



Research Article

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# ‘You Ain’t Going in There’: Patient Perceived Promoters and Barriers to Colonoscopy Screening in an Urban Population, Baltimore, Maryland

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## Abstract

**Introduction:** Colorectal cancer (CRC) is the third leading cause of new cancer cases and the second leading cause of cancer mortality. Moreover, African-American women and men are more likely to die from colorectal cancer than their white counterparts. We report qualitative data from nine focus group discussions (FGD) conducted in centers serving a low-income, primarily African-American population in East Baltimore.

**Methods:** Nine FDGs were conducted in health, drug treatment and social service centers across East Baltimore with a total of 127 individuals. A structured interview guide was developed with a focus on three key areas: 1) participants' understanding and interpretations of health, 2) understandings and knowledge about cancer and colorectal cancer, and 3) promoters and barriers to colorectal cancer screening. Transcripts of interviews were coded and analysis was performed using grounded theory methodology and Nvivo software.

**Results:** Key facilitators for seeking colonoscopy were friend and family support systems, having a family member with CRC, seeking medical care for symptoms, viewing the doctor as a partner, and radio, television, and print advertisements. Participants also described barriers to undergo screening including challenges with colonoscopy preparation, colonoscopic procedural and test-specific concerns, insurance and cost concerns, generalized fear, poor relations with physician, and failure of a physician to make a recommendation and referral.

**Conclusions:** Knowledge about facilitators of and barriers to CRC screening (CRCS) are necessary for effective initiatives. Interventions targeted at increasing education, knowledge of CRC, and open conversations between patients and providers may be viable options to improve CRCS, early diagnosis and treatment.

## Keywords

Colorectal cancer; Colonoscopy; Colon; Rectum; Screening

## Introduction

Colorectal cancer (CRC) is the third leading cause of new cancer cases and second leading cause of cancer mortality in the United States. In 2014, CRC was estimated to account for 50,310 deaths [1]. African-American women and men are both more likely to die from colorectal cancer than their white counterparts [2].

Colorectal cancers usually begin as precancerous polyps, presenting a unique opportunity for both diagnosis and preventative care. In June 2016, the United States Preventative Services Task Force (USPSTF) recently updated their 2008 guidelines to reinforce that the recommended age for screening begins at 50 years of age and that patients should receive a colonoscopy every ten years, an annual fecal immunochemical test (FIT), annual fecal occult blood test (FOBT), or flexible sigmoidoscopy every five years combined with FOBT every three years [3]. Rather than offer substantial changes on recommendations for colonoscopy, the USPSTF emphasized that colorectal screening remains underused and that a concerted effort among providers, patients, policymakers and advocates must be utilized to bridge this gap. Colonoscopy remains the gold standard for screening. Overall, African-Americans are less likely to receive colorectal cancer screening (CRCS) than other demographics [4].

The typical referral process for colonoscopy occurs based on age appropriate guidelines or the presence of symptoms associated with colorectal masses (e.g. palpable mass on exam, rectal bleeding, iron deficiency anemia) [5]. A family practitioner or primary care physician would typically then refer the patient to a provider experienced in endoscopy (e.g. gastroenterologist, general surgeon) for further screening and detection of possible malignancy.

Several promoters and barriers to colonoscopy exist for the colonoscopy process, especially among low income populations, urban populations, and African-Americans [6-12]. Beyond notions of fear, procedure related concerns, and questions of cost, many African-American men also note additional barriers about the procedure with regard to sexual connotation and sedation with the procedure, as well as confusion between colorectal cancer screening and prostate cancer screening [13,14].

Mortality remains significantly higher among African-Americans than Whites within the state of Maryland with an age-adjusted mortality rate among blacks of 19.0 per 100,000 population and a rate of 13.0 per 100,000 population among whites. In Maryland, over 30% of the general population does not receive appropriate screening for colonoscopy [15]. Moreover, similar disparities exist with regard to colon cancer screening among low-income minorities [16-18]. In an effort to analyze reasons behind less-than-ideal screening rates, especially among African-Americans in Maryland, we conducted FDGs at multiple centers throughout Baltimore, especially those that serve vulnerable populations. This study aims to add to the growing body of literature on CRCS among vulnerable populations including, but not limited to, screening among homeless individuals, uninsured patients, and substance users.

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## Methodology

### Study setting and recruitment

In the Fall and Winter of 2014 and 2015, nine FGDs were conducted in health, drug treatment and social service centers primarily across East Baltimore, an area that is affected by poverty and less-than-ideal access to healthcare. For example, the Old Town/Middle East neighborhood—a neighborhood in East Baltimore where Johns Hopkins is located—has a population of 10,200 that is 89.5% African-American with 67.2% of households earning less than \$25,000. Discussions were held at facilities that serve individuals experiencing homelessness, people with substance abuse issues, and underinsured and uninsured patients.

When held at Johns Hopkins, focus group participants were recruited from community events (e.g. street fairs, community festivals). For all the other sessions, the hosting agency that serves at-risk populations recruited the participants. Each participant received a \$25 gift certificate. Johns Hopkins IRB deemed the study outside IRB purview and thus agreement to participate in the focus group was taken as consent. All sessions were audio recorded and participants were informed of the recording device in advance.

### Focus group questions and moderation

A structured interview guide was developed with a focus on three key areas: 1) participants' understanding and interpretations of health, 2) understandings and knowledge about cancer and colorectal cancer, and 3) promoters and barriers to colorectal cancer screening. Sample questions are available in Table 1. A total of 127 people participated in the nine focus groups. Each session lasted on average 60 minutes, with a range from 34 to 72 minutes. The range in size of focus groups was 9 people to 25 people (Table 1).

### Coding and analysis

Thematic analysis was performed on the transcripts of the nine audiotaped focus group discussions (FGDs). In line with grounded theory, the FGDs were used as cases to create larger, abstract themes and theories about promoters and barriers to colorectal cancer screening in East Baltimore neighborhoods. Nvivo (Nvivo qualitative data analysis Software; QSR International Pty Ltd. Version 10, 2014), a qualitative research software, was used to create nodes (themes) based on the transcripts. References (participant comments) were coded to specific nodes (e.g. fear, insurance, support systems), and the frequency of how often a single theme emerged was recorded (Table 2).

## Results

### Participant/Sample characteristics

The mean reported age was 58 years (range from 30 to 93 years)<sup>1</sup>. Over 95% of the participants were above the age of 45. A total of 111/127 (87.4%) of participants were African-American. Approximately 60% of FGDs participants had obtained and completed a colonoscopy previously. In the target population, there was also a mix of both insured and uninsured patients.

### Major themes

The first segment of every focus group addressed attitudes about health. The major themes coded and created across the nine

<sup>1</sup> Author's note: Ages from participants at one session, a senior center, were not recorded. Given that it was a senior center, however, all participants were over the age of 50. Thus our average age reported is an underestimate.

focus groups displayed similarities. With regard to promoters for colorectal cancer screening, the following themes emerged: support systems, family history of cancer, symptomology, the role of physicians, and public media campaigns. With regard to barriers for colorectal cancer screening, participants reported the following to be key challenges: preparation, procedural concerns, insurance and cost, fear, tensions with physicians, and lack of physician recommendation (Table 2).

Throughout all focus groups, there was a spectrum of knowledge regarding CRC, CRCS and the details about screening.

### Promoters to colorectal cancer screening

Participants provided numerous references to ways in which they were encouraged to complete a colonoscopy, as well as ways in which other members of their communities and neighborhoods could be encouraged.

### Support systems

Participants consistently referenced the role that friends, family and other community members play in encouraging and promoting colonoscopy screening. Comments reported ranged from having family or friends accompany patients on appointments to the role that FGDs like ours could play in promoting increased CRCS. Several participants noted the importance of "get[ting] somebody to go do it with you." In addition to encouragement, many mentioned witnessing their loved ones suffer from and die from "conditions that could have been avoided," and emphasized the importance of seeking preventative care.

Table 1: Sample Focus Group Discussion Questions - Moderator Guide.

Example Questions
1. What does being healthy mean to you?
2. What is cancer?
3. What is colon cancer?
4. Who gets colon cancer?
5. What has been your experience with colorectal cancer screening?
6. What are some of the things that make it hard for you to obtain or complete colorectal cancer screening?
7. What are some of the things that make it easier for you to obtain or complete colorectal cancer screening?
8. How do you think we could engage the community to promote more colorectal cancer screening?

Table 2: Promoters and barriers to colorectal cancer screening in focus group participants, East Baltimore, MD.

Major Promoters and Barriers	Frequency of Comments
<b>Promoters</b>	
Support Systems	(37)
Family History	(36)
Role of Doctors	(38)
Symptomology	(38)
Media and Campaigns	(12)
<b>Barriers</b>	
Test Preparation	(57)
Procedural/Test-Specific Concerns	(30)
Insurance/Cost	(27)
Fear	(65)
Tensions with Doctors/No Recommendation	(65)

## Family history

Several participants mentioned having a personal experience with a family member living with or dying from colorectal cancer. Several FGD participants emphasized the overarching "need to be checked" especially "if somebody else in your family has had colon cancer...like your father, sister or brother." There was a high level of understanding that family history is a major risk factor for developing CRC.

## Symptomology

Participants made references to the symptoms—or lack thereof—of colon cancer. The general sentiment was that experiencing symptoms encouraged people to seek medical care. Even though it turned out not to be CRC, one participant mentioned, "going to the doctor because [he] was having irregular bowel movements, pain in [his] side." Participants also expressed awareness of the need to "have it done earlier" if one has gastrointestinal symptoms. Overall, there seemed to be a lack of knowledge of particular symptoms, with even one participant saying: "You do need to put out [medical] literature and put out the symptoms." Similarly, one participant also mentioned the necessity of getting tested in the absence of symptoms. "Even though you are feeling well, I felt good, I had no idea that I had cancer."

## Physician-patient partnership

Another major promoter was the role that primary care physicians play in offering screening. Most participants who had received CRCS were encouraged to do so by their physician at or around the age of 50, when the "doctor thought it was time for me." Participants across the focus groups consistently mentioned receiving a recommendation for CRCS from their physician. One participant stated, "[m]y primary doctor is forcing me; I told him I feel fine." Another participant expressed how she "wanted information" and that her doctor gave her a book to read about "how it is going to be and everything like that," highlighting the role that giving printed materials to patients plays to increase patient education and physician-patient partnership.

## CRC and the media

Participants in our FGDs also discussed the role that the media can play in encouraging more people to receive CRCS, especially in African-American populations and neighborhoods. When discussing methods to increase CRCS awareness, FGD participants noted the use of television, movies, radio and flyers. One participant knew he should get tested "by listening to...TV shows and stuff like that: information." Additionally, in one FGD, targeting barbershops and "other places where men congregate" came up as an idea to both reach and encourage more testing among African-American males. Similarly, participants also noted that seeing their photos after the procedure is a potential way to "know what the inside of my body looks like." Lastly, multiple participants mentioned the need to "do a campaign" to explain "the history about it, other ways it can be done...and [to] make them really understand that at a certain age you should be tested for it."

## Barriers to colorectal cancer screening

Participants identified many barriers and obstacles to completing CRCS, as well as ways in which members of their communities and neighborhoods encountered barriers to screening. Generally, these barriers fell under the following major content areas: challenges with

colonoscopy preparation, colonoscopic procedural and test-specific concerns, insurance and cost concerns, generalized fear and poor physician-patient relationship.

## Bowel preparation

Participants expressed awareness of the necessity of cleaning out the bowel prior to the colonoscopy. Across seven of the nine FGDs, participants noted the difficulties with preparation for a colonoscopy. Specifically, participants noted the "nasty" and "vile" taste of the fluid. Additionally, many participants discussed the challenge of being "in the bathroom the whole day" and that drinking the fluid "made for a long night." The overwhelming sentiment was that the fluid was both distasteful and burdensome in terms of preparation for the colonoscopy. In addition to the fluid, other patients discussed the use of tablets to clean out their systems; those who took tablets seemed to prefer this option over drinking a gallon of a "nasty" fluid.

## Procedural and test-specific concerns

Many discussed discomfort with the procedure itself, even after finishing the unpleasant preparation. For both men and women, there was a discomfort and uncertainty regarding the use of recording devices in the procedure, and the fact that "you don't know who the people is, and they got a camera going up there." The general feeling among participants was a wish to be put to sleep during the test itself, although a few members had a desire to watch the camera or receive pictures following the procedure. For the men specifically, there was a deep-seeded emotion expressed about the passage of colonoscopic instruments through the rectum. For example, one participant was "always worried about them messing with my body parts," and he "didn't want them sticking anything up in me." Similarly, one participant offered that going for CRCS may make men feel that their "manhood" and "masculinity" are now in question.

## Insurance and cost concerns

In our discussions, the cost of screening and the role of insurance played a major factor in the decisions of participants to complete CRCS. Many participants expressed the sentiment that "a lot of times we don't have the proper insurance that will allow us to get these exams." Others mentioned that "the better your insurance, the better you get treated." Several of our sessions took place at centers that work with high-risk populations (homeless, uninsured, substance users), and the overall sentiment was that without insurance it is not possible to receive these screening tests, even though many participants wish it was more "convenient and [at] no cost." Resources available through represented agencies was also mentioned, and these agencies even provide colonoscopies. Finally, one participant also mentioned that "because a lot of people don't have insurance...they need to know that they can get it done for free."

## Fear

Participants' attitudes towards health screening were sometimes rooted in fear of the unknown or fear of a potential diagnosis with a poor prognosis and/or inability to obtain or afford treatment. One participant mentioned she was just "scared...that they are going to find something." Participants spoke very openly of the fear associated with a medical procedure, test or surgery and that you "never know what is going on, so of course you are going to have some type of

**Table 3:** Promoters to colorectal cancer screening discussed across nine focus group discussions.

Major Theme	Example Excerpt
Support Systems	"I remember when I was growing up my grandmother always said you must take things from other people and she used to say, when people's house catches on fire you start throwing water on yours, so when you know somebody was suffering you go and start to get tested or you talk to somebody and they will tell you, so you should do that. I take that advice and go."
Family History	"If somebody else in your family have had colon cancer close like your father, sister or brother; you know you need to be checked." My brother had colon cancer and my mother had colon cancer, and one of my sisters. I understand that two other of my sisters, I know one sister had it, and so you know like they told me that you know I need to be checked,
Symptomology	"One thing that people really do need to have people understand that they need to be screened for colon cancel; ... People that tell me they stay constipated all the time, I say when is the last time you had a colonoscopy. They look at me like what in the world is that?" "Like you said some people have their bowels are real small, blood in your stool like he said, it is things like that make you want to go and get tested, whether you have it in your family or not. If something is wrong with your bowel, hat's the first thing they do."
Physician-Patient Partnership	"During a physical exam the doctor said it was time to get that screening." "I went for my complete physical, my doctor wanted me to have that." "My doctor recommended mine, because I do have a lot of health issues,"
CRC and the Media	I noticed that people like, I don't know how many of you watch Madea, but I notice that movie stars like Tyler Perry will put it in the play that if you are age 50 you should go, I'm talking to the men, go and get your colonoscopy. "[Put] posters out and just say, and that it is important to have a colonoscopy you know."

**Table 4:** Barriers to colorectal cancer screening discussed across nine focus group discussions.

Major Theme	Example Excerpt
Bowel Preparation	"Before you take have a colonoscopy there is a preparation that you have to go through and that usually involves drinking a whole lot of thing; don't plan to do anything the day you do that because you will be in the bathroom the whole day...and some people even upchuck because it is just too terrible trying to go down. So that was the worst part of it for me." The preparation is worse than the test.
Procedural and Test-Specific Concerns	"I don't like it, I know I wouldn't like it because I'm a man, you know what I mean. This is me, it has nothing to do with being in-telligent, if there is another way it can be done, I'm all for it; but other than that, I mean I am 61 years old, 61 on July 19th; I am in excellent health, the only thing I didn't do was that colon cancer and that's the reason why.
Insurance and Cost Concerns	"I'll tell you, because a lot of times we don't have the proper in-surance that will allow us to get these exams because they just started very recently where they giving grants for these exams now, just recently, I know because I am scheduled for one in a couple of weeks and you know if you don't have the proper insurance that's sad man, I should be saved irregardless of your ability to pay".
Fear	Well we understand that now, but growing up man the thought of penetration where? who? That's not happening. That's not going on under no circumstances, I am going to tell you something and I'm gonna keep it one hundred with you because they figure the only man that's being penetrated that way is a homosexual, and I'm not kidding. Maybe it's a misconception,...But that's what it is, that is a truthful thing right there. You ain't going in there, under no circumstances, whatever it is I just die and I'm gone.
Physician-Patient Tensions	"So and I asked the doctor when you ask them, well why are you giving me this with all these side effects? They don't know. They know, they don't answer. You know that is money in their pocket." "Doctors need to talk to their patients about is colon cancer, pros-tates and all those other stuff. And sometimes doctor don't do that."

fear." Similarly, it is also important to note the fear associated with going to get tested if a known family member has been diagnosed with colon cancer. One participant even mentioned his hesitancy to be tested because he had "just lost [his] father from colon cancer."

### Physician-patient tensions

While many participants in our focus group mentioned pursuing CRCs at the recommendation of their doctors, others shared less positive stories about their relationships with their physicians. For several of the participants, their doctors "never mentioned it." Additionally, several patients discussed contentious interactions with their providers, citing that doctors "don't give you 15 minutes," and that they "charge you a million dollars." On top of feeling as if "doctors are doing an assembly line," several participants even discussed switching providers altogether. More specifically, men in our study also expressed a general lack of desire to see physicians on a regular basis and that "the last thing we want to do is go to the doctor, to go get a checkup, to go get an exam." Lastly, some participants mentioned the importance of self-advocacy by gaining knowledge, advocating for their care, and demanding better services from their health care providers.

### Discussion

The primary goal of our study was to examine both promoters and barriers to CRCs among members of primarily African-American, low-

income neighborhoods in East Baltimore with a particular focus on populations including, but not limited to, persons experiencing homelessness, persons recently incarcerated, and uninsured and underinsured individuals. Our study confirmed and builds on several key themes that exist in the literature on CRC and promoters and barriers to CRCs.

The contextual nature of the opening questions played a significant role in our study because understandings of health (preventive, curative, etc.) have deep implications for the role of cancer screening. Results from our study add to the body of existing literature on promoters to colonoscopy screening. Our study builds on other studies that emphasize the importance of physician recommendations to obtaining and completing colonoscopic screening [7,8,14,19]. Tables 3 and 4 also note the key role that physicians play in encouraging or impeding colonoscopy usage. In line with other studies, we also found that both physical symptoms (gastrointestinal disturbances and blood in stool) and family support play key roles in facilitating colorectal cancer screening [9,20]. Given that men tend to receive more yearly physical examinations as they age, our findings offer salient evidence of the need for targeted interventions and initiatives for at-risk populations [21] (Tables 3 and 4). Such interventions could also occur in the form of media [10].

Targeting the aforementioned areas for intervention is important when considering how best to combat the racial disparities in

colorectal cancer among African-Americans. In fact, several times throughout our own FGDs, participants mentioned the importance of holding educational sessions or other similar group meetings to educate the community on CRC and CRCS. During our sessions, participants and sponsoring agencies consistently requested that we come back to conduct a thorough educational session on CRC. As a result of the nine FGDs, several participants also inquired and decided to be screened for CRC.

Our results also build on previous studies in key ways regarding barriers to CRCS. First, participants discussed the major role that difficult bowel preparation plays in deterring follow through with completing colonoscopy. This evidence suggests that more education and interventions targeted at the process of bowel preparation, as well as the role that physicians play in facilitating increased CRCS, might prove useful in curbing reduced screening rates [22,23]. A more detailed study on patient attitudes on improving the taste of the preparation fluid might be indicated. Building off previous studies that highlight the role of primary care physicians in increasing CRCS rates, we encourage future interventions to target physicians and physician networks in addition to patients [11,24].

Fear and discomfort with the test remain key barriers to CRCS. Participants consistently mentioned discomfort with the scope going through the rectum, confirming findings of other researchers [13]. Stigma, especially in African-American populations, is a major deterrent and should be addressed in future interventions. Previous research has noted the discomfort of some men with the digital rectal exam and a sense of threat to one's masculinity [25]. Our study confirms such findings of fear and vulnerability. More details on the procedure itself should be offered to patients and open conversations should be encouraged between providers and patients. Given that physician recommendations and advice have been shown to be high predictors of cancer screening in a large systematic review [26], increased conversation about patient discomfort with the test could promote increased CRCS rates.

## Limitations

It is important to note several limitations with the study. There is an inherent bias with the selected populations and assumed access to healthcare services. While our population might comprise a substantial part of the under-screened, it is important to note that access to these social service centers may inherently improve access to care and services. Similarly, given the sensitive nature of the topic, FGD settings may have underappreciated some patient stories and input. Participants also received a gift voucher which should be understood in light of their recruitment, their participation and the results reported herein as a possible source of bias.

## Conclusions and Next Steps

The many barriers that remain for African-Americans living in East Baltimore demonstrate that much opportunity remains for interventions to increase CRCS and decrease CRC incidence and mortality. Knowledge about symptoms and understandings of CRCS are necessary for effective initiatives. Interventions targeted at increasing education, knowledge of CRC, and open conversations between patients and providers may be viable options in changing current CRC trends.

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