Colorectal Cancer Screening and African Americans: Findings From a Qualitative Study

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Background: Colorectal cancer (CRC) screening has been found to be an effective tool for the control and prevention of this type of cancer; yet it is underutilized by African Americans. Consequently, African Americans with CRC are diagnosed at late stages and suffer disproportionately higher mortality rates for CRC.

Methods: To understand factors that influence the decision to participate in CRC screening, in-depth personal interviews were conducted with 36 African Americans in the Washington, DC, metropolitan area. Predisposing factors, enabling factors, and reinforcing factors were identified and categorized using the Predisposing, Reinforcing, and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation (PRECEDE) framework.

Results: Findings suggest that distinct differences exist between individuals who are adherent to screening guidelines and those who have not undergone screening. Adherent individuals were more knowledgeable about CRC and held positive beliefs about the benefits of screening. Nonadherent individuals placed little importance on prevention and early detection. Physician recommendation and insurance coverage/cost also differentiated the two groups.

Conclusions: Study findings suggest that efforts to increase awareness and promote the benefits of CRC screening are needed among African Americans. Also, efforts by healthcare providers to recommend CRC screening are important in promoting adherence. Further low- or no-cost CRC screening is needed to increase participation by individuals who are economically disadvantaged.

Introduction

Colorectal cancer (CRC) is a leading cause of cancer-related death in the United States. However, the majority of these deaths are preventable through routine screening, beginning at 50 years of age, as outlined and recommended in clinical practice guidelines. Although screening has been found to be cost effective, screening rates are generally low for the entire US population, with only about half of adults 50 years of age or older being screened according to guidelines in 2004.

In comparison with non-Hispanic whites in the United States, African Americans suffer disproportionately higher incidence (62.3 vs 52.6 per 100,000) and mortality (28.1 vs 20.4 per 100,000) rates for CRC. One possible explanation is that African Americans are less likely to participate in and complete CRC screening procedures, which results in late-stage diagnosis, more difficult treatment, and decreased survival. Although evidence has clearly documented lack of participation in screening as a major factor, new but limited evidence also suggests that biological and genetic predispositions, as well as behavioral (eg, diet) and environmental (eg, access to care) influences, might contribute to some of the disparity seen for CRC.

Research that examines factors associated with CRC screening among African Americans is limited. Several cross-sectional studies have identified lack of health insurance and not having a usual source of healthcare as important factors that potentially explain the limited use of CRC screening by African Americans. Fear of cancer, fear of pain, fatalism, and embarrassment have also been identified as reasons why African Americans do not participate in CRC screening.

The overall purpose of this study was to identify factors influencing adherence to CRC screening among African Americans. Qualitative findings published thus
far are limited in number and have primarily used focus group methodology consisting of study populations not adherent to screening guidelines. Differentiating why African Americans participate or fail to participate in CRC screening has not been well established. This study seeks to add context to the issue by conducting in-depth personal interviews to help identify what differentiates individuals who have and have not undergone screening for CRC.

Methods

Study Recruitment

In-depth personal interviews were conducted in the Washington, DC, metropolitan area between August 2005 and March 2006. Participants were recruited by placing an advertisement in a free local newspaper for 3 weeks and by distributing flyers to African American churches, area senior centers, and community organizations. The advertisement and flyer provided a project telephone number to call. Study participants were also approached at a community-based health clinic serving primarily African Americans. Potential study participants who expressed interest were then screened to ensure that they were 50 years of age or older, did not have a history of CRC, and identified themselves as being African American or black. Interviews lasted approximately 1 hour. As an incentive, participants were offered a payment of $25. Informed consent to participate was obtained from each study participant.

Data Collection

One female interviewer conducted all individual interviews. She used a guide that included a series of open-ended questions that asked about general health, healthcare-seeking behaviors, healthcare experiences, barriers to healthcare, cancer and cancer screening, and health information seeking. When needed, the interviewer probed to obtain additional information or to clarify what the participant expressed. All interviews were audiotaped. The interviewer took notes during the interview and also summarized the interview when it was completed. After each interview, if necessary, the guide was modified by the interviewer to include additional questions to explore ideas that had emerged. Data collection ended when the final study participants communicated content already expressed by early study participants and when no additional information was identified by the research team.

Analysis

Audiotaped recordings of the interviews were transcribed. Transcripts were then uploaded into NVivo software, a qualitative data management program (NVivo version 2.0, QSR International Pty Ltd, Doncaster, Victoria). Data analysis was a continuous process. To begin summarizing the data, all members of the research team independently reviewed the first 10 transcripts to create a list of themes. These themes were subsequently discussed and any disagreements were resolved. These themes were then used to code data. Throughout the data analysis process, research team members independently coded transcripts and, when necessary, resolved any disagreements. New themes were also created as they emerged. Upon completion of the data collection, two research team members reexamined all transcripts to ensure appropriate coding and then examined relationships between themes.

To assist in organizing the themes identified in this study, the Predisposing, Reinforcing, and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation (PRECEDE) model was used. PRECEDE provides a framework to diagnosis and understand why health conditions exist. For this study, themes were identified and categorized based on factors consistent with PRECEDE: predisposing, reinforcing, or enabling. Predisposing factors provide the motivation for the behavior; enabling factors occur prior to the behavior and facilitate behavior; and reinforcing factors follow a behavior and increase the likelihood that the behavior will be repeated. Themes where then compared and contrasted based on CRC adherence. For our study,

Table 1. — Sample Characteristics (N = 36)

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* One participant declined to provide this information.
adherence to CRC screening was defined as having had either a fecal occult blood test (FOBT) within the past year, a flexible sigmoidoscopy within the past 5 years, or a colonoscopy within the past 10 years.

Results
A total of 36 individuals participated in the study (Table 1). Of these individuals, 42% were adherent to CRC screening. The sample was equally divided by gender. Approximately two thirds of the sample participants were between 50 and 55 years of age. The majority of participants had some college experience, were not married, had health insurance, and were currently employed.

Upon examining the data, themes emerged that revealed similarities and differences between adherent and nonadherent study participants. Table 2 outlines the themes identified according to adherence to CRC screening. Themes identified are discussed below and contain quotes that represent ideas and opinions that were often expressed by study participants.

Predisposing Factors

**CRC Screening Knowledge:** Compared with individuals who had not adhered to CRC screening guidelines, those who understood the guidelines were adherent. Adherent individuals, regardless of gender, demonstrated a more in-depth understanding of CRC screening including the purpose of the screening, types of CRC screening tests, and appropriate testing intervals. Men and women who were nonadherent were unclear about CRC screening recommendations and held many misperceptions. One nonadherent man said, “For the colonoscopy, I think you have to drink something like barium for when they do the x-ray.” Another said, “I think it’s well worth it once or twice a year for men, definitely black men, to take that test.” Nonadherent women expressed the belief that CRC screening was primarily for men. A nonadherent woman said, “It occurs more with men and that’s why it’s a good idea for them definitely to have colonoscopies.”

When asked about the actual screening test, a majority of nonadherents had some familiarity with the word “colonoscopy.” However, when asked, these individuals were unable to provide a description of the test. Even fewer nonadherent individuals were familiar with the fecal occult blood/stool card test. Nonadherent men also confused prostate and CRC screening. This confusion led some individuals to believe that they are being screened for CRC when they are actually being screened for prostate cancer. One nonadherent man noted, “I thought it [referring to colon and prostate cancers] was all the same thing. I thought it all was hooked up together.”

**Outcome Expectations:** Study participants who expressed that CRC screening leads to early detection and increases survival were adherent to CRC screening. One adherent woman said, “I’ve heard that it’s one of the easier cancers to treat if it’s caught early enough,” while an adherent man said, “If you found it early, I mean, you can nip in the bud, you have a good chance.” However, nonadherent participants were more likely to view CRC screening as a tool for diagnosis rather than prevention or early detection. Nonadherent study participants who witnessed family and friends die of CRC or other cancers were less likely to see a benefit to screening. One nonadherent woman mentioned that she didn’t see a benefit to early detection “because I know people who found out they had cancer and they died in 2 months.”

**Perceived Susceptibility:** Study participants who believed they were at increased risk for CRC were adherent. Individuals who believed that being African American or having a family history of CRC were screened. One adherent man stated, “Black folks get those kinds of cancer [referring to colorectal and prostate] at a higher percentage than non-blacks. It’s something in our genetics.” Study participants also mentioned increasing age as a reason for having increased perceptions of developing CRC; however, this view was shared by both adherent and nonadherent participants.

In general, nonadherent individuals felt they were at lower risk for developing CRC. Nonadherent women believed that CRC is a disease that affects primarily men and therefore women are at lower risk. Nonadherent individuals also believed that their lifestyles reduced their risk of devel-
Nonadherent men and women discussed risk from certain sexual acts. One woman stated, “I never tried anything sexual in that area or anything like that. Like I said, it may sound silly to you but to me I think that might be an important factor.” Other nonadherent individuals mentioned having lowered risk because of diet. One nonadherent participant stated, “I don’t eat enough meat and I drink enough fluids and I eat enough vegetables.”

**Negative Perceptions About Testing:** Study participants who have never had a colonoscopy held negative perceptions about this screening test. This was true for both FOBT adherent and nonadherent study participants. Although women mentioned that colonoscopy was or seemed invasive, this belief was mainly expressed by men. As one nonadherent man noted: “It just makes you feel a little queasy, you know; somebody putting something up in there like that you understand as a man.” Participants also described colonoscopy as “painful” and “uncomfortable.”

**Fear of Detection:** A theme that emerged only in nonadherent participants dealt with the fear of detection of CRC. One participant described why he decided not to have a colonoscopy: “What if I do this and what if they find, oh, God no, I don’t want to know.” Another participant said, “I think a lot of black people don’t go to get diagnosed for cancer or don’t have access to screening for colon cancer because they don’t want to know. I think they are scared to know.”

**Distrust of Medical Establishment:** Distrust of the medical establishment emerged in discussions with nonadherent men and women, but this was generally absent in discussions with adherent individuals. Nonadherent study participants mentioned that they use healthcare services less frequently since they did not trust the healthcare they received. One nonadherent woman indicated, “You know, because doctors don’t get much money from Medicare. I really think that has a lot to do with their treatment of me or of patients because they don’t get paid that much money.” Another woman said, “I don’t want to say I distrust healthcare professionals, but sometimes I am just not sure that they know all that’s going on.” A nonadherent man said, “I want a second opinion,” when discussing what he would do if his doctor recommended a colonoscopy.

### Enabling Factors

**Healthcare Provider Recommendation:** Interactions with healthcare providers played an important role in CRC screening. Adherent men and women discussed the importance of healthcare provider recommendations in their decision to screen. An adherent man said, “My doctor recommended colonoscopy, so I did it in an attempt to have good health.” Nonadherent men and women repeatedly mentioned that their healthcare providers did not recommend CRC screening. Nonadherents noted that they depend on their healthcare provider to recommend tests. One individual said, “So I’m pretty sure if he had a reason for me to get screened [for CRC], I mean like, he would tell me.”

**Healthcare-Seeking Behavior:** Adherent women were more likely to have a more active role in their healthcare. The majority of adherent women discussed how they personally requested CRC screening. One participant mentioned, “I take responsibility for my health, I don’t just leave it in other people’s hands anymore. I research and find out what’s going on, and then tell the doctor what I think, and let him tell me what he thinks, and then we can work on something together.” In contrast, adherent men and nonadherent men and women were less likely to engage healthcare providers in discussions about CRC screening. Also, nonadherent men and women were more likely to say that they do not actively seek preventive healthcare, stating that they did not go for regular checkups. Individuals who did not see the doctor regularly noted that they did not frequent the doctor’s office enough for the doctor to recommend CRC screening. One nonadherent man noted, “I just haven’t been taking the time to go to the doctor and telling him what I want and get it done.”

**Insurance and Cost:** Two significant barriers that emerged in interviews were the cost of healthcare and the lack of health insurance. Nonadherent participants noted the cost for medical tests and described waiting until they have insurance to have CRC testing. One nonadherent woman said, “I got to wait on insurance.” Even individuals with insurance who were nonadherent discussed the barriers that co-payments had on seeking healthcare. One woman said, “You know, I have to pay the co-payments out of my pocket, Medicare only pays 80%.” Adherent individuals discussed the importance of insurance in completing CRC screening. An adherent woman said, “But you know, it might be a different story if I didn’t have insurance.”

**Accessibility:** Both adherent and nonadherent participants described difficulty in accessing CRC screening services. Adherent individuals described the hurdles they had to overcome (eg, obtaining a referral to a specialist, scheduling a ride home after the procedure) and discussed how these obstacles delayed their compliance to CRC screening. Discussions of access, however, were more pronounced with nonadherent individuals. Repeat-edly, individuals cited obstacles in obtaining healthcare as reasons why they had not had a CRC test. One individual noted in response to her trying to obtain a free CRC screening, “I didn’t have a phone, so they couldn’t call me back.” Another nonadherent woman said, “I never heard of free screening programs [for CRC].”

**Cue to Action:** Nonadherent men and women noted that they would not be screened unless they were experiencing symptoms, as these symptoms
would provide an indication of CRC. One nonadherent man said, “If I don’t feel bad then I guess I feel okay, and if I feel okay then I am okay.” Common to most nonadherent participants was the idea that they would get screened only if they experienced abnormal symptoms. For example, one nonadherent woman noted, “I guess the only way I would is if I would see blood in the stool.” Noting that his body would provide a signal of illness, one nonadherent man said, “My body is what I know, and I can tell if there’s something wrong before any doctor. Can’t no doctor tell me more than what I can tell. I go to a doctor and I’m gonna tell him what’s wrong with me.”

**Competing Priorities:** Competing priorities emerged as a distinct difference between adherent and nonadherent study participants. CRC screening priority was reduced when chronic health conditions existed and when individuals faced financial and personal obligations. A nonadherent man said, “I got tired actually of being probed and stuck and I actually put it off.” A nonadherent woman said, “I want to stop smoking. I want to lose weight. It’s just too much on my plate.” When asked why he does not get screened for CRC, like other men his age, a nonadherent man noted, “Most people are barely living or they are living on the edge or from paycheck to paycheck. It’s getting so expensive to live in DC now and nobody is really worried about that [CRC].”

**Reinforcing Factor**

**Peace of Mind:** Although not a predominant theme, several adherent individuals discussed wanting to know if they had CRC so that they could have peace of mind. For adherent individuals, participating in CRC screening gave them a sense of relief, helping them feel “on the safe side.”

**Discussion**

Increasing the rates of CRC screening is a national priority. For African Americans, who experience disproportionate rates of this disease and higher morbidity, CRC screening is an effective strategy that has the potential to reduce this disparity. Understanding what factors influence CRC screening decisions among African Americans is essential for guiding effective public health interventions targeting this population. Data from the present study provide insight into these potential factors by examining differences between African Americans who have participated and are adherent to CRC screening and those who have not yet undergone screening. Broadly examined, the present findings indicate there is not one main reason that separates the two groups, but rather overlapping themes that represent both cognitive and attitudinal components, as well as community and societal level factors. Interventions should take into account all of the factors identified since they may uniquely, or in combination, influence the decision to have a CRC screening examination.

Findings from this qualitative study reveal that there are several themes that clearly differentiate adherent and nonadherent study participants. A prominent theme is knowledge. Adherent individuals were more knowledgeable about CRC and screening. Nonadherent individuals were generally unfamiliar with CRC screening and also held various misperceptions. Two of these misperceptions emerged consistently. The first was that nonadherent women believed that only men needed to screen for CRC. The second was that nonadherent men confused CRC screening and prostate cancer screening, which has previously been documented by Bastani et al. These findings highlight the need for better education and suggest that CRC screening be discussed and differentiated by healthcare providers when other cancer screening examinations are conducted. Further, if individuals are participating in other screening examinations, it might be an opportune time to promote CRC screening.

Given the misperceptions and lack of knowledge about screening, it is no surprise that nonadherent individuals held negative outcome expectations regarding CRC screening compared with the more positive ones held by adherent participants. Efforts are needed to increase awareness and knowledge about CRC screening among African Americans while also stressing the benefits associated with CRC screening, especially its effectiveness for early detection of CRC and potential for prevention when colonoscopy is performed.

Perceived susceptibility was another factor that differentiated study participants. Risk perception was important in activating study participants to seek screening. This finding supports others that have also identified a relationship between CRC screening and perceived cancer risk. Our findings indicate that those who felt at risk were screened, while the majority of nonadherent participants felt they had no risk or were at low risk for CRC. Finding new ways to communicate and portray actual risk might be an intervention strategy that could increase participation in CRC screening.

Distrust of the healthcare system was also mentioned as a reason to not participate in screening. This finding is shared in other qualitative studies examining CRC screening. The reasons for this distrust were not well established in this study or in previous studies. Future research needs to clearly delineate what influences these perceptions. Perhaps it is the historical injustice and discriminatory practices in healthcare that continue to resonate. Nonetheless, there is no simple solution to remedy this. A healthcare system is needed that recognizes the unique cultural characteristics of African Americans and then tailors interactions and experiences in healthcare around these values and norms.
Several additional predisposing factors identified in the study are consistent with previous research identifying barriers to screening. In this study, nonadherent individuals discussed fear of a cancer diagnosis as a reason for avoiding screening. The identification of this theme is not novel. However, it stresses that interventions need to address the benefits associated with screening and convey that a cancer diagnosis does not always result in death, a common outcome expectation held by nonadherent individuals. Additionally, negative perceptions associated with colonoscopy screening also existed. Nonadherent participants were generally welcoming of FOBT. Studies examining test preference reveal that African Americans prefer FOBT over endoscopy procedures. However, the American College of Gastroenterology has taken the position of recommending colonoscopy as the preferred screening method for CRC screening. Given that there are several testing options available, healthcare providers should engage patients in shared decision making to ensure that the patients understand the benefits and risks of each testing procedure.

Provider recommendation emerged as a key enabling factor for participation in our study and is consistently supported in the literature. As in other qualitative studies, nonadherent study participants mentioned that they did not have a CRC screening examination since it was not recommended by a healthcare provider. Given the important of recommendation, efforts need to focus on ensuring that providers recommend CRC screening to African Americans. However, even if a recommendation is made, CRC screening must be available. In our study, we found that nonadherent participants had difficulty accessing CRC screening services and that inadequate or no health insurance coverage prevented study participants from screening. Nonadherent study participants also discussed competing priorities as reasons for not participating in CRC screening. In part, these priorities were economically driven. Nonadherent individuals commonly expressed the sentiment that paying bills was a priority over paying for unnecessary screening examinations. Removing the barrier of cost is essential to increasing screening, especially among the financially disadvantaged.

In our study, adherent women reported that they were more actively involved in their healthcare. They sought out preventive health services and participated in decision making about their health. Several women even shared stories in interviews of how they had to insist on CRC screening from their doctors. Recent research has emerged that highlights the importance of patients being actively involved in their healthcare decisions since they are more likely to have better health outcomes. Our findings suggest that a large number of adherent men and nonadherent study participants were not actively involved in their healthcare. Given that involvement in healthcare appears to be important, there is a need to identify strategies that will engage participants to be more actively involved.

Study findings also suggest that efforts must be undertaken to influence perceptions of priority relating to prevention. Our findings suggest that nonadherent individuals placed less focus and importance on prevention. Many nonadherent participants reported having a CRC examination only when they experienced a problem or “cue to action.” This finding is also supported by Jernigan et al. This health-seeking behavior is problematic, especially since overt symptoms are usually indicative of advanced disease. Interventions and health messages must promote CRC screening as a preventive tool rather than a diagnostic tool. The importance of CRC as a preventable disease must be stressed in this population group.

The current study did not find any support for fatalism and social support as factors that influence CRC screening. Although other published studies that have examined cancer screening have identified these factors as relevant, the lack of confirmation in our study does not imply they are not important. Fatalistic beliefs have been clearly identified in the cancer screening literature as reasons why African Americans do not pursue cancer screening. Study participants also mentioned that CRC is not discussed among family and friends, suggesting that little or no social support is offered for CRC screening. Efforts are needed to make CRC screening normative to help facilitate open discussions about screening. More research is warranted to investigate what roles these possible determinants may have on CRC screening. Research should also focus on investigating why participants did not acknowledge reinforcing factors for screening. Only three individuals reported a sense of satisfaction for screening or “peace of mind.” The fact that most participants failed to mention any sense of personal satisfaction or extrinsic reinforcement needs further investigation and might indicate an important strategy to include in future interventions.

Results of this study are influenced by certain limitations. Self-report of CRC screening was used to determine if study participants were adherent to CRC screening and was not validated. All participants were asked to explain the CRC screening procedure they had in detail to identify individuals who may not have had CRC screening. In doing this, two individuals who initially reported being adherent were found to be nonadherent. Additionally, although qualitative research can yield rich data, the results are not necessarily generalizable to the general population and the findings must be interpreted cautiously. Our study sample was selected using a convenience sample and findings may not be representative of our population as a whole.
However, several of our themes are consistent with other studies examining African American CRC screening behavior. Further, the use of an interviewer guide might have restricted our exploration of themes and might have influenced participant responses. Lastly, the interviewer was a woman and thus discourse might have influenced the data obtained from study participants who were men. Conversely, a strength of the present study is that it differentiates CRC screening adherence among African Americans. To date, qualitative studies using focus groups have examined CRC screening in African Americans and have failed to differentiate differences between those who have undergone screening and those who have not. These studies have generally provided reasons why African Americans are not screened. Understanding why African Americans are screened can provide an important insight on how to activate individuals who are disengaged or in precontemplation.

Findings from this study have several implications for cancer prevention and control. Our findings suggest that limited knowledge about CRC and screening is a large component of why African Americans are not participating in screening. Efforts must be made to increase awareness and educate African Americans about the importance of early detection. Similarly, these interventions must also counterbalance the negative beliefs that African Americans have about CRC. Strategies need to be put into place that stress the benefits of screening (pros) and also address and decrease the barriers (cons) of screening. One significant barrier identified in this study was access to care. If increasing CRC screening is to be achieved and the Healthy People 2010 goal of reducing CRC mortality to 13.9 deaths per 100,000 individuals is to be achieved, no-cost or low-cost screening must be made available since lack of insurance and competing financial priorities decrease the likelihood of CRC screening participation.

Another key finding of this study, which has considerable implication, is that healthcare providers must recommend CRC screening to their patients. The importance of healthcare provider recommendation is well documented for cancer screening, including CRC. Emerging from this qualitative study are findings that suggest African Americans rely on their healthcare providers for screening recommendations and that these recommendations are important in the CRC screening decision-making process. However, national data suggest that providers are not recommending screening at optimal levels for the general population. Future research needs to determine what prevents healthcare providers from recommending CRC screening to African American patients, and it also needs to develop effective interventions that facilitate provider-patient communication about CRC.

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

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References


