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Understanding Factors Related to Colorectal Cancer (CRC) Screening Among Urban Hispanics: Use of Focus Group Methodology

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Abstract

Colorectal cancer (CRC) is a major cause of cancer deaths among US Hispanics. Screening decreases mortality through early detection. To understand factors related to CRC screening among Hispanics, focus groups were conducted. Reasons for getting screened included peace of mind; influence from family and friends; and wanting to prevent CRC. Barriers included fear of finding cancer and fear of the examination. These results informed a survey to better understand CRC screening among Hispanics in a cross-sectional study. The information from both will direct the development of interventions to increase CRC screening among Hispanics.

Keywords

Colorectal cancer; Focus groups; Hispanics

Introduction

Hispanics are the fastest growing minority group in the USA [1]. In East Harlem, New York (the study location), Hispanics comprise close to 61% of the population. Colorectal cancer (CRC) is the third leading cause of cancer death among Hispanic women and ties with prostate cancer as the second deadliest cancer among Hispanic men [1]. A key and modifiable way to decrease mortality from CRC is to increase rates of CRC screening and early detection. Indeed, CRC screening with colonoscopy allows for the prevention of CRC. Clinical research indicates that a substantial number of CRC deaths could be prevented through appropriate screening followed by relatively simple surgical procedures to remove polyps before they become cancerous [2]. Unfortunately, the majority of Hispanics do not get screened for CRC. Hispanics' adherence to screening recommendations for CRC is lower than that of Whites or Blacks [3]. For example, in 2007, the New York City Department of Health and Mental Hygiene (NYC DOHMH) reported that the percent of Hispanic New Yorkers 50 years of age

and older who have had a colonoscopy, lags behind that of Whites, with 51% of Hispanics as compared to 57% of Whites and 55% of Blacks [4]. All the more troubling is that CRC screening rates are low even for Hispanics who receive routine medical care and, thus, do not count this as a barrier to care [5]. The rates of CRC screening among Hispanics are low in contrast to their rates of screening for other cancers. The NYC DOHMH report also suggests that the rates of Hispanic women receiving mammograms and Pap tests (78% and 84%, respectively) are not very different from the rates of White women receiving these tests (74% and 79%, respectively). These data suggest that the low rates of CRC screening among Hispanics do not stem from a universal tendency to forgo cancer screening or from a lack of access to care. Rather, there seem to be barriers related specifically to CRC screening among Hispanics. Understanding these culture-specific barriers and then developing interventions to increase CRC screening in Hispanics is warranted.

Screening guidelines for CRC are complex, with seven different exams from which to choose [6]. Overall, however, the American Cancer Society et al. conclude that structural screening tests such as flexible sigmoidoscopy and colonoscopy should be used because they have the potential to both detect and treat CRC [6]. Furthermore, given that many cases of CRC occur at sites beyond the reach of the flexible sigmoidoscopy, increased screening by colonoscopy will save lives [7]. Colonoscopy is now considered the gold standard for CRC screening [8]. While barriers to CRC screening in other minority groups, such as African Americans, have been explored, there is little reported on understanding why Hispanics have such high rates of non-adherence to this proven method of cancer prevention.

This research study was designed to learn more from Hispanics that seek primary care at one of three healthcare centers in the East Harlem neighborhood of Manhattan, New York. The overall study will be conducted in two phases. Phase one, the focus of this paper, consisted of nine focus groups. Their purpose was to gain a better understanding of the factors (both barriers and facilitators) that affect the decision, by Hispanics, to have (or not have) screening colonoscopies. In phase two, we will use this information to design an assessment battery that could, with more detail, assess culturally specific factors in a larger sample of Hispanics. Ultimately, the findings from both study phases will contribute to interventions designed to increase the rates of CRC screening for Hispanics.

Previous research has shown that one of best predictors for colonoscopy adherence is physician referral [9,10]. However, as seen in our own work, only 40% of the patients who were both referred for a colonoscopy at our institution and assisted by a professional in the navigation of the healthcare system (e.g., making appointments, explaining the preparation) completed their colonoscopy [5]. In other words, neither having a primary care physician nor receiving a referral for a screening colonoscopy guarantees completion of the procedure. Through qualitative research, we sought to better understand the factors that prevent Hispanics from undergoing screening colonoscopies, as well as those that motivate them to complete the exam.

Methods

Focus Groups

Focus group methodology was chosen for the first phase of the project, as it is a well-established tool for understanding issues relevant to a population [11] and because it increases the validity of research findings [12]. The focus groups were used to corroborate previously researched barriers and facilitators to CRC screening among Hispanics, as well as to suggest additional factors that need to be included in the second phase of this study, a quantitative, community-based survey. The groups were conducted in either Spanish or English depending on the participants' preferences.

Recruitment

We initially planned to conduct six focus groups, with ten participants in each, organized by gender and nationality (Dominican, Puerto Rican, and Mexican). Recruitment was conducted by a bilingual health educator and took place at three East Harlem sites: two healthcare clinics and one social service community organization that also provides healthcare services. However, recruitment proved more difficult than originally expected, and we did not meet our original recruitment numbers. Over the course of 1 month, at a rate of about 2.5 h/weekday, we spoke with 67 interested and eligible community members. They were informed of the focus group process (including that the groups would take approximately 2 h), the research aspects of the project, and that they would be reimbursed \$40 for their participation in a focus group. If they agreed to participate, they were asked for their names, a phone number at which to contact them, and a Hispanic nationality of association, e.g., Dominican, Puerto Rican, etc. Of the initial 67 interested people, only 35 participated in the scheduled focus groups.

At each of the recruitment sites, the interaction with potential participants was a balance between adequately answering questions and confounding future focus group findings. The goal was to be clear about the purpose and content of the study, specifically addressing the role and projected commitment of the interested party, without providing too much information about CRC and colonoscopy, two topics that would be covered in detail during the focus groups. Only if the potential participant was clearly disinterested in participating—i.e., he/she did not give us any contact information or he/she expressed disinterest—did the recruiter then offer standard (e.g., NCI, CDC) educational brochures about colorectal cancer prevention.

The Sites

IMA—Located on Mount Sinai Medical Center’s campus in East Harlem and affiliated with the Mount Sinai School of Medicine, Internal Medicine Associates (IMA) is a health clinic that provides a general internal medicine practice to a predominately Hispanic and Black or African American population. Because of its proximity to, and affiliation with, the Mount Sinai School of Medicine, IMA has a rich history of education and research. This history, along with the relevance of this study to its patient population, made the clinic an ideal setting for recruitment.

IMA providers were informed of the study and criteria for participant eligibility. If the provider deemed his/her eligible patients appropriate to participate in the focus groups, the provider informed the patient by way of an IRB-approved recruitment flyer that had contact information or by directing the patient to the study recruiter, who was positioned in the lobby of the clinic. The environment within the clinic permitted the recruiter and the clinic’s patrons to interact freely and informally.

SH—As a primary healthcare center, Settlement Health (SH) has been providing services in East Harlem since 1977. Its location, close to several medical centers, including Mount Sinai, has made it an ideal setting for outreach and research recruitment. Clinic management was supportive of our goals because of its continued support of public research and education and because of its support for the Hispanic communities of East Harlem and throughout New York City. Medical providers were informed of the study and asked to refer their participants to recruitment staff located just outside of the waiting area of its Adult Primary Care Clinic, where there was the heaviest flow of potentially eligible patients, i.e., patients over the age of 50.

LSA—In addition to the traditional health clinics, we recruited participants from a social service organization that provides health services in East Harlem. Originally established in 1958 to provide nursing care to poor families, Little Sisters of the Assumption Family Health Services (LSA) has grown to be a comprehensive source of “physical, emotional, educational,

and spiritual” care for Hispanic families in East Harlem (<http://www.littlesistersfamily.org>). Recruitment at this venue proceeded differently than at the other venues. A staff member at LSA felt that due to the relationships that she and the organization had with the majority female patients/clients, she would have more success recruiting participants for us. In addition, she wanted to help us meet our goals. She merely asked how many people we needed and on which date and time, and she was able to successfully recruit participants.

Instruments

Based on the available screening colonoscopy literature, an outline of topics was constructed to guide the focus groups (available from LJ). As recommended by Krueger [11], these topics became the guide to help solicit information about the barriers and facilitators that Hispanics encounter regarding CRC and screening colonoscopies. The guide was designed to gather both information about the focus group participants’ experiences with screening colonoscopies as well as broader perspectives about screening colonoscopies in their Hispanic communities.

Health behavior research shows that one’s belief in a higher power (e.g., God) plays a role in his/her health decision making [13–15]. Similarly, health behavior is determined by one’s beliefs about prevention (fatalism); what he/she knows about CRC and colonoscopy (knowledge); the influence of family and friends; the relationship with a primary care provider; fear; previous experiences in health care and with cancer; and trust in the healthcare system. The guide covered each of these topics.

In addition, an educational component was incorporated into the focus group guide. Study staff determined that the discussion would be stymied if the participants did not have some understanding of the colon, CRC, and colonoscopy. A rudimentary explanation of these topics was the best method of putting all of the participants on a somewhat even playing field, without biasing their conversations.

Participants also completed a sociodemographic questionnaire that included questions regarding age, income, marital status, race, ethnicity, income, education, insurance status, and relationship with primary care provider. The average group size was 3.5 persons (range 3–8), with each lasting approximately 2 h. At the beginning of each group, the participants signed informed consent and HIPAA documents. The focus group facilitator reviewed the documents with the participants and gave them copies (in either Spanish or English) to take home. A light meal was also provided at each session. And at the end of each group, the participants were given \$40.00 as compensation for their time.

Results

Thirty-five participants participated across nine focus groups. Groups were organized by gender and colonoscopy-screening status (except for the group conducted at LSA, which had both screened and unscreened participants), with a total of five female groups and four male groups. Twenty-three Hispanic women participated in the focus groups; the 12 previously screened women were, on average, 61.3 years ($SD = 7.1$ years) of age. The 11 previously unscreened female participants were, on average, 59.8 years ($SD = 7.8$ years) of age. For the 12 Hispanic men, the six previously screened men averaged 62.2 years ($SD = 6.6$ years) of age, and the six previously unscreened men averaged 70.3 years ($SD = 2.8$ years) of age. Although we did not reach our original recruitment goal of 60 participants, with an equal number of Puerto Ricans, Dominicans, and Mexicans, our sample came close to mirroring the population of Hispanics in East Harlem (Table 1).

As noted earlier, a primary goal of the groups was to understand the factors related to undergoing CRC screening as a preliminary step to developing effective interventions. Factors

were categorized as facilitators or barriers. Facilitators—ideas, thoughts, and behaviors that helped people get screened—are shown in Table 2. These nine topics were endorsed in at least half of the nine groups. A key facilitator that arose in all nine groups was *peace of mind*, the idea that having a colonoscopy would confirm CRC status. However, this was also endorsed as a barrier in the groups, often expressed as the fear of having cancer and getting sick. Eight of the nine groups also expressed that *the role of the physician*, including trusting one's doctor and having good communication with one's doctor, is an important component.

Table 3 shows the barriers to getting a colonoscopy. It is important to note that *ignorance about the colonoscopy procedure* was endorsed by all the groups. Close behind was *mistrust* (endorsed by eight of the nine groups), both of the physician and the healthcare system overall. Seven of the groups noted *fear of the exam* (e.g., pain) and *lack of time* (e.g., not being able to miss work) as barriers. Six of the nine groups noted *embarrassment* (e.g., discomfort with nudity). Also seen as barriers by more than half of the groups were *not having symptoms* (e.g., I feel fine); *not having the means* (generally financial) to having the exam; *inaccessibility* (e.g., hard to schedule the exam); and *myths* (e.g., anesthesia not being used).

Discussion

We were successful in recruiting male and female Hispanics to participate in focus groups, which bettered our understanding of the barriers and facilitators to having a colonoscopy. A diverse group of Hispanics, matching the demographics of our community, participated.

We attribute our recruitment success to the participating community health clinics and community-based organizations, which supported our efforts willingly and energetically. They appreciated that this research was aimed at learning more about the Hispanic communities that they serve. In fact, the leaders at IMA, SH, and LSA were eager to learn more about the barriers and facilitators to screening colonoscopies for their own clinical services. As primary care providers, the members of these organizations concern themselves with bridging the gap between their services and the specialty care of other community providers. This is especially important in light of the facts that CRC can be deadly, even though it is preventable.

On many levels, the support, or buy-in, of the community health providers was essential. On an organizational level, this project helped to strengthen the relationship between Mount Sinai and these community-based organizations. On a community-level, it helped the Hispanic community and the East Harlem community as a whole, by linking resources and, consequently, making them more accessible. On an individual level, the support of the providers allowed us to disseminate valuable information about CRC and screening options.

From the perspective of the study, the buy-in from clinic staff, including the providers, encouraged community members to approach us and to trust us. Medical mistrust caused by a history of scientific abuses of minority populations is a major deterrent to research participation for many minorities, especially African Americans and Hispanic Americans. The suggestion of a medical provider or the allotment of recruitment space within the confines of the community organization was sometimes enough to spark dialog between study staff and a community member and to break down parts of the wall between research and community.

In some cases, buy-in was more than just a facilitator to recruitment. One of our community partners felt that its relationship with its clients would make it a more successful recruiter of participants for the focus group conducted on its premises. Without this generous support, we would not have reached our recruitment goals at this location.

From the perspective of the recruiters, buy-in was also essential. Knowing that they were welcomed and supported by the medical providers and support staff of the health clinics legitimized their presence and served as a motivating factor.

In any project, what is learned during the process can be just as important as the results. This is no exception. As mentioned above, it is essential to have buy-in from your community partners. Such support, however, should not be limited to the (very important) management staff. Medical providers and support staff should be aware and supportive of the study and the recruitment conducted in their organization. Initially, we did not make contact with all of the providers and staff, but we found that the more contact we had with them, the more likely we were to encounter interested parties. This means that future research may require more pre-recruitment meetings and introductions with host staff.

In order to complete recruitment, participants were encouraged to refer friends or neighbors, who fit the recruitment criteria, to the focus groups. Future recruitment can take this word-of-mouth approach into consideration, as it may be a more reliable method for recruitment, because it relies on the trust between members of the same social network. This may be one way to increase focus group attendance. It might also prove worthwhile to over-recruit participants. Eight of the nine focus groups conducted had a 50% attendance rate. While some of this may be attributable to the recruitment staff, i.e., lack of preparedness or human error, we assume that most of the poor attendance is the result of “life”—commitments, forgetfulness, etc. By inviting a few more participants per focus group—10 or 12 instead of eight—we might have met our initial recruitment goals.

The focus groups were instrumental in providing information for the next phase of our work: a community-based, cross-sectional survey with 400 Hispanics. We were able to adapt existing psychosocial scales to address the findings from the focus groups. For example, we had previously not included specific items on *embarrassment* or *machismo*, but the focus group data directed us to include them in the survey assessment. Based on the results of the focus groups and the data to be collected from the community survey, we plan to develop targeted educational materials to promote CRC screening via colonoscopy for Hispanics. Such educational materials could be used as part of a faith-based program similar to the Witness Project for breast cancer [16] or as part of a public health intervention delivered on television, the internet, or via print media. This educational information would address identified facilitators and barriers to most effectively promote CRC screening (e.g., peace of mind, curability of CRC, fear, and lack of symptoms). In conclusion, despite the study limitations, the results of this study support the use of qualitative research to inform quantitative research (i.e., the use of mixed methods).

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Table 1

Demographics of study population

Country of origin/ ethnicity	All participants (N = 35)	Women (N = 23)	Men (N = 12)	East Harlem ^a Hispanic population
Puerto Rico	60%	13	8	58%
Mexico	14%	5		17%
Dominican Republic	11%	2	2	
Ecuador	6%	1	1	
Peru	3%		1	
Nicaragua	3%	1		
Colombia	3%	1		

^aSource: US Census Bureau, American Community Survey 2006

Table 2

Facilitators: why people get (or should get) a colonoscopy

Topic	Examples
To know one's cancer status	Family peace of mind One's own peace of mind
Physician Factors	Trust in one's doctor Share common culture (language or ethnicity) with doctor Good communication with doctor
Knowledge	Having information about colorectal cancer
Sphere of Influence	Family support for getting screened Family member having gotten screened Peer encouragement
Prevention	To avoid or prevent cancer Cure existing cancer
Physician referral Diagnostic	Having symptoms Pain
Family History of CRC Living	Also, history of other cancers Wanting to live longer Wanting to be healthy for oneself and for family

Table 3

Barriers: why people do not get a colonoscopy

Topic	Examples
Ignorance	Lack of education Lack of knowledge about CRC and/or colonoscopy
Cancer Insecurity	Fear of cancer Fear of getting sick Fear of results; hearing that you have cancer
Mistrust	Lack of trust in physicians Lack of trust in the health care system
Machismo	Men who think they know it all
Fear of the exam	Painful Invasive procedure
Time	Cannot miss work Too many competing pressures
Embarrassment	Shame and embarrassment about the nature of the exam Discomfort with nudity
No symptoms	I feel fine
Means	Not have the money/health insurance
Inaccessible	Hard to schedule
Myths	No anesthesia during the procedure Negativism from others