack of funding and referral sources for colonoscopy as a key barrier to performing screening, even with lower-cost fecal occult blood tests, as colonoscopy follow-up would not be available. Patients favored receiving CRC screening recommendations from their usual continuity physician, but were open to receiving information on test procedures and indications from a Spanish-speaking health educator.

Conclusions: Efforts to improve funding and availability of colonoscopy for low-income persons could proceed in tandem with linguistically and culturally appropriate clinic-based efforts to improve CRC screening among Latinos. (*Ethn Dis.* 2006;16:255–261)

Key Words: Colorectal Neoplasm/Prevention and Control, Hispanic, Insurance, MeSH, Primary Health Care, Safety Net

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Introduction

An estimated 145,290 new cases of colorectal cancer (CRC) and 56,290 CRC deaths are expected in the United States in 2005. Colorectal cancer (CRC) is considered the second most common cause of cancer death. Regular colorectal cancer screening with early treatment can reduce death from the disease 4, however, CRC screening rates are low nationally: population estimates of a fecal occult blood test (FOBT) in 2002 were 17%–49%, and estimates of the rate of receipt of an endoscopy in the past 10 years were 24%–30%. CRC

Latinos are significantly less likely than non-Latinos to receive a timely home FOBT or screening colonoscopy. Nationally, only 9.8% of Latinos have had a recent FOBT, and 24% have had a recent endoscopy. Though Latinos have a lower incidence rate of CRC in comparison to White non-Latinos and African Americans, they have a similar age standardized mortality-to-incidence ratio for colorectal cancer. Latinos are more likely to be diagnosed at a late stage of disease and have a poorer prognosis than White non-Latinos. Though Latinos.

Most Latinos in the mid-Atlantic region come from Central and South America; this population is distinct from Latinos in the Southwest and in California who predominantly originated from Mexico. Central and South

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Americans are less likely to have a usual source of health care and to be insured.11 Most CRC prevention research on Latinos to date has focused on those from California, Texas, Florida, and New York. 11,12 To date, little to no research has been specifically focused on a Central and South American population and the barriers and facilitators they face regarding CRC screening. In one recent study of cancer screening among various Latino subgroups, FOBT rates for Central and South Americans were low (11%).¹¹ Central and South Americans were nearly half as likely to have an endoscopy to detect colorectal cancer compared to other Latino subgroups, which included Cubans, mainland Puerto Ricans, Mexican Americans, and "other" Latinos. The purpose of this study is to examine patient and provider barriers to the use of colorectal cancer screening among mid-Atlantic Latinos seeking care at safety-net, primary care sites. In addition, we discuss the implications of identified barriers and facilitators for designing interventions to promote CRC screening in primary care.

METHODS

Setting and Recruitment

This study was approved by the Medstar-Georgetown University Insti-

tutional Review Board (IRB) and by the clinics from which participants were recruited. Focus group participants were recruited by clinic research coordinators, nurses, and by flyers circulated at four primary care clinics serving Latinos in the metro-DC region. These clinics were selected because they provide primary care to low-income and/or uninsured Latinos and are part of the Latin American Cancer Research Coalition, funded as a Special Populations Network by the National Cancer Institute. The primary care providers at these three clinics combined see an average of 2000 unique Latino patients older than age 50 per year.

Focus Group Participants

Inclusion criteria for patients included: speaking Spanish or English, age >50 years, no history of CRC, use of the clinic for primary care or living in the immediate neighborhood of the clinic, and being able to give informed consent. Patient participants were reimbursed \$50 for their time and effort. Volunteers for the separate provider focus groups were selected to represent the various roles of clinic staff (physicians, nurse coordinators, social workers, intake persons, physician assistants, and nurse practitioners). To participate, providers had to have worked at one of the clinics for at least three years.

Conduct of Focus Group Sessions

The focus groups occurred between September and December 2003. Male and female patient focus groups were held separately. All six patient focus groups (three focus groups among women and three focus groups among men) were conducted in Spanish, in safe and convenient community settings, and clinic staff was not present at the patient focus groups. Each focus group lasted approximately two hours. The focus group moderators were bilingual, experienced, and age and culturally

matched to the patient participants. They used a moderator guide developed by the investigators that had been translated and back-translated. A series of open-ended questions was asked of participants to elicit feelings about and experiences with colorectal cancer screening (specific questions are available from the corresponding author). Visual aids (eg, FOBT cards) were shown to participants before discussing screening tests. No new issues arose by the completion of the third focus group for each gender, indicating saturation of themes. 13 At the end of each focus group, a demographic questionnaire was read aloud to participants in Spanish as they confidentially recorded their responses. Three provider focus groups were conducted in English, the providers' preferred language, by a physician-researcher moderator (ASO) and two assistants (MG, IP).

Development of Codes and Analysis

The bilingual, bicultural moderators performed verbatim transcription and then translation in context for each of the patient focus group tapes. Content analysis of the transcripts 13-16 from the nine focus groups was used to identify barriers and facilitators of colorectal cancer screening. Together, two reviewers identified and highlighted in the transcripts every codable unit of text (a statement that conveyed a singular idea). If the same person repeated a statement, it was only counted once. Initially, to avoid imposing any particular framework onto participants' comments, reviewers independently did inductive coding.¹³ The second phase of coding consisted of two reviewers independently re-coding each transcript by using the agreed-upon set of codes, their definitions, and coding rules. The two coders then compared the codes each had assigned independently. When coders differed on the code into which a unit of text fit, the constant-comparative method was used to come to an

agreement. The frequency that a theme was mentioned by different respondents, and the specific content area into which that theme fit, were then summed to identify the relative importance of each thematic area to the participants.

RESULTS

Participant Characteristics

A total of 27 men and 43 women participated in the patient focus groups. Their ages ranged between 50 to 80 years (mean 60 years). Sixty-one percent of patients were either married or living as married. All patients selfidentified as foreign-born Latino and were uninsured. Fifty percent of the women were from countries in South America, including Peru, Bolivia, and Colombia, while 29% were from Central America, including El Salvador, Honduras, and Guatemala. Most men (41%) were from South America, and 22% were from Central America. Consistent with the population served by the primary care safety-net clinics, most participants had incomes <\$20,000 (86%), and 61% worked either part time or were unemployed. Nine percent of participants had no formal school training, 44% had a primary school education, 30% had a high school education, and 16% had continued on to higher education such as college and university. More than 50% of the participants had dependant-care responsibilities at least part time, and all spoke Spanish as their primary language. Most of the patient participants had never undergone colorectal cancer screening: 81% had never had a colonoscopy and 78% had never had an FOBT. Of the 27 providers, 48% were Caucasian, 44% were Latino, and the rest were Asian or African-American. Seventy percent of providers were permanent employees, and 56% spoke both English and Spanish. Most providers were nurses or nurse practitioners (26%) and

physicians (26%). The rest included a health educator, diabetes program coordinator, medical assistants, case managers, receptionists, and referral specialists.

Major Content Areas

A total of 554 codable units of text (distinct comments capturing a single idea) fell into 10 different content areas. Table 1 lists these 10 content areas and the themes within each area by the frequency with which participants mentioned them.

The most prominent barrier to screening for patients and providers was the lack of funds for both initial screening and for follow-up. Patients repeatedly mentioned that cost of screening and, if needed, a colonoscopy was more than they could afford. Most patients stated that if funding were not an issue, they would be willing to have these exams. One woman, when asked if she would do a colonoscopy, stated, "I'd like to have it done, but I do not have the money." For the providers, the situation is even more problematic as they are serving an increasing population while undergoing budget cuts. The most pressing issue for the providers was that there were no funds for colonoscopies and few referrals for "free" colonoscopies for even their symptomatic patients. This issue created a disincentive for providers to screen with FOBT. As one provider stated, "There isn't a point [to doing FOBT] if you're not going to provide the colonoscopy to follow-up." Most of the providers were reluctant to set up an intervention to encourage people to start getting regular CRC screenings because the clinics lack the infrastructure and funds to handle an increase in demand for screening. Even an FOBT-based screening intervention was not acceptable to providers in the absence of funding for follow-up colonoscopy of abnormal FOBTs or a guaranteed list of available gastroenterologists willing to perform follow-up colonoscopy on the clinic's nonpaying patients.

Knowledge of test indications and the tests' sensitivity was also frequently mentioned as a barrier to CRC screening. Patients lacked a clear understanding of what a home FOBT was and how its effectiveness differed from that of an office digital rectal exam. Patient participants often did not understand age eligibility for CRC screening and the fact that CRC screening does not require one to be symptomatic. Some of the providers worked in a clinic with a designated health educator who explained the specifics of FOBT and colonoscopy procedures in person to patients. These providers, in particular, felt that patients had a much better understanding of these tests than providers in clinics where no health educator was assigned to this role. Health educator focus group participants stressed the importance of doing the patient education in Spanish and immediately after patient receipt of a provider recommendation for the test. Other differences in perception of barriers to CRC screening between different types of providers from varying disciplines, clinical functions, and clinics were not expressed.

Patients reinforced the importance of the delivery of health information to them in person and in Spanish. Patients also identified their problems with "medical English," stating that even if they do speak some English, they do not understand medical jargon, which creates a further barrier to screening. For example, in the focus groups, a few female patients were not familiar with the word "colon" or "intestine" and were not at all familiar with simple drawings of a person's digestive tract.

Participants also expressed fatalistic attitudes towards cancer. Most participants, both male and female, were fearful of cancer and of finding out that they may have cancer. Many participants saw cancer as a "death sentence." Similarly, the concept that one goes to

the doctor only when sick, and that Latinas (women) tend to put themselves last, ^{19,20} was acknowledged by patients and recognized as a barrier by providers.

Providers also mentioned the lack of guidelines and policies surrounding screenings in the clinics as a barrier. In addition, these resource-constrained clinics are struggling to keep up with the growing population and to prioritize issues of greatest urgency. Patients most often come to the clinic for acute care needs or for the management of chronic conditions such as diabetes, hypertension, and heart disease. Physicians stated that the people that they see at the clinic are "generally quite ill" and that when treating them, "you're really not that worried about colon cancer screening." Thus, CRC screening takes on a lesser importance than the care for chronic conditions. In fact, based on two recent random chart reviews conducted in 2001 and 2004 among patients over age 50 who had a visit to these same clinics in the past three years, 18% and 17% had ever received an FOBT, and 4% and 9% of patients sampled had received a screening colonoscopy or flexible sigmoidoscopy.²¹

Gender Differences Between Patients

Generally, men more often expressed confusion around test procedures for CRC screening, whereas women expressed more confusion about risk factors. More men than women expressed some embarrassment in completing FOBT; however, both expressed concern regarding colonoscopies in relation to perceived pain and embarrassment about the exam. In one focus group, men expressed their discomforts and taboos about colonoscopies through jokes about homosexuality. Several men stated that barriers to having these tests might be because of "embarrassment, machismo, and fear." When they were asked to elaborate by the moderator, they stated that this embarrassment "may be manly pride."

Table 1. Facilitators and barriers to CRC screening identified by Latino patients and their primary care providers, Mid-Atlantic, United States

Patient Theme (%)

• Specific themes (frequency)

Primary Care Site Characteristics 25%

- Organizational accessibility of clinics as a barrier (28)
- Patient-physician relationship and continuity of care with one's physician is important promoter (26)
- Insufficient primary care clinic infrastructure (personnel, space, data support etc) as a barrier (17)
- Personal attention from a concerned provider as a promoter (13)
- Poor follow-up from the GI sites as a barrier (1) (provider comments)
- Prefer CRC screening recommendation from doctor over other health professional (8)

Knowledge 18%

- Test indications and sensitivity; confusion between CRC and prostate cancer among men or between the pelvic exam and FOBT among women (49)
- Risk factors for CRC/symptoms and misconceptions about symptoms (19)

Cost/Insurance Coverage 10%

- Screening test (no funds for FOBT or colonoscopy)/clinic lacks FOBT cards (34)
- Follow-up or treatment if one has abnormal test (3)

Attitudes 14%

- Fatalism (41)
- Gender issues, machismo (13)

Ordering of Priorities 10%

- Lack of preventive orientation, only goes for acute care when one has symptoms ("descuido") (14)
- Laziness/mislaid card/forgot/no time (18)
- Trust in home remedies and use of natural remedies before doctor or if can't afford doctor (5)
- Triage on part of provider or of the patient (1)

Language 12%

- Spanish language is required for person giving me care or for information from clinic (40)
- Illiteracy (in both languages)/health literacy (4)

FOBT Procedural Issues 6%

- Embarrassment & discomfort handling stool/food restriction, preparation for FOBT, too complicated (10)
- Need better explanation from provider on how to do test (12)

Barriers to Colonoscopy (other than funding) 2%

 Pain/discomfort associated with prep for procedure; need better explanation (9)

Discrimination because Low-Income/Minority 2%

 Perception of different treatment if one is low-income; perception of ethnic discrimination (8)

Transitional Population of Recent Immigrants .2%

• Citizenship or legality issues (1)

Provider Theme (%)

• Specific themes (frequency)

Primary Care Site Characteristics 21%

- Organizational accessibility of clinics as a barrier (3)
- Patient-physician relationship and continuity of care with one's physician is important promoter (5)
- Insufficient primary care clinic infrastructure (personnel, space, data support etc) as a barrier (14)
- Personal attention from a concerned provider as a promoter (4)
- Poor follow-up from the GI sites as a barrier (8)
- No guidelines, or clinic policies concerning CRC in clinics as a barrier (4)

Knowledge 12%

- Test indications and sensitivity; confusion between CRC and prostate cancer among men or between the pelvic exam and FOBT among women (20)
- Risk factors for CRC/symptoms and misconceptions about symptoms (1)

Cost/Insurance Coverage 25%

- Screening test (no funds for FOBT or colonoscopy)/clinic lacks FOBT cards (35)
- Follow-up or treatment if one has abnormal test (10)

Attitudes 7%

- Fatalism (7)
- Gender issues, machismo (6)

Ordering of Priorities 11%

- Lack of preventive orientation, only goes for acute care when one has symptoms ("descuido") (10)
- Laziness/mislaid card/forgot/no time (4)
- Trust in home remedies and use of natural remedies before doctor or if can't afford doctor (1)
- Triage on part of provider or of the patient (4)

Language 7%

- Spanish language is required for person giving me care or for information from clinic (9)
- Illiteracy (in both languages)/health literacy (4)

FOBT Procedural Issues 6%

- Embarrassment & discomfort handling stool/food restriction, preparation for FOBT, too complicated (8)
- Need better explanation from provider on how to do test (1)
- Not as good as a colonoscopy (2)

Barriers to Colonoscopy (other than funding) 4%

 Pain/discomfort associated with prep for procedure; need better explanation (8)

Discrimination because Low-Income/Minority 1%

 Perception of different treatment if one is low-income; perception of ethnic discrimination (1)

Transitional Population of Recent Immigrants 6%

- No data from prior country on medical history (7)
- Citizenship or legality issues (4)

Most, however, asserted that despite their fears, they would have the procedure done if recommended by the doctor or if it was necessary. A few men stated that the barriers for getting screened include not having the time or money to perform the tests, especially given their work schedules. For men working in construction, maintenance and office cleaning, their hours and terms of employment are not conducive to clinic hours. A few felt that they would be risking their employment by taking time off to get screened; putting them in a position of having to choose between their income and their health.

Discordance between Patients and Providers

In most cases, patients and providers identified similar barriers to CRC screening. However, a few issues arose in which the two groups disagreed. Generally, patients expressed more willingness to perform home FOBT than providers had perceived them to have. Most patients stated that the procedure seemed simple and practical and was something that they "have to get done." Most were willing to have the test, provided that the instructions from the providers were given in Spanish. Patients also frequently mentioned that personal attention from the doctors and/or other healthcare providers would promote screening at the clinics, something that the providers did not mention.

Patients mentioned that they perceived discriminatory treatment because of their low-income status or ethnicity more often than providers. However, providers, more often than patients, cited problems with citizenship or legality as possible barriers to screening. Only one male participant in the focus groups stated that legal issues might hinder the receipt of CRC screening. Providers also cited the transitional nature of this immigrant population and the lack of patients' knowledge of

their family medical histories as a barrier to screening.

Facilitators of CRC Screening

As mentioned, patients generally expressed a willingness and openness to CRC screening methods. A few of the patients had positive attitudes towards screening test and prevention. Many of the patients expressed that the FOBT procedures did not seem too complicated as long as they were provided with clear instruction in Spanish on how to do the test.

Information sources that both patients and providers saw as facilitating screening were: health fairs, community centers, clinics, and churches. Women generally preferred to receive information through discussion groups and presentations, while men preferred written materials in the form of brochures. newspapers, and radio. Male participants suggested that health providers should employ women to educate their husbands, fathers, and brothers. One male stated, "Wives have influence over them [husbands/males]. They will press them, insist and convince them and their family members." One physician had a similar comment stating that he "gets the spouses after them." Other popular methods of obtaining health information were the primary care clinics, local notices and flyers, radio, and television. Mailings from doctors and clinics received mixed comments; most participants and providers agreed that mailings are not likely to be helpful. Neither patients nor providers mentioned the use of computers or the Internet as a source of health information for this low-income population.

DISCUSSION

This qualitative study of patient and provider focus groups identified numerous barriers and facilitators to colorectal cancer screening among low-income Latinos living in the metropolitan Chief [barrier] among these is the lack of adequate funding and providers for colonoscopy.

Washington, DC area. Chief among these is the lack of adequate funding and providers for colonoscopy. Other low-income groups share this barrier. In a separate study of low-income African Americans in Washington, DC, primary care providers were similarly reluctant to recommend FOBT for their patients, since colonoscopy was not available for the follow-up of abnormal FOBTs. ²²

Another financial barrier is the lack of adequate resources to operate organizationally accessible primary care clinics for a growing, low-income population. Patients identified after-hours office visits and reducing waiting time for an appointment as areas for intervention. Patients' lack of basic knowledge and awareness about CRC screening was also a commonly mentioned theme, especially around indications and eligibility for CRC screening. Attitudinal barriers frequently mentioned were fatalism and gender-related issues (machismo among men). Participants felt that education around CRC screening, especially around FOBT procedures, clearly need to be delivered in Spanish if it is to effectively reach this

Our participants mentioned embarrassment about FOBT and colonoscopy, and participants in a California study found this barrier to be even greater among Latinos than in other ethnic groups. Our participants had low awareness of CRC screening indications and did not understand that one did not need to be symptomatic to get screened. The California study identified a similar lack of awareness and also found this knowledge gap to be more prevalent among Latinos than among other ethnic groups.

Similar to findings in a study of low-income African Americans and Latinos in New York City, we found that patients had an interest in participating in colorectal cancer screening, once the methods of performing these tests and the fact that they met eligibility for screening were explained to them. ²⁴ Our participants, like those of this other study, also felt that because they were low-income, CRC screening was not raised as a topic with them during their encounters with healthcare providers.

Limitations

Research questions were investigated through focus groups and qualitative analysis. Such methods, if mindful of established standards, can yield well-grounded, rich, and detailed data; however, we cannot ascertain their generalizability. Second, qualitative data are subject to researcher bias. Use of three independent raters in this study and careful attention to coding with established methods should have minimized this potential bias. Strengths of this study include its attention to an understudied but vulnerable group, low-income Latinos in the mid-Atlantic United States. Examination of both patient and provider perspectives is another strength, in that it permits triangulation of themes to identify areas around which feasible interventions may be built.

Implications for Interventions and Policy

Educational efforts directed at Latino patients need to be increased and to focus on indications for screening. They must also address cultural barriers of fear, embarrassment, and fatalism. Participants in our focus groups stressed inperson education as preferable to written forms of education. While little research has been done on CRC interventions for Latinos, the breast cancer screening literature shows that in-person, tailored and theory-based educa-

tional messages have been effective at increasing mammography rates. ^{25,26} Efforts to examine the efficacy of similar in-person, culturally appropriate educational interventions for CRC screening among Latinos are warranted.

While providers may feel that their hands are tied in terms of the limited availability of colonoscopy, educational efforts can still target providers. Awareness of CRC screening among primary care providers is high, but knowledge gaps still exist around issues of timing and evidence-based modes of delivery.²⁷ In light of the low rates of FOBT screening in these community clinics, providers can be targeted by academic detailing efforts around the high-quality (randomized controlled trial) evidence of the effectiveness of FOBT. Providers can also be encouraged to work in concert with patient navigators and social workers to coordinate followup colonoscopy. Efforts to develop formal CRC screening guidelines within each clinic can be facilitated by existing and freely available materials from the Centers for Disease Control and Prevention (CDC)'s "A Call to Action" website. This site is geared toward improving primary care providers' awareness and use of CRC screening.²⁸

Given the resource constraints in safety-net clinics and the need to prioritize efforts during the patientphysician encounter, a logical intervention that addresses the language and cultural needs of Latino immigrants is the use of a combined physician/ health educator approach. In one of the clinics from which our participants were drawn, the physician would make a verbal recommendation to the patient that a CRC screening test was needed. The physician would then introduce the patient to the bilingual/bicultural health educator who explained the reasons and procedures for a screening FOBT on an individual basis. The health educator also provided short and informal educational talks in the clinic waiting rooms while patients were attending their appointments. During this time, the health educator was available to the patients to answer questions about CRC screening in a comfortable setting. Providers and patients from this clinic reported high satisfaction with this approach. Such an intervention can minimize demands on the clinician's time as well as deliver patient education in an acceptable, tailored, and interactive format.

While patients and providers in theory were willing to receive and prescribe CRC screening, this willingness in reality has been diminished given the financial barriers. Guidelines for regular screening need to be implemented at the clinics, but clearer guidelines or establishment of formal screening policies is likely to be insufficient in the face of limited funding and referral sources for colonoscopy. Networking between community clinics and providers of colonoscopy needs to be facilitated to provide a larger pool of available referrals for colonoscopies. In 2000, CDC began a national assessment of the capacity to perform CRC screening and follow-up in the United States. Data collection for year one states has been completed, and preliminary results on CRC screening capacity have been published. 29-31 Capacity for widespread screening with FOBT exists, but creating capacity to screen with sigmoidoscopy or colonoscopy could take 10 years.³¹ However, these studies do not take into account issues regarding access to health care for Latino patients, such as language, insurance, cost of screening, and other cultural barriers. Armed with the information from the national assessment and from research such as outlined in this paper, national and state efforts to plan more equitable CRC screening availability need to be undertaken.

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