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Perceptions of Colorectal Cancer Screening in Urban African American Clinic Patients: Differences by Gender and Screening Status

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Abstract

African Americans have higher colorectal cancer (CRC) morbidity and mortality than whites, yet have low rates of CRC screening. Few studies have explored African Americans' own perceptions of barriers to CRC screening or elucidated gender differences in screening status. Focus groups were conducted with 23 African American patients between 50 and 70 years of age who were

patients in a general internal medicine clinic in a large urban teaching hospital. Focus groups were delimited by gender and CRC screening status. Focus group transcripts were analyzed using an iterative coding process with consensus and triangulation to develop thematic categories. Results indicated key thematic differences in perceptions of screening by gender and CRC screening status. While both men and women who had never been screened had a general lack of knowledge about CRC and screening modalities, women had an overall sense that health screenings were needed and indicated a stronger need to have a positive relationship with their doctor. Women also reported that African American men do not get colonoscopy because of the perceived sexual connotation. Men who had never been screened, compared to those who had been screened, had less trust of their doctors and the health care system and indicated an overall fear of going to the doctor. They also reiterated the sexual connotation of having a colonoscopy and were apprehensive about being sedated during the procedure. Overall, men expressed more fear and were more reluctant to undergo CRC screening than women, but among those who had undergone CRC screening, particularly colonoscopy, men expressed advantages of having the screening. All groups were also found to have a negative attitude about the use of fecal occult blood testing and felt colonoscopy was the superior screening modality. Results suggest that messages and education about CRC screening, particularly colonoscopy, might place more emphasis on accuracy and might be more effective in increasing screening rates among African Americans if tailored to gender and screening status.

Keywords

CRC screening; Colonoscopy; African American

Introduction

Colorectal cancer (CRC) is the third leading cause of cancer death in the United States, with approximately 146,970 new cases reported each year [1]. It disproportionately affects African Americans, especially African American men, who have a 20% higher incidence rate and 45% higher mortality rate compared to whites. Despite the higher risk, CRC screening, particularly colonoscopy, is underutilized in this population [2–4]. Although knowledge of CRC screening modalities is essential, perceptions of barriers and facilitators to screening also greatly affect screening status [5–8].

Despite the fact that every major medical and cancer association recommends CRC screening for those 50 years of age and older [9–11] including the US Preventive Services Task Force, the American Cancer Society Colorectal Cancer Advisory Group, the American College of Radiology Colon Cancer Committee, and the American Gastroenterological Association, more than 45% of Americans 50 years or older have not received CRC screening in the past 5 years [2], and almost 60% of African Americans specifically have not been screened, making this population especially vulnerable to late diagnosis [12].

Studies indicate that common barriers to CRC screening include the perception that it is unpleasant, inconvenient, and embarrassing [7,13,14]. Studies of African Americans have also indicated that lack of CRC knowledge, lack of physician recommendation, and a distrust of the health care system and providers [5,6,15,16], as well as fatalism (beliefs that screening and treatments are “futile” since it is in “God’s hands”) also have been reported [5,7].

Given that women are more likely than men to be screened for all types of health issues and to make regular use of medical care systems, particularly for preventive services [17], we believe it is important to examine differences in CRC screening perceptions and status by

gender among African Americans. The objective of this qualitative study was to elucidate if/how gender and screening status may be related to perceptions of barriers to CRC screening in an African American general internal medicine primary care continuity clinic population, located in an urban teaching hospital, to enable the research team to develop strategies to overcome barriers in a CRC screening intervention program being designed for this population.

Methods

Participants and Setting

During September 2007 through February 2008, 23 African Americans (15 women and 8 men) between the ages of 50 and 64 participated in one of eight focus groups that explored perceptions of CRC screening. Focus groups were delimited by gender (male, female) and CRC screening status (ever, never screened). Groups consisted of three to five participants and were gender-specific on grounds that men and women might have different opinions about CRC that they would be more comfortable expressing in a single gender group. Similarly, groups were delimited by screening status to ensure that participants could discuss factors related to making the decision about whether or not to be screened with others who made the same screening decision. Each group met for approximately 1 hour and participants received an incentive of a \$20 dollar gift card for a local pharmacy. The study was approved by the institutional review board.

We recruited patients from the primary care continuity clinic of a large urban teaching hospital that primarily serves low-income African Americans who have Medicare or Medicaid insurance. Scheduling records were used to determine age eligibility of patients scheduled for routine office visits. During the visit, patients were approached by a research assistant (RA) and invited to participate in the study. Patients who agreed completed a screening survey that included contact information, age, gender, and screening status. Participants also were referred to the study by their physicians. Following initial contact, RAs called interested individuals to schedule the focus group date and time. All interested individuals received reminder fliers by mail 1 week prior to the focus group and were called to confirm their attendance on the day before their scheduled group. Of the 54 patients who completed the initial screening survey, 35 (65%) agreed to attend a focus group and 23 individuals (66% of those who agreed) actually participated. Those who agreed but did not participate were unable to attend because of bad weather, illness, change in schedule, or lack of transportation.

Implementation

Focus groups were moderated by gender-matched study investigators with degrees in public health and communications. Each focus group was exposed to a brief tutorial on two CRC screening methods, colonoscopy and fecal occult blood testing (FOBT). The tutorial included information on how the screening tests are implemented as well as general information about what CRC is and who is most at risk. This was provided at the beginning of the focus groups for those ever screened and after a first block of questions on general cancer attitudes and knowledge of CRC for those never screened. The tutorial was based on the Patient Education Institute's X-Plain online tutorials (www.xplain.com), with content changed and developed to be culturally sensitive and written at a sixth-grade reading level. Participant questions that could not be answered by the moderator were referred to the General Internal Medicine doctor on-call at the clinic.

Moderator guides were developed for this study and tailored for ever-screened or never-screened men or women. We used the existing literature on CRC Screening in African

Americans [5,18–21] as well as other literature on CRC attitudes and perceptions [6–8,22] to develop the moderator guides (available at <http://www.temple.edu/chp/departments/publichealth/rc/pjt.htm>.) Focus group questions were separated in four topic areas: (1) feelings about cancer; (2) a general understanding about colonoscopy, FOBT, and CRC; (3) barriers to screening; and (4) information needs. The first block of questions focused on general attitudes about cancer and were asked of both ever- and never-screened groups. Questions focused on participants' feelings about cancer, what types of cancer they thought most people think of when hearing the word, and if they felt CRC was a concern in their community. They were also asked general knowledge questions about risk factors for CRC. The second block of questions focused on CRC screening modalities. The never-screened participants were asked about what types of CRC screening they had heard of, and what they believed were the risks and benefits of CRC screening, including colonoscopy and FOBT. Ever-screened participants were instead asked about their own CRC screening, including what type they had, when they first heard about it, why they decided to have the screening, whose opinions were important to make the decision to have screening, and what they believed to be the advantages and disadvantages of colonoscopy and FOBT. The third block of questions focused on barriers to CRC screening. The never-screened participants were queried on what had kept them from getting screened and what they felt they needed to help overcome barriers to screening. Ever-screened participants were asked what they felt were the major barriers to screening and how they believed they overcame those barriers. Finally, the fourth block of questions asked both never- and ever-screened participants about information needs and outlets they would want to help their community understand the need for CRC screening and increase actual screening rates.

Evaluation

Audiotapes of the focus groups were transcribed verbatim by an RA and analyzed by study investigators using an iterative coding process with consensus and triangulation to develop thematic categories [23]. The investigators, who included the two focus group moderators, reviewed the transcripts and met multiple times until consensus was reached on how to classify each theme, ensuring that the themes accurately represented participants' discussion. The coding process was documented and reviewed by all study staff to maximize reliability and validity of the evaluation methods.

Results

Focus Group Themes

Five themes consistently emerged in all of the focus groups: (1) the importance of the role of the physician in CRC screening decision-making; (2) gender differences in perceived barriers to colonoscopy; (3) perception of screening as providing the benefit of "peace of mind"; (4) a general lack of information about CRC screening; and (5) a universal dislike of FOBT as a CRC screening modality.

Importance of Physician's Role—Physicians are perceived as critical for providing information about CRC screening as a means to encourage screening and also for helping the patient make the decision to be screened. In ever-screened groups, many participants indicated that if their doctor told them to be screened, they were. In the never-screened groups, most participants indicated that if their doctor would spend time discussing CRC screening, they would be more willing to be screened (see Table 1).

Gender-Specific Perceptions—Both men and women indicated that men were less likely to have CRC screening than women, regardless of screening status. Women reported

that men do not like doctors and that women were more concerned about getting CRC screening. Women also generally believed that a main barrier for men having CRC screening was the embarrassment of the procedure and the sexual connotation that was perceived by African American men related to having a colonoscope placed into the rectum while they were unconscious. Male participants also expressed these concerns, especially those who were never screened. Most men expressed their lack of desire to go to the doctor and their uneasiness with the colonoscopy procedure. Men also indicated a general fear of being screened because of what might be found; this sentiment was not seen in the female participants, regardless of screening status (see Table 1).

“Peace of Mind”—Both men and women who had ever been screened for CRC indicated that the main benefit of screening was the “peace of mind” it provided. Women especially indicated they felt it important to have a colonoscopy and not “waste time”, as one woman described, on other screening measures (such as FOBT) that were not as reliable. Others said that knowing the results of the test was comforting and that having “...no ifs, ands or buts or questions about what was happening” provided a sense of security. While never-screened individuals said that the screening could provide valuable information, they remained wary of getting screened, feeling that sometimes not knowing was better.

Lack of Information and Understanding—We observed an overall lack of information about CRC and CRC screening, even among ever-screened men and women. The CRC tutorial we provided to both ever- and never-screened participants elicited a number of questions in all focus groups that indicated lack of understanding of cancer in general and CRC in particular, especially who is most at risk and the screening modalities commonly used. Participants also specifically said that they felt many within the African American community do not have screening because of a lack of understanding of this type of cancer and the screening modalities (see Table 1).

Dislike/Mistrust of FOBT—Finally, all participants, regardless of screening status or gender, provided very negative feedback about FOBT as compared to colonoscopy. While the tutorial presented balanced information on both screening techniques, participants had very negative reactions to FOBT and felt there were no benefits to having this type of screening. Despite the invasiveness of colonoscopy, all participants expressed that they felt the benefits of having the colonoscopy far outweighed the possible risks or barriers. Participants indicated they did not like the dietary restrictions needed with the FOBT test, the length of time the test takes, and having to touch or handle stool (see Table 1). Participants reported the benefits of colonoscopy included knowing with greater certainty if cancer existed, as well as being under anesthesia, as key benefits to this procedure. Very few participants, even those never screened, were concerned with the possible risks of colonoscopy, including the risk of perforation. Rather, it was the “personal nature” of the procedure, the cultural perception of cancer, and not wanting to know if cancer existed that were the greatest perceived barriers to being screened. These barriers were perceived as far less problematic for colonoscopy compared to FOBT.

Comparison of Perceptions of Ever vs. Never Screened

While the themes described above were observed in both the ever- and never-screened focus groups, there were some differences between the groups by screening status. These included overall knowledge of CRC screening and potential strategies for reaching African American communities with screening information.

Knowledge of CRC Risks and Acceptance of Screening—Both men and women who had been screened said that they were happy to have had CRC screening and would do

it again if directed by their doctors. They also had fewer questions about the colonoscopy procedure and fewer misconceptions about CRC than those never screened. Although there was a general knowledge gap in both groups about who is most at risk for CRC and how it develops, those never screened had more misperceptions such as reporting that CRC was related to frequent diarrhea in the past or that only men were at risk. The ever-screened groups had a more accurate perception of dietary risks of CRC, citing eating too much fast food, high-fat foods, or red meat as risks. Neither group, however, discussed race or other behavioral risks such as smoking or alcohol consumption as risks for CRC.

Strategies for Communicating About CRC in African American Communities

—Another key difference observed by the screening group was that the ever-screened participants were much more vocal about how information should be presented to African American populations about CRC and screening options. For example, ever-screened participants suggested a number of strategies to get information to African American communities beyond the usual health education materials. They specifically suggested using wellness vans, word-of-mouth through community organizations, churches and community stores, and using influential people, such as spouses and celebrities, to provide information more effectively (see Table 2). In comparison, those never screened offered few ideas about how to provide information to the community, focusing mostly on getting information from their doctors or the media.

Discussion

Analyzing transcripts by gender and screening status revealed interesting differences between groups. Most importantly, the ever-screened groups reported far more positive attitudes about the need for being screened and were far more likely to be engaged in discussing the need for getting information to African American communities. We cannot know, however, if the experience of being screened actually fosters the perception of the benefits far outweighing the risks and barriers of CRC screening. To a great degree, it is likely that in this primary care urban clinic population, those who hold these views are more likely to have completed screening than those with less positive views and our sampling procedure that assigned participants to focus groups by screening status simply captured these two subgroups of patients.

Another important finding was that in all groups, regardless of gender or screening status, participants were universally negative about FOBT as a CRC screening option. This was a surprising finding since many interventions with African American populations have used distribution of FOBT kits to encourage CRC screening [24]. The results of this study seem to contradict this practice, indicating that focusing on the benefits of and widening access to colonoscopy may be a better strategy to increase screening rates in an African American clinic population.

Participants also indicated that they believed CRC screening provides a “peace of mind”; this was a prevalent theme even in the never screened. While the never-screened participants were more apprehensive about screening, they said that they were more comfortable with the idea of screening, particularly colonoscopy, after the brief tutorial was provided. This finding suggests that the reservations participants had about CRC screening might be addressed with targeted, culturally relevant education and materials that emphasize accuracy and getting “peace of mind.” The views of the ever-screened participants also illustrate that once screened, at least some feel the need to “educate” others. In the groups, many discussed how they have talked with their sons, daughters, friends, and family about the need for CRC screening and its importance. This was also evidenced in their detailed discussions of how best to provide information on CRC screening to African American communities. It should

be noted, however, that it may be that a subset of the ever screened, who felt so positively about screening, was more likely to agree to participate in a focus group on CRC screening compared to those who had had more negative experiences.

While the never-screened participants had few ideas about how to increase screening other than having doctors or the media provide information, the ever-screened participants offered a variety of ideas on how to engage the community through the use of community-based organizations, churches, and relevant spokespeople. Being screened may have “converted” some of them into being advocates for screening, but the potential selection bias noted above must be kept in mind. If screening does increase patients’ commitment to the importance of CRC screening and providing information to others who have not been screened, patients themselves are an important resource for enhancing screening rates. This result is also important in that using African American individuals who have been screened for CRC may be a particularly important strategy for spreading the word in African American communities. Similar initiatives have worked with other communities (e.g., the use of promotoras to increase cervical cancer screening among Latinas, particularly immigrant Latinas) [25].

Limitations

As with all qualitative studies, limitations include the inability to generalize results to broader populations because they represent the opinions of a small group of people; in this case urban African American patients in a large teaching hospital. Findings may not reflect other groups of African Americans, especially those who may not have easy access to primary medical care. In the case of this study, findings on FOBT and barriers to CRC screening may be dependent on the participants’ individual experiences, geographical location, and health care access. In addition, because all the participants were patients in a primary care continuity clinic in an urban teaching hospital, perceptions of CRC and screening modalities may be different than in other African American populations, including other practice sites in the same community. These participants had access to health care, health insurance, and their physicians had access to specialists for colonoscopy referral, as opposed to the Federally Qualified Health Centers where the wait times may be longer to see a physician. Results may thus be affected by this access or by the type of health information they had already been given by health care professionals about CRC screening. The sample in this study was also younger, in that no participants were over the age of 65 when screening adherence increases. The low acceptance rate and high rate of no-shows to the focus groups, both of which contributed to the small sample size, could also have biased the sample as well as the fact that though study personnel were gender matched to groups they were not ethnically matched, possibly influencing results.

Finally, because of selection biases noted above, we cannot determine whether the actual experience of screening contributed to the positive views expressed by the ever screened or these very qualities are what led them to complete CRC screening. Similarly, the perceptions of the never-screened participants may reflect a particularly hard to reach subgroup and not be typical of others who have never had CRC screening.

Conclusion

This focus group study of African American primary care patients delimited by gender and screening status provides new insights into important factors and perceived barriers to CRC screening among ever and never-screened patients who use an urban continuity clinic as their usual source of care. While other studies have looked at perceived barriers in African Americans, none have separated groups by gender and screening status. This stratification

provides information that can be used when developing education materials or public information for African American communities about CRC screening. This is vitally important as African American populations have higher CRC morbidity and mortality and lower screening rates compared to whites. Targeting messages by gender and utilizing those who have already been screened for CRC as message vectors may be important strategies to increase screening rates in African American communities.

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Table 1

Focus group themes: examples of patients' responses by gender and screening status

	CRC ever screened		CRC never screened	
	Male	Female	Male	Female
Importance of physician's role	<ol style="list-style-type: none"> 1. ...when the doctor told me to get it, I decided to go take it. 2. Doctors telling me you need to do this, you need to do that. I don't have a problem doing anything. 	<ol style="list-style-type: none"> 1. So if I routinely go to my doctor and he suggests that I do this and tells me it is time to do this, then I go step by step by what he says... 2. Anything he says because I trust him if he tells me it's time for this because you are this age...you need to do this. I am going to listen to him. 	<ol style="list-style-type: none"> 1. That is how I found out by going to the doctor and finding you know for one thing about me. He could tell me listen check out this. That is how I found out. 2. I'm not much on going to the doctor, you know. If I don't need it and it's not an emergency I don't go see the doctor. 	<ol style="list-style-type: none"> 1. It has to do with how your doctor discusses things with you. 2. I want to be comfortable with you and if I'm not comfortable with you, find me somebody else who is going to take the time with me because people get scared often.
Gender-specific perceptions	<ol style="list-style-type: none"> 1. Some men think, "they aren't putting anything up there, they aren't going up into my rectum like that" 2. ...you know, guys are usually reluctant to have colonoscopies because I guess it a male ego thing you know, having something inserted into your rectum. 	<ol style="list-style-type: none"> 1. I think the women would be more concerned about getting it... we have much more things going on in our bodies than men. 2. I think with men there is a masculinity problem that they because it is a certain area they feel that it is like invading them or they are being raped or something. 	<ol style="list-style-type: none"> 1. They stick some type of camera up in you and they said that it is fairly long. I have been putting it off. I am not prone to having that. I also heard they do a finger test which is a second intrusion... It is an uncomfortable feeling for me. 2. It is not so much the worry. It is the intrusion part...it is just in my make up. It is an intrusion to keep having to go in a man's rectum. 	<ol style="list-style-type: none"> 1. I think once there is something wrong with us and we have that discussion from our doctors, we will be faster to do it than they will. 2. Men, they are holding out to the bitter end because of the procedure. They take some type of dignity from you or it is embarrassing to them.
Peace of mind	<ol style="list-style-type: none"> 1. There is no question about it you know. It is a life saving procedure and you just have to put it in your mind that this is not what you want to do but this is what you should do. 2. Now you don't have to worry about it. ...Do what you got to do, I know I am going to get over it because I been through it. I know I am going to get over it. What ever it is going to take. 	<ol style="list-style-type: none"> 1. I think it is a security of knowing what is happening with you is the best I could get out of it. I knew once I had that test and the results. That was the end of it. There were no if, ands, or buts or questions about what was happening. 2. Personally I think that if you are going to take the time to make sure your body is okay, why not go for the sure shot. Why waste your time doing A and B when you are going to go to C anyway. I just don't think it is necessary. 	<ol style="list-style-type: none"> 1. You know, I don't want to take that risk and find out later that I had a problem I could have taken care of a long time ago. 2. The primary choice, I would want to get 100 percent shot that you examined me thoroughly. I'm clear. 	<ol style="list-style-type: none"> 1. ...I would just want to have the other test (colonoscopy) done. I would like to have the accuracy. I would like to know that there are no polyps there. 2. Both my aunts and my mother (had colonoscopy). They just looked like they were sleeping peacefully when I got there to pick them up...There was no side effects, no anything...They were glad they had it done.
Lack of information/understanding as barrier to CRC screening	<ol style="list-style-type: none"> 1. It just is not talked about. It has to be talked about. It has got to be out there. It has to be publicized to take away some of the fears of the examination... 	<ol style="list-style-type: none"> 1. A lot of people don't have the test because they don't know how serious it is. 	<ol style="list-style-type: none"> 1. Not, it is just the point that they do not have the education about it. They don't even know they could have it... That is why they never 2. That will make them feel "I am not going to get that" because they don't know how it is going to be. 	

		CRC ever screened		CRC never screened	
	Male	Female	Male	Female	
	2. I don't think that it is being presented as fully as it should be in our neighborhood, our community.	2. Well at one time they wouldn't tell you nothing but now since more things are in the open some give you a little bit and some still won't tell you anything.	2. A lot of people don't know anything about it. It is just coming out now.	2. ...colon cancer to me, I never knew how they go about it, testing you for colon cancer, and I was wondering how they do that.	
Dislike/mistrust of FOBT	1. I prefer colonoscopy because it's quicker, easier and the side effects are less and it is an outpatient job.	1. I think I would prefer doing that the night before than going three days trying to make sure I didn't have a banana which I love... So I would probably get a false positive because I probably wouldn't do it right.	1. Me personally, I wouldn't rely on it (FOBT) to be a 100 percent sure shot that I am cancer free, the stool testing.	1. Gross... It takes too much work. You have to be real consistent, responsible. You have to have a whole lot of things to follow that kind of schedule.	
	2. I figure...99.9% of the time they can catch any kind of growth that could appear there. So I am pretty confident about the colonoscopy.	2. I think it (FOBT) is a waste of time. ...It is not something that is secure.	2. I still have all of these questions, all of these unanswered questions...I didn't know they did stool testing for colon cancer.	2. You might really have a problem there and you are delaying the situation when maybe something could be taken care of.	

Table 2

Screened participants' suggested strategies to reach African American communities with CRC prevention and screening information (selected)

Use of community organizations, services	1	The church, the schools, the rec(reaction) centers, the playgrounds, your community stores, your corner stores...It has to be word of mouth and that has to be getting into your community organizations.
	2	At my church we have a lot of groups and things like that, you know like medical stuff, and it's nice to get in the group and learn stuff from each other.
Influential people		People look up to celebrities. They have a tendency to value what they say what they may think.
Events		I noticed that they have a whole month for breast cancer so share the calendar for colon cancer.
Utilizing media		Sitting on the subway you can always see about an accident lawyer but you can't see nothing about when is the last time you been checked, are you in that age group, or whatever medical professionals are asking of the population.
Targeting black media sources		I would like to see advertisements in black newspapers, magazines, radio stations.