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## African American and Caucasian Perceptions and Attitudes Toward Colorectal Cancer Screening: A Qualitative Study

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## African American and Caucasian Perceptions and Attitudes Toward Colorectal Cancer Screening: A Qualitative Study

### Abstract

This study examined the attitudes held by both African Americans and Caucasians regarding colorectal cancer screening and the reasons why they avoid screenings even when clinically indicated by their physicians. Colorectal cancer (CRC) is one of the most common and easily preventable types of cancer in the United States. If diagnosed and treated early prior to metastasis, the five-year colorectal cancer survival rate is approximately 90%. However, many patients avoid screening procedures for colorectal cancer due to a number of reasons. Qualitative data was gathered from focus groups and found four major themes that emerged in both groups: (1) reported barriers to screening, (2) level of knowledge about CRC, (3) knowledge of risk factors for CRC, and (4) suggested strategies for improving CRC screening. African Americans and Caucasians reported differential concerns for each of those themes, including on physician vs. access issues (barriers), environmental vs. hereditary diseases (risk factors), community vs. physician-based interventions (strategies), and substantial differences with regard to CRC knowledge.

### Keywords

colorectal cancer, screening, health promotion, prevention, focus group

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## **African American and Caucasian Perceptions and Attitudes Toward Colorectal Cancer Screening: A Qualitative Study**

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This study examined the attitudes held by both African Americans and Caucasians regarding colorectal cancer screening and the reasons why they avoid screenings even when clinically indicated by their physicians. Colorectal cancer (CRC) is one of the most common and easily preventable types of cancer in the United States. If diagnosed and treated early prior to metastasis, the five-year colorectal cancer survival rate is approximately 90%. However, many patients avoid screening procedures for colorectal cancer due to a number of reasons. Qualitative data was gathered from focus groups and found four major themes that emerged in both groups: (1) reported barriers to screening, (2) level of knowledge about CRC, (3) knowledge of risk factors for CRC, and (4) suggested strategies for improving CRC screening. African Americans and Caucasians reported differential concerns for each of those themes, including on physician vs. access issues (barriers), environmental vs. hereditary diseases (risk factors), community vs. physician-based interventions (strategies), and substantial differences with regard to CRC knowledge.

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Colorectal cancer (CRC) is the third most common cancer and the second leading cause of cancer death in the United States (American Cancer Society [ACS], 2022). While CRC screenings, including fecal occult blood test (FOBT), multi-target stool DNA test, flexible sigmoidoscopy, colonoscopy, and double contrast barium enema (DCBE), have been shown to greatly reduce the number of individuals dying of CRC, national survey data (Centers for Disease Control [CDC], 2020) show that approximately 20% of eligible, average-risk adults over the age of 50 have never been screened and approximately 1 in 3 were not up-to-date with screening (ACS, 2022; CDC, 2020; US Preventative Task Force, 2021). As per the updated U.S. Preventive Task Force colorectal cancer screening recommendation, the age at which to begin screening for CRC has been reduced from 50 to 45 years (CDC, 2020). Barriers that contribute to less-than-optimal CRC screening rates may be categorized as patient, provider, and healthcare system factors (Kiviniemi et al., 2018; Klabunde et al., 1995).

Barriers appear to be more pronounced among racial minorities, females, and older adults (Etzioni et al., 2004; Jackson et al., 2016). Although African Americans have the highest incidence of CRC, they are typically the least likely to have been screened (ACS, 2019; Rie, Wallace, & Small, 2015). Previous research suggests that for African Americans fear, mistrust of the healthcare system, belief that screening would not help to destroy the cancer (fatalism), and a lack of knowledge about CRC and CRC screening may be reasons for lower screening

rates (Williams et al., 2018). Women report fear of the screening, discomfort, and embarrassment caused by male physicians as reasons for their lower screening rates (Farraye et al., 2004; Friedmann-Sanchez et al., 2007). For adults over 75, access to care barriers could account for lower screening rates despite increased risk of polyps and CRC being the leading cause of cancer death for that age group (Clipp et al., 2004).

Psychosocial screening barriers include patient embarrassment (Hughes et al., 2015; Kiviniemi et al., 2018), anxiety or fears (Klabunde et al., 1995), limited knowledge (Holmes-Rovner et al., 2002; Horne et al., 2015), adverse attitudes, beliefs or skepticism about provider intent, underestimates of risk especially among first degree relatives of persons with CRC (Griffith et al., 2007), and mistrust of the provider (White & Itzkowitz, 2020; Williams et al., 2016). Mixed-race focus groups of African Americans and Caucasians on Medicaid indicate powerful and recurrent themes of lack of knowledge and skepticism (Holmes-Rovner et al., 2002).

Physician factors that reduce patient participation in screening include lack of physician recommendation and inadequate physician communication, thus reducing patient awareness of need for screening (Jones et al., 2010; Wee et al., 2004). Physicians state that they refrained from recommending CRC screening because of lack of opportunity to discuss screening with patients, their assessment that the cost of the screening would be a problem for the patient, distraction by other life issues or health problems, forgetfulness, and expected patient refusal (Levy et al., 2007). However, despite the reasons that physicians may have for not informing a patient about their need for screening, those patients whose doctors recommend, or mention screening are more likely to get screened for CRC than those patients whose doctors refrain (Laiyemo et al., 2014; Shokar et al., 2006). Moreover, patients may benefit from physician-initiated conversations about CRC screening barriers and how to overcome them (Johnson Shen et al., 2020).

System factors that reduce screening rates are underscored by socioeconomic barriers such as income, education, health insurance, and not having a usual source of care (ACS, 2022; Etzioni et al., 2004; Patel et al., 2012; Williams et al., 2016). Rural residents are also less likely to have CRC screening than urban residents (Brittain et al., 2012), suggesting an access to care factor. Insurance coverage for screening varies by state. Since July 2001, Medicare (2022) provides a full range of CRC screening coverage for beneficiaries. Medicaid coverage generally varies state by state and by managed care plans (ACS, 2022). A study comparing individuals with dual Medicare – Medicaid care status (duals) and individuals with Medicare only or with other healthcare coverage (non-duals) found those with dual status were older, had a lower socioeconomic status, and were less likely to get screened because of their economic status than the non-duals (Koroukian et al., 2006). However, in January 2011 the Affordable Care Act (ACA) eliminated cost-sharing for preventative services such as CRC screening for those with Medicare coverage, making screenings more widely accessible to those facing financial barriers (Song et al., 2019).

The purpose of the current study was to determine similarities and differences between insured African Americans and Caucasians with regard to their CRC knowledge and source of knowledge, CRC screening modalities, and CRC screening beliefs and perceptions. We limited our study to individuals with some form of health coverage to rule out the impact of CRC screening availability as a predictor of screening and to examine underlying beliefs and values that influence screening behavior when such screening is economically viable. Our research team functions in a Primary Care setting, and often works closely with individuals who have avoided CRC screening until they are symptomatic and are then requiring more intense intervention. CRC is one of the most preventable causes of death if caught early, and our hypothesis was that these barriers needed to be better understood to tailor interventions to specific populations. We hope that by conducting this investigation, we are able to identify

means of removing, or at the very least mitigating, some of these barriers and help our patients live longer, more fulfilling lives.

## **Method**

### ***Sample Characteristics***

Advertisements (radio, newspaper, announcements on the medical school's website) and fliers recruited thirty-one English-speaking African American (N=14; 45.2%) and Caucasian (N=17; 54.8%) adults aged 45 and older [20 females (64.5%), mean age = 58.8 years] with health insurance for this study. Forty-five percent (N = 14) of participants reported having private insurance only, 29% (N = 9) reported having Medicare or Medicaid only, and 25.8% (N = 8) reported having some combination of Medicare, Medicaid and private insurance. Modal income for African Americans was reported at \$10,000 - \$20,000 a year, while modal income for Caucasians was reported at \$20,001 - \$30,000 a year. Modal household income for our overall sample was reported at \$10,000 - \$20,000 a year. The modal level of education was reported as high school or having received a GED.

### ***Focus Group Methodology***

Qualitative research methods can be useful in providing researchers with a broader understanding of the diverse perspectives and lived experiences of individuals. This methodology is particularly valuable in multicultural research; it can foster greater cultural sensitivity and understanding through eliminating predetermined instruments and tools, and evaluate subjective attitudes, beliefs, feelings, and actions of each individual (Ponterotto, 2010). Focus groups are an effective qualitative method for gathering multiple perspectives about the same subject matter in ways that may not be feasible using other qualitative methods (e.g., observation, surveys, one-on-one interviews; Gibbs, 1997). For instance, it allows for exploration of level of agreement on a topic and collection of much valuable information within a short timeframe (Gibbs, 1997). Our focus groups' purpose was to record the opinions, beliefs, and experiences of older adults regarding various aspects of CRC and CRC screening. Given that many of our hypothesized barriers to CRC screening, and those previously identified in literature are emotional or cultural in nature, we felt that a qualitative approach was most appropriate to reach the basic motivations behind an individual's decision to not be screened. From a logistic and economic perspective, CRC screening is affordable, relatively painless, and requires a minimum of time investment. It is those personal, attitudinal factors that we felt were driving this phenomenon, and for those variables, a quantitative approach would miss both the nuance and the *personal* side of our patients' beliefs about screening. The institution's review board approved this study, and participants gave written informed consent. Same race participants composed each of the seven focus groups (4 African American groups, 3 Caucasian groups) to facilitate later racial comparative analysis of themes. Focus groups typically took 1 to 2 hours to complete in the same conference room, followed a standard trigger-question script, and were facilitated by either a Family Medicine medical resident or a master's level psychological or health professional with experience in behavioral research in a medical context (accounting for a total of 5 facilitators). At the conclusion of each focus group, participants were offered educational material about CRC and CRC screening tailored to their racial group.

## Analysis

All group sessions were recorded and transcribed by an independent transcription service. Field notes were also recorded by group facilitators for later review. Transcripts were reviewed and coded for recurrent themes independently by two separate researchers. Themes were then combined by agreement of the two researchers, theme tags based on the recurrent themes were created, and the transcripts were jointly re-reviewed by the two researchers to tag all instances of the themes. Major themes and sub-themes were developed via an iterative review process. Groups continued until saturation of themes was reached. The two racial groups were compared via frequencies of each major theme and sub-theme and by qualitative content. Relevant quotes were pulled from transcripts that captured each theme.

## Results

### Themes

Four major themes were derived from the gathered qualitative data (see Table 1): **barriers** to screening, **risk factors** for CRC, general **knowledge** of CRC, and ideas to help improve screening rates (**strategies**).

**Table 1.**

*Theme Percentages Within Groups*

<b>Barriers</b>	African American (%)	Caucasian (%)
Psychological barriers	41	39
- <i>Fear of cancer-related issues</i>	13	25
- <i>Unpleasantness of screening</i>	28	14
Physician-oriented barriers	26	31
Economic / Healthcare access	21	11
Lack of information	11	9
<b>Risk Factors for CRC</b>		
Lifestyle choices	28	18
Family history	6	11
Environment	9	0
<b>CRC Knowledge</b>		
What people know about CRC	32	37
Sources of CRC information	35	33

<b>Strategies to Improve Screening Rates</b>		
Physician-oriented solutions	15	30
Community outreach	16	13

### ***Barriers to Screening***

The most common theme endorsed was barriers to screening for CRC. This theme involves something that the respondents felt prevents or stands in the way of screening for CRC. Four sub-themes resulted: psychological barriers, physician related barriers, economic barriers, and lack of information. Psychological barriers refer to a person's state of mind that limits or prevents specific actions (e.g., obtaining CRC screening). Psychologically-based issues were the most frequently mentioned barriers to CRC screening.

*“The cancer itself will never kill you; it’ll be something else, but it will get your body in such a condition that it can’t continue to function, and you’ll die. The cancer will continue to eat . . . I don’t think the average person wants to even think about that”* (Caucasian group 1).

*I think a lot of African Americans that I’ve talked to and been around that we are afraid for those tests. Now I’ve talked to some guys I met at the VA and other places you know and told them that I was going to get my test here before long, and they really were afraid to go along and get the test, and one guy, whoever it was, told me, if I have something wrong with my colon I don’t really want to know. They get the attitude that’s bad, if somebody tells you that, that’s really bad...”* (African American group 2).

Not only were patients apprehensive about the emotional (embarrassment) and physical (discomfort) aspects of CRC screening procedures and preparation, but participants also stated that people might be afraid to even talk about having cancer or about their own mortality, suggesting great angst with the underlying reasons for screening. These excerpts highlight how the fear of the testing procedures themselves and negative effects of cancer may make someone avoid obtaining CRC screening. Although no particular theme was unique to either racial group, Caucasians tended to talk about the fear of cancer discovery more, while African American talked more about the physical and emotionally unpleasant nature of CRC screening.

Physician-related barriers were also frequently discussed. Physician-related barriers refer to characteristics and actions of physicians that limit or prevent specific actions (e.g., obtaining CRC screening).

*“[Physicians] don’t want to spend that kind of time with you; if he stays in there 5 minutes with you, that’s all. They don’t even talk to you a lot of times”* (African American group 1).

*“Sometimes doctors don’t listen 100 percent, and they think it’s one thing and you’re trying to describe the symptoms and certain aspects of what you’re going through. I know my body and it isn’t right; it’s doing this, and the doctor hears*

*it a different way, and that I think is sometimes a problem” (Caucasian group 2).*

These excerpts highlight that participants felt that doctors may not be taking enough time with their patients, may not be attentive enough, or may not provide enough or even accurate information to their patients. Since trust in one’s physician among older patients is associated with greater adherence to cancer screening and general routine care (Musa et al, 2009), this is an important finding that suggests this distrust may stem from some patients’ belief that some physicians may not be engaged enough in their care or do not take them seriously.

Economic and service-related barriers were mentioned more by African American groups than Caucasian groups. Economic and service-related barriers refer to systemic factors, related to the healthcare system, that limit or prevent specific actions (e.g., obtaining CRC screening).

*“We have people who cannot go see a doctor, and it’s a choice. Either I’m going to eat or I’m going to see a doctor, so they eat. There’s a lot of people in this country who do not have health care and can’t go to the doctor and that’s why their health is so bad and they’re dying of cancer because they don’t have healthcare. They come up with Medicare and they just keep raising Medicare and want to cut this out and cut that out right, and you’re a senior citizen with a no-win situation, you can’t win” (African American group 3).*

This excerpt highlights that factors such as lack of insurance, prohibitive healthcare costs, and inherent disparities in healthcare access could contribute to an individual not getting screened. While the Affordable Care act and other population-based initiatives have helped mitigate some of these concerns, access to quality health care is still an obstacle for many Americans due to factors such as excessive deductibles for those on limited incomes, transportation, and dependent care, among others.

The last major potential barrier mentioned by our participants was categorized as “lack of information” as supported by a lack of education and information about CRC and screening procedures available to the public.

*“How many people in the country have colon cancer a day, what percentage? I have no clue” (Caucasian group 1).*

*“Not too much I know about [CRC], but I do know that it exists, and I know that it is a disease” (African American group 3).*

These excerpts highlight a general lack of information about colon cancer (e.g., prevalence rates) and CRC screening modalities. It is important to note that this lack of information is independent of a source and refers to individuals not knowing about and acting on screening and health recommendations.

Personal factors, such as lack of time, gender, and cultural-based prohibitions against going to doctors, or just being simply “too stubborn” to go, were a minor theme uncovered from our analyses. Caucasian groups were almost exclusively the sources for this theme.



### **Knowledge of CRC**

Knowledge of CRC and screening procedures emerged as the second major theme. Within this topic, two sub-themes evolved: *where* people get their information and *what people know* about CRC. Family and friends, as well as the media, are prevalent sources of information on CRC and CRC screening. Approximately half of the discussions about CRC information sources involved participants learning what they knew from their own efforts and experiences, as seen in the excerpt below.

*“I like to read and watch a lot of TV on that, that’s all my knowledge”* (African American group 2).

With regard to participants’ CRC knowledge, most of the discussions dealt with information about screening techniques and their uses, along with preventative measures to protect against CRC. It should be noted that we did not check the accuracy of the information they discussed, and we did not make distinctions between correct and incorrect knowledge held by the participants. For this theme, we wanted to assess the pure volume of information our patients knew, or thought they knew, about CRC. Patients also discussed what they understood about the symptoms of CRC. A few individuals mentioned looking into current findings in CRC research. Knowledge about CRC was consistent between both African American and Caucasian groups.

### **Risk Factors for CRC**

The most prevalent theme of risk factors had to do with lifestyle choices. This involved personal and deliberate decisions to engage in behaviors that may impact the risk of CRC. A commonly endorsed lifestyle choice centered on the idea that an individual’s diet was a major contributing factor to CRC.

*“...a lot of people don’t have enough fiber in your daily nutrition as we should”* (Caucasian group 3).

As seen in the excerpt above, a nutritious diet (e.g., fiber consumption) may be important. Other lifestyle factors were also mentioned, such as lack of exercise, use of certain medications, and life stress. Furthermore, family history was another heavily mentioned risk factor throughout our discussions.

*“I would think that like one of your immediate family that had polyps or something like that, you would have a better chance of developing polyps than somebody who doesn't have any in the family at all”* (African American group 2).

As highlighted in the excerpt, the group spoke on how family history can influence genetic factors that cause growth of cells in the colon and rectum (i.e., polyps).

Additionally, African American groups uniquely talked about environmental factors, such as industrial chemicals and excess additives in food that contributed to an increased risk for CRC. African Americans also felt that aspects of an individual’s culture related to food and food preparation may increase risk for CRC. However, Caucasian groups talked more than African American groups about age and other health conditions possibly contributing to CRC risk.

*“ . . . somewhat culturally as in what we eat, fried foods, and using s, the tradition is to have those oils kept on the cooking stove and you continue to use the same oil or those carcinogens in the oil itself” (African American Group 3).*

It is known that carcinogens found in the reused oil of fried foods may contribute to an increased risk of CRC (Ganesan, Sukalingam, & Xu, 2019). Our African American participants recognized that some of their cooking traditions centered around conservation and re-use of cooking oil, may contribute to increased risk for CRC.

### ***Strategies to Increase CRC Screening Rates.***

Two CRC screening rate improvement suggestions were found. The most frequent solutions were physician-oriented, such as providing more pertinent information, giving more screening reminders, and showing patients more care and attention.

*“My doctor sends me a card in the mail to remind me that I need to have it done” (Caucasian group 3).*

This excerpt provides an example of how physicians can increase screening rates through mailing screening reminders. As healthcare has become increasingly augmented through the use of tools such as electronic health records, automated reminder calls and emails, and online portals with secure messaging capability, these services have become incredibly valuable for reaching patients in need of routine screening.

Caucasian groups mentioned physician-focused solutions twice as frequently as African American groups. Another suggestion discussed community outreach strategies and using communities to inform the public about CRC.

*“Community like the elderly clubs...” and “Maybe have a guest speaker or someone come and talk to them” (Caucasian group 3).*

*“Health Fairs that might provide information on screenings” (African American Group 4).*

These excerpts provide two distinct examples of how community resources (e.g., elderly clubs, guest speakers, health fairs) can increase knowledge on CRC screenings. These resources are incredibly useful for many older adults and provide easy access to health educators wishing to reach as wide an audience as possible to provide information about CRC and CRC screening.

## **Discussion**

More similarities than differences were found in comparing insured African American and Caucasian individuals with regard to their perceptions and knowledge about CRC disease risk and screening. Four major themes resulted: **barriers** to screening, **risk factors**, general **knowledge** of CRC, and **strategies to improve screening rates**. For barriers to screening, Caucasian groups said more about the fear of cancer as a screening deterrent, while African American groups talked more about the physical and emotional embarrassment and unpleasantness of CRC screenings. These findings contrast previous research that indicated that African Americans have more fear about screening (Williams et al., 2016; Williams et al.,

2018). African Americans, who often spoke of others of their race being influenced by access issues, mentioned economic barriers more than Caucasians.

Importantly, physician barriers and the major theme of lack of knowledge about CRC were perceived as very important by both groups. Considering importance of taking a patient-centered approach care and meeting the patient where they are in terms of their level of understanding regarding risk and protective factors for CRC, health care providers and medical education systems need to recognize this important communication dilemma in order to improve screening rates. Opportunities for patient education, both in the office and on a public health level, should be encouraged, especially tailored to the level of information fluency of a particular group. Interestingly, unlike other studies that have looked at barriers to CRC screening (Klabunde et al., 1995), our study did not find differences between the two groups in terms of how often the physician recommended having any type of CRC screening; however, the perception remains important to these study participants.

Under the risk factors theme, diet and eating patterns were more likely to be mentioned by African Americans than Caucasians who, in turn, mentioned hereditary factors and related diseases more often. Also of note, is the fact that African Americans mentioned environmental risk factors and contaminants whereas these potential risks were never mentioned in the Caucasian groups. Emphasis of risk factors has been shown to encourage screening (Sarfaty & Wender, 2007). Our results suggest that risk factors may need to be individually specific and targeted to specific populations.

Interestingly, Caucasians emphasized strategies to increase CRC screening via physician-based solutions whereas African Americans slightly emphasized community-based approaches more. Cultural differences in the importance of the larger community versus the importance of the individual may explain this finding.

Recruitment was a challenge and a limitation of this study, perhaps due to the intimate and potentially uncomfortable nature of this topic. Although theme saturation was reached, we hoped for a larger cohort size. While word-of-mouth resulted in more participation, we must view our results as potentially biased, since roughly half of those who participated were referred by someone who had participated in the study or someone who had heard of the study (such as a community contact). Thus, some focus groups participants may have already had strong opinions and/or greater knowledge regarding CRC screening than the average person in our study population. Another limitation was the classification of household income (i.e., coding income in \$10,000 blocks instead of using an integer response). While this coding allowed for easier and less intrusive collection of income data, we were unable to review themes by income, a variable that was different between our two groups. Since our main purpose was to examine racial differences and not socioeconomic differences, this limitation is relatively minor to our findings but should be considered for future research.

In conclusion, this study's findings help identify possible areas of intervention to overcome commonly reported barriers to CRC screening, therefore assisting with earlier detection of CRC. We found no difference between African American and Caucasian groups with respect to knowledge and availability of CRC screening. Differential perceptions of barriers and risks were observed and should be included in both predoctoral and residency training programs. Barriers such as fear of cancer, mistrust of healthcare systems, or the physically or emotionally uncomfortable aspects of CRC screening may vary in specific racial groups. For that reason, additional information for patients of different backgrounds may lead to greater screening rates and subsequently better health outcomes.

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