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Knowledge and Attitudes About Colon Cancer Screening Among African Americans

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Abstract

Objectives—To explore knowledge and attitudes about colorectal cancer (CRC) screening among African American patients age 45 and older at a community health center serving low-income and uninsured patients.

Methods—We conducted 7 focus groups and 17 additional semistructured interviews. Sessions were audio-recorded, transcribed, and analyzed using standard text analysis.

Results—Most participants who were age eligible for CRC screening were nonadherent according to national guidelines. Themes included low CRC knowledge, low perceived norms, high barriers, and other screening beliefs.

Conclusion—Lack of knowledge, low perceived risk, and attitudes about CRC screening may be important targets for interventions in low-income African American patients.

Keywords

colon cancer; focus groups; African American; low-income

Colorectal cancer (CRC) is the section leading cause of cancer death in the United States. Screening for CRC can be effective (and cost-effective) because it detects early stage cancers and premalignant growths. Five-year survival for early-stage CRC is nearly 90%, but low rates of screening have led to the majority of cases being diagnosed at later stages. National data from the Behavioral Risk Factors Surveillance System showed that in 2006, approximately 59% of African Americans and 63% of whites age 50 years or older had a fecal occult blood test in the past year or lower endoscopy in the past 10 years. Increases in CRC screening could reduce mortality through earlier detection of malignancy and could reduce incidence by facilitating the identification and subsequent removal of premalignant growths in the colon or rectum. Previous studies have documented many reasons for the relatively low rates of CRC screening among US adults. Many studies report that patients do not have specific knowledge about CRC or CRC screening, and those who are knowledgeable about screening may not perceive that they are at risk, do not perceive benefits of screening, or face many barriers to screening completion. 4-7

Similar to other health conditions, significant disparities have been documented in CRC and CRC screening. Persons who are of lower income, underinsured, uninsured, have fewer years of formal education, or are members of racial/ethnic minority groups tend to have lower rates of screening, later-stage diagnoses, and poorer survival once diagnosed with CRC.^{2,8-11} A small but growing proportion of the published literature focuses on these underserved populations who are at increased risk for negative outcomes. Thus, there is a need to examine whether these underserved patients have different beliefs about screening that could be addressed in interventions to improve screening rates and reduce the disparity.

A few studies that have targeted low-income or racial/ethnic minority adults report lower than average knowledge about CRC screening. 6,12-14 Other research has described financial and access barriers to screening and treatment, fatalistic attitudes, distrust, and concerns about discrimination and have linked these factors to reduced screening use. 15-17 A growing body of literature suggests that low socioeconomic status is associated with reporting not only more barriers to CRC screening but also different barriers. Concerns about logistics and consequences of screening have been associated with socioeconomic status, 18 and cognitive factors such as perceived risk have been proposed to explain part of the disparity in screening. 19

Based on these findings and the growing interest in cancer disparities and to promote a deeper understanding of reasons for and against screening in this population, we conducted an exploratory qualitative study with patients at a federally qualified community health center ("safety-net" clinic). Our primary goal was to assess levels of knowledge, identify prominent barriers, and identify attitudes associated with CRC screening that might inform development of future interventions to improve screening rates. The qualitative approach is well suited to exploring the meaning of these factors in a sample, can identify factors inductively rather than deductively, and allows participants to name and define their own thoughts about this health behavior.

METHODS

Study Description

This was a qualitative research study using focus groups and semistructured interviews. Prefocus group surveys were used to collect data on participants' demographic characteristics and screening histories. We chose focus groups as our research method in order to facilitate group discussion and interaction, which we deemed important for the topic. The semistructured interviews were implemented after completion of all the focus groups in order to follow up in-depth on ideas that emerged from the groups and to continue accruing participants in each of our a priori defined stratification cells (gender, screening status). We continued conducting interviews until the research team felt the data were saturated, meaning that no new findings appeared to emerge. Together, the 2 qualitative methods provided breadth and depth to the data and allowed participants to use their own words and descriptors to describe and discuss CRC screening. The university institutional review board and the administration of the health center approved the study and all procedures.

All research activities, including recruitment, focus groups, and interviews were conducted on-site at an urban federally qualified health center serving low-income, Medicaid, Medicare, and uninsured adults. The health center is established in the community, accessible by public transportation and has offices dedicated to clinical primary care, behavioral health, outreach, and community services. Participants were considered eligible if they were age 45 years or older. Altogether, data from 7 focus groups were analyzed in this report (2 with men, 4 with women, and 1 with both men and women). Focus groups ranged in size from 2 to 5 participants each. Seventeen interviews were completed with additional

participants. One participant was found to have participated twice; her latter data were not analyzed in this report. All participants self-identified as African American.

Recruitment

We used purposeful and snowball sampling^{20,21} for this study in order to gain insight from both genders and people with different screening histories. Study staff set up a recruitment table in the main lobby of the health center. The table was visible to persons going to clinical areas, the pharmacy, behavioral health offices, and outreach program activities. Additionally, a large poster advertising the study was displayed in the lobby and flyers were posted in the adult medicine and outreach clinics. Study staff explained the study and assessed eligibility for individuals who approached the table. Eligible individuals who were interested in participating were asked to provide contact information and CRC screening status (for stratification purposes).

Procedures

After recruitment, participants were contacted by telephone by a member of the research team to confirm interest in the study and schedule a focus group or interview time. All participants received a reminder call 1 to 2 days before their scheduled time. Participants provided written informed consent immediately prior to participation. Focus groups were led by a trained moderator (ASJ) who has conducted or assisted with several focus groups among underserved patients; interviews were conducted by trained research staff who had attended the focus groups. At each session, an assistant moderator or interviewer was present to take notes, help with the consent and survey, and operate the recording equipment. Each focus group lasted approximately 90 minutes; interviews lasted between 30 and 60 minutes. Participants received a \$25 gift card and light meal or snack for their participation. Except for group size, the procedures were the same for focus groups and interviews, and similar questions were used for both. A semistructured format was employed; question probes were dependent on participants' answers. All sessions were audiotaped and transcribed verbatim.

Measures

Immediately prior to the focus group or interview, participants completed a brief close-ended survey that included questions on demographics (age, gender, education, insurance status, and marital status), personal history of cancer diagnosis, family history of cancer, colon cancer screening history, physician discussion of CRC screening, and screening decisional stage based on the Precaution Adoption Process Model.²² The semistructured moderator's questions for the focus group addressed the following broad topics: CRC knowledge, thoughts about getting screened/norms, barriers and benefits to screening, and beliefs about cancer. These questions reflect constructs from health behavior theories (Health Belief Model²³ and theory of planned behavior²⁴) that have been shown to affect screening behaviors and were designed to reflect multiple stages of decision making²² (awareness, engagement, deciding, decided to, decided against).

Data Analysis

A subsample of transcripts was checked for accuracy against the audiotape; very few discrepancies between the transcripts and the audio were detected, and all were minor. Data were analyzed using standard text analysis and supplemented by a modified grounded theory approach. Some themes (eg, "knowledge") were deductively driven by the questions in the moderator's guide, whereas others emerged from the data. In an iterative analytic process, members of the research team (principal investigator, coinvestigator, and coders) read each transcript to generate themes. The research team then met to review themes, discuss

subthemes, and develop the codebook. Three trained independent coders then coded all transcripts using the codebook, meeting regularly to clarify theme definitions, discuss progress, and compare and contrast discrepancies. The principal investigator reviewed the coded transcripts, cross-checked approximately 10% of the codes for intercoder reliability, and met with the coders to resolve discrepancies through consensus. Coder agreement was high; thus no additional modifications to the codebook were necessary. The research team then met to discuss themes and identify representative quotes. Codes, themes, and quotes were reviewed by a clinician coinvestigator who was familiar with the community and patient issues concerning CRC screening. The final transcripts and codes were entered into Atlas-ti to facilitate the final analysis. Only themes that were determined to be saturated are reported here.

RESULTS

Participants

Table 1 reports participant demographics. In brief, nearly all participants were age 50 or over (guidelines recommend starting CRC screening at age 50 for those at average risk). Slightly less than half (55%) had some medical insurance (mostly Medicaid or Medicare). Most participants had a high school diploma or further education (79%). Only about one fifth (19%) of participants were employed; remaining participants tended to be on disability or unemployed.

More than half of participants (66%) had previously been screened for CRC, mostly through stool testing (38% ever had a stool test) or colonoscopy (36% ever had). Most of those who reported stool blood test screening were not "up to date" (79%), but 69% of those who reported colonoscopy appeared up to date. Few (22%) participants had previously had colorectal polyps, 30% reported a family history of CRC, 41% said they had discussed CRC screening with their doctor. The age and gender distribution and screening prevalence were driven by the sampling frame and may not be representative of the health center's patient population.

Data Themes

Knowledge of CRC—Most participants felt that they knew very little about CRC or expressed a lack of confidence in their level of knowledge and a desire to learn more. "Yeah, I just heard the name. I'm more familiar with like prostate. I'm not familiar with colon cancer at all." Several knowledge deficiencies or misperceptions emerged, (eg, "I thought it [CRC] was a man's disease."), and many comments reflected unfamiliarity with anatomy ("I'm not even sure where the colon is"). More than once, it became evident partway through the focus group or interview that a participant was discussing prostate cancer rather than CRC because of the way the individual described the test, biopsy, or examination.

Cancer risk factors—Nearly all participants were familiar with established cancer risk factors, such as age, smoking, diet, physical activity, and genetics. Environmental carcinogens (such as food contamination or air pollution) and occupational hazards also were discussed by participants as factors that increased cancer risk. Although this study focused on CRC, participants tended to discuss risk factors for CRC and risk factors for cancer in general together, rarely distinguishing the 2. Although this tendency to generalize may reflect the reality that one risk behavior may increase risk for several cancers, it may also present an opportunity for educating patients about how types of cancer are different. Several subthemes were related to perception of cancer risk, which we describe below.

Family history and cancer risk—Many participants mentioned a family history of cancer and described how this affected their perception of cancer risk or prompted their interest in learning more. Participants accepted that having cancer in their family affected their risk for getting cancer themselves. However, participants did not usually distinguish between first- and second-degree relatives in assessing their personal risk. A common expression was how cancer "runs through my family." As one participant said, "My mom, my grandmother, my cousin, my auntie... I mean, it's just been going on and on." Although family history was usually associated with perceived increased risk, a few participants stated that family history decreased their risk based on gender or generational status of the affected family members. For example, participants talked about how cancer "affects the women in my family, not the men" or "the women in my family don't have a problem." A few participants mentioned how cancer would "skip" a generation in their families.

Mistrust and skepticism of risk information—Participants often commented on the changing or contradicting messages about which factors are associated with increased cancer risk, as well as the sheer number of recommendations for lowering cancer risk. As one participant said, "Pretty much anything's bad." Another participant commented that "I think anything gives you cancer now..." and "so it gets to the point where you're so confused." An example of how participants expressed frustration with recommendations for reducing cancer risk appears below:

As far as what they say about what causes [cancer], I wonder about that because you have some people that never smoke and they have cancer, and die of lung cancer, but they said it's because of the smoke from somebody else. But how are they to know, really? That's a hard question, I guess, really to answer because, yes it do make me wonder where it come from. But I don't know whether to believe what they say it come from because you hear so much now. Today they might say, 'greens cause you cancer', 5 months later they might come back and say they went back over it and it's not the greens. So what are you to do?

This quote exemplifies statements that seem to reflect skepticism and exasperation rather than a literal and fatalistic belief that "everything" causes cancer or that nothing can be done to reduce cancer risk. Many of these participants who expressed frustration with risk recommendations also offered hope that healthy choices could improve survival, though at other times, more fatalistic or distrustful perspectives emerged.

Perceived Social Norms Regarding CRC Screening

There were 3 subthemes around normative perceptions about CRC: talking about cancer, CRC screening, and cancer treatment and survival.

Talking about CRC—Participants reported that, in general, cancer was not commonly discussed in conversation: "We're not going to sit at the table and talk about cancer." There were exceptions such as if an acquaintance was sick or had recently died: "No, we do not talk about cancer...our conversation being about cancer is our friend that's passing away from cancer." Another exception noted was if a participant were particularly concerned about something: "We don't spend much time discussing each others' medical activities until there's something...a crisis that happen." Two notable exceptions were a woman who reported that she had discussed the focus group with a friend and was planning to talk to the friend about getting screened the afternoon after the group and another woman whose sister was getting a colonoscopy the following week who said: "My oldest sister has one coming up this week so after she go and have hers, then I'm gonna follow her...if she don't feel too bad afterward." It appeared that typically cancer and screening were discussed only when there was a trigger or cue. However, this lack of discussion appeared to extend beyond

cancer and may reflect a lack of discussion of close others' health issues. The research literature often alludes to the idea that patients avoid talking about CRC because it is an uncomfortable topic, but there was little indication in our study that participants were more reluctant to discuss CRC than other types of cancer or diseases. Only one person said that "some people don't want to talk about it because of where it is."

Perceived prevalence of screening—Participants reported that "some" of their acquaintances had been screened but very few reported that "most" or even "half" of acquaintances or family members had been screened. It is possible that participants did not accurately know if their acquaintances had been screened because, as noted above, they did not discuss the topic. Although the mean age of participants was over 50 years of age, it is also possible that participants considered some people who were not yet age eligible for screening in their mental calculation. However, based on prevalence of screening and the reports of participants, one could conclude that perceived social norms for screening are likely below actual screening rates or that the question deserves further inquiry.

Cancer survivorship—When asked whether participants knew people who had survived cancer, many respondents referred to local television news personalities rather than personal acquaintances. Participants were less likely to mention survivors from their own social networks, saying that they "knew more people who had passed" from cancer than who had survived. Few peer role models for screening or survival were mentioned.

Benefits of Screening and Early Detection

Most participants endorsed the value of early detection and a willingness to engage in screening. As one participant said, "I think the key is catching it at an early stage." Those who discussed screening benefits said that it was important to know if one had cancer and felt that early detection offered the best opportunity for survival. Although there were some exceptions, most participants who had been screened reported that the colonoscopy experience was not painful and that they would do it again or recommend it to someone else:

It's an experience in which you know you're reluctant because of the way they go in for entry but they give you a shot and.... I don't remember nothing until they came and shook me after the testing was over...it wasn't painful at all. I don't recall anything.

Although some participants had diagnostic colonoscopies due to symptoms or a CRC-specific family history, one participant described her colonoscopy as a "present" to herself: "I was turning 50 and I thought I would do it for a birthday present to myself because both of my parents [had cancer]."

Barriers to CRC Screening

Barriers to CRC screening that were discussed by participants included not only personal-level barriers but also health care system or provider factors that affected their decisions to get screened.

Personal barriers—Not surprisingly, participants mentioned many of the same barriers that have been commonly found in other studies, such as cost, dislike of the preparation ("the most disgusting stuff about it is [the preparation]...") and discomfort with the tests ("The tube that big up you, I don't think so. I don't think so. I mean, it's that big" (participant made hand gesture to emphasize the point)). Despite the stated barriers, most participants said that they would get tested or would try to despite the discomfort with the testing method: "I don't know if I'll be able to do that test [colonoscopy], now there's got to be another way of doing that kind of a test."

A fear of cancer or fear of the tests could inhibit screening for some people and was mentioned by some participants. A minority of participants said they would be reluctant to get tested because "if I got it {cancer}, I don't want to know I got it." Fear of cancer or not wanting to know was sometimes linked to concerns about treatment and ultimate death:

I guess I am afraid or something of what I'm going to hear or...I don't know. I don't know. I think it's just that I'm afraid but I know that it's crazy and I need to go.

One of my fears of getting cancer is not being cured and prolonged illness. Prolonged, agonizing, sick, you know...that's what I fear. But...that's good if that's not going to happen, but that's my fear.

Some participants feared cancer treatments, especially those who believe that surgery for cancer would cause it to spread and would hasten a painful death.

System-level barriers—Some participants mentioned specific providers that they trusted and thought were "good" and said that they would get screened if that provider told them they should. Often, however, the experiences with providers and systems that emerged in the discussion of CRC screening were those that impeded care-seeking. For example, such experiences included participants' questions about providers' abilities or intentions and feelings of being disrespected or not treated appropriately. Other participants reported that paperwork for Medicaid delayed access and caused frustration, and some participants attributed their dissatisfaction with care to being uninsured. Participants also described long waits to get an appointment or mentioned that once they got to the appointment, they spent only a few minutes with the doctor:

You know, he [the doctor] get(s) the big bucks because when it comes down to it his expertise is what's going to get you the prescriptions you need and it's going to get you the health care that you need, if you have to go into the hospital. ...So actually I think 15, 20 minutes with my doctor is good. But, man, that 2 and a half hour wait just to see him for 5 to 10 minutes; I don't think too many people like that. I don't like that.

Some participants who were patients of medical institutions with residents or medical students expressed distrust or lack of confidence because the provider was still "seeking that experience." These participants expressed frustration with having to repeat themselves with an attending physician after meeting with a student, though other participants did not seem to find issue with this practice.

Often a reported reason for the participant (or an acquaintance) not going to the doctor was simply put as "don't like to go to the doctor." Participants described instances in which they had to self-advocate for tests they felt they needed and that they did not get care unless they "demanded" it. These references to demanding care sometimes related to feelings that the doctor did not believe them or talked down to them or that the doctor did not encourage services because the patient was uninsured. Other times, these participants described changing providers or just not going back to the doctor at all. Several described a doctor they "won't be going back to" because of the way they were treated.

But there's some...[doctors who] treat you really nice, when you're going through something, you know, like the test and [then] there's some people just like that doctor I had, it was just horrible. He told me, he said, I hate to do this [medical procedure] too. ...But a lot of people won't come {to a doctor} because other people tell them about their [experiences].

I went about a year or 2 ago to get this colon cancer [screening]. They irritated me so bad I never went back.

When these frustrations combined with other care-inhibiting factors, the participants' self-perceived likelihood of returning for other services decreased.

DISCUSSION

Our findings are consistent with several other qualitative reports in that we found low levels of knowledge and high numbers of perceived barriers to screening. 5-6,12-13,15,17,23 However, our findings explore in-depth issues about knowledge and attitudes and investigate the intricacies and details about how people think about CRC screening and how they see that affecting their ultimate use of screening. The value of such qualitative research is that we can explore the meaning of participant's statements about screening to better understand participants' experiences using their own words.

Regarding knowledge, low levels of CRC knowledge were found along with confusion between the prostate and colon, not being sure where the colon is, and other misperceptions that could hamper communication and intervention efforts. Men in our study who thought they had been screened for CRC because they knew they had prostate screening, women who thought CRC only affects men, and patients who were not sure know what "colon cancer" really referred to would likely ignore recommendations because they do not perceive a need for screening. Thus, it seems that the most effective messages might involve pairing basic educational information along with screening recommendations.

Generally, our participants knew many of the standard risk factors for cancer. Most participants knew that diets low in fat and high in fruits and vegetables reduced cancer risk. They knew that smoking, lack of exercise, and being overweight increased their risk. Although the specific details of health recommendations (eg, number of servings per day or amount/intensity of exercise) were not probed in our study, participants had definitely heard the basic message about these behaviors and cancer risk reduction. One interesting finding that warrants further study is the complex role of family history in perceived personal risk. Several participants hypothesized decreased risk because most of their cancer-affected family members were of the opposite gender. Further, participants in this brief investigation did not appear to differentiate between a parent (ie, first-degree relative) having cancer or an aunt, uncle, or cousin having cancer when estimating their personal risk. Although some respondents specified that their parents' cancer history increased their risk, discussions about cancer in the family usually included extended relatives.

Participants were attuned to public health messages regarding cancer risk and "caught" the conflicting or changing messages that are often put forth by media outlets and researchers. We suspect that those respondents who agreed that everything can cause cancer were not necessarily fatalistic or uninformed, as might be inferred; rather, most of them sounded frustrated. Like many people, they saw and questioned exceptions to the evidence (such as the family member who smoked several packs a day and never developed cancer and the acquaintance who never smoked yet died of lung cancer). These personal experiences cannot be discounted when trying to encourage informed decision making about cancer prevention. Communications might be stronger if these apparent contradictions were acknowledged and openly addressed. Furthermore, it would be interesting to investigate the potentially detrimental effect of repeatedly changing risk and health behavior recommendations.

Anecdotal reports indicate that people do not want to talk about cancer or more specifically colon cancer. The themes about perceived screening norms in our data reflected a tendency to not discuss medical conditions in general, but rarely was a specific hesitancy to discuss

the topic of CRC verbalized. This does not indicate that such hesitancy was not present, but simply that we did not find evidence of it in our data. Perceived norms, powerful hypothesized correlate of behavior in multiple theoretical models, ²⁴ have not been well explored for CRC and warrant further investigation.

Many of the barriers brought up by our participants (such as dislike of the tests) are consistent with the growing literature on perceived barriers to CRC screening in underserved populations. However, we did detect some intricacies that are not often explored in the literature. For example, many participants who mentioned not wanting to know or being afraid that they would find cancer often expressed that they had already fought too many hurdles in life or that what they feared most was a prolonged and painful illness resulting in death. Concurrent with a lack of survivor role models, participants described watching a loved one suffer painfully throughout cancer treatments, only to not survive. Thus, future screening campaigns and messages might include reminding participants that early detection improves survival and that treatments for CRC have improved over time in addition to helping underserved patients learn about the resources and assistance available to them should they be diagnosed with cancer.

The nonprobabilistic sample limits our abilities to generalize much beyond this study, but our study suggests factors relating to cancer (such as perceived risk or normative beliefs) that might be addressed by future programs to address disparities in CRC screening in low-income African American patients in community health centers. The findings highlight subtle distinctions and deeper meanings about cancer risk, cancer communication, and barriers to care that could inform cancer disparity research and screening promotion efforts. Gaining this perspective inductively and from participants' spoken experiences is critical to developing culturally sensitive, appropriate, and effective intervention programs.

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Table 1

Description of the Study Sample^a

	Total N=38 % (N)
Demographic Factors	
Age (Mean, in years)	
Range 47 - 75 (Median = 56)	56.5
Sex, female	68.4% (26)
Health insurance, % uninsured	55.3% (21)
Education, % with less than a h.s. degree	21.1% (8)
Employment, % employed	18.9% (7)
Marital status, % Married or with partner	18.4% (7)
Colorectal Cancer Screening History b	
Ever had any screening	65.7% (23)
Ever had fecal occult blood test	38.2% (13)
Ever had sigmoidoscopy* (n=32)	20.6% (7)
Ever had colonoscopy* (n=31, plus 2 missing)	36.4% (12)
Decisional stage	
Never heard or Never thought about screening	18.2% (6)
Not decided	3.0% (1)
Do not want testing	3.0% (1)
Do want testing	60.6% (20)

Notes.

^aNumbers represent valid percents (with missing cases dropped).

 $[^]b$ Two participants were under the age of 50 (respective ages, 47, 49). Screening questions include only responses age 50 and over.