



Colorectal Cancer Brochure Development for African Americans

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## Colorectal Cancer Brochure Development for African Americans

### Abstract

**Introduction:** African Americans are more likely to die from colorectal cancer (CRC) than any other racial/ethnic group in the United States. Unfortunately, African Americans are also less likely to undergo screening for CRC than their White counterparts. Focus groups methodology was used to refine educational brochures designed to increase CRC screening among African Americans.

**Methods:** Two series of focus groups were completed, with a total of seven groups and 39 participants. Six different brochures (stage-matched and culturally sensitive) designed to promote CRC screening among African Americans were evaluated.

**Results:** All participants thought that the brochures motivated them to talk with their health care providers about screening. Cost, pain, medical mistrust and fear were identified as major barriers and the brochures were modified to address these concerns.

**Conclusions:** Focus groups methodology with African Americans can be used to inform brochures designed to increase African Americans CRC screening that addresses their major concerns.

### Keywords

African Americans; Colon (Anatomy) – Cancer – Prevention; Colorectal cancer screening; Health education; Focus groups; Rectum – Cancer – Prevention

### Cover Page Footnote

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## **Colorectal Cancer Brochure Development for African Americans**

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### **ABSTRACT**

**Introduction:** African Americans are more likely to die from colorectal cancer (CRC) than any other racial/ethnic group in the United States. Unfortunately, African Americans are also less likely to undergo screening for CRC than their White counterparts. Focus groups methodology was used to refine educational brochures designed to increase CRC screening among African Americans. **Methods:** Two series of focus groups were completed, with a total of seven groups and 39 participants. Six different brochures (stage-matched and culturally sensitive) designed to promote CRC screening among African Americans were evaluated. **Results:** All participants thought that the brochures motivated them to talk with their health care providers about screening. Cost, pain, medical mistrust and fear were identified as major barriers and the brochures were modified to address these concerns. **Conclusions:** Focus groups methodology with African Americans can be used to inform brochures designed to increase African Americans CRC screening that addresses their major concerns.

**Keywords:** Colorectal cancer screening, focus groups, African Americans

### **INTRODUCTION**

Low screening rates for colorectal cancer (CRC) is a major health-care challenge in the United States (US). Despite evidence that CRC screening among average risk adults (e.g., those without a family history of CRC or personal history of bowel disease), age 50 years and older can decrease the incidence and mortality rates for CRC, CRC screening rates remain low and are lower than screening rates for other cancers (e.g., cervical and breast)<sup>1-5</sup>. Generally, 91% of new cases and 94% of deaths from CRC occur in average risk individuals 50 years and older<sup>6</sup>. The recommended screening

guidelines for individuals at average risk include an annual fecal occult blood test (FOBT), flexible sigmoidoscopy (FS) every 5 years (or both FOBT and FS), double contrast barium enema every 5 years, or colonoscopy every 10 years<sup>6</sup>. In 2004 (the year before this study), only about half (52.1%) of US adults aged 50 or older were screened using any of the above mentioned procedures within the recommended time interval<sup>7</sup>.

Screening for CRC is of particular importance for African Americans because they have the highest incidence and mortality rates from CRC compared to any racial and ethnic group in the US<sup>8-10</sup>. From 1997-2001 the CRC incidence rate among African Americans was roughly 15% higher than among Whites. Mortality rates during the same period were about 40% higher in African Americans than in Whites<sup>6</sup>. African Americans are less likely to undergo screening than their White counterparts<sup>8</sup>. Moreover, African Americans are at increased risk for the occurrence of and mortality from CRC if they reside in low socioeconomic areas<sup>9, 11, 12</sup>.

African Americans living in New York City (NYC) have the highest mortality rates from CRC than all racial and ethnic groups in NYC<sup>13</sup>. The NYC Department of Health and Mental Hygiene conducted a cross-sectional telephone study of 34 neighborhoods including descriptions of the CRC screening practices among adult New Yorkers aged 50 years and older. The study concluded that the city's poor and uninsured had particularly low levels of CRC screening (i.e., FOBT and endoscopic testing) and that Non-Hispanic Blacks and women were less likely to have a colonoscopy<sup>5</sup>. Colonoscopy has been designated as the recommended strategy for screening by the NYC Department of Health and Mental Hygiene because of the reported higher sensitivity of colonoscopy compared with other screening modalities and the local capacity in NYC to perform the procedure<sup>5</sup>. Additionally, studies have shown that screening colonoscopy in average risk populations detect more than double the number of adenomas when compared to flexible sigmoidoscopy and may reduce mortality and the incidence of CRC through early detection and the removal of precancerous polyps<sup>8,9</sup>. To address the issue of low CRC screening rates among African Americans, this study employed focus group methodology as a means to inform the development of print educational materials designed to increase CRC screening, particularly colonoscopy, among average risk low income African Americans living in NYC.

## METHODS

The use of focus group methodology is the first of two phases of an ongoing study to investigate the impact of an educational intervention to increase CRC screening among African Americans. The second phase of the study is a randomized clinical trial, investigating the impact of the educational brochures described here. The goal of this paper is to report on the focus groups and to describe the process used to develop and improve the content and messages in CRC brochures targeting African Americans. The brochures will be used in the clinical trial study phase.

Focus groups were used in the development and design of the materials in order to collect informal and spontaneous reactions for the target population to the issues of interest<sup>14</sup>. During the focus groups two educational material formats were compared to a standard brochure (i.e. The Centers for Disease Control and Prevention (CDC) Screen for Life - National Colorectal Cancer Action Campaign brochure entitled Colorectal Cancer Screening Saves Lives). The first format was based on the Transtheoretical Model (TTM) and the second was based on Kreuter and colleagues' strategies for developing culturally sensitive (C-S) educational materials<sup>15-18</sup>.

Prior to the focus groups, the research team designed six educational brochures. Five included concepts from the TTM and the sixth used guidelines for creating C-S educational materials. The brochures were also based on themes derived from previous studies for CRC screening and other studies conducted with African Americans in East Harlem, NY by the research team<sup>1, 19, 20</sup>.

The TTM proposes that behavior change takes place in stages on a continuum rather than as a single, distinct event and is most successful when specific promoters (Pros) and barriers (Cons) are applied to the appropriate stage of change<sup>27</sup>. Stage-of-change refers to an individual's readiness to either adopt a healthful behavior or stop an unhealthy one. The TTM stages are termed pre-contemplation, contemplation, preparation, action/maintenance and relapse risk; each stage has its own characteristics<sup>17, 18</sup>.

For the purpose of our study the traditional TTM stages and their corresponding characteristics were supplemented by early stages of readiness or adoption, from Weinstein's Precaution Adoption Process Model (PAPM); thus new stages and characteristics were created. PAPM was added as it incorporates several characterizations for the early pre-contemplation stage such as, being unaware of an issue and being unengaged by an issue<sup>21</sup>. Having a larger, more comprehensive pre-contemplation stage was an important aspect of the study since we anticipated: 1) having most of the participants fall into pre-contemplation stages due to the low screening rates among African Americans in NYC, 2) the study protocol called for only participants who have never undergone an endoscopic procedure (which meant that there would not be an action/maintenance or relapse risk stage), and 3) we wanted to better understand the earlier pre-contemplation stages, again because of low CRC screening rates among African Americans<sup>5, 8</sup>. Five stages, each with its own characteristics and each determining a participant's stage-of-change or readiness to undergo an endoscopic procedure were defined as shown in Table 1.

### **Standard & Staged-Matched (S-M) Brochures**

The Centers for Disease Control and Prevention (CDC) Screen for Life - National Colorectal Cancer Action Campaign brochure entitled Colorectal Cancer Screening Saves Lives was used as a guide for the content and layout of the S-M brochures. The CDC brochure was used as the standard control brochure because of its broad appeal to all racial and ethnic groups and its mainstream subject matter. The S-M brochures were designed to look similar to the CDC brochure as well as deliver standard messages. Both have sections entitled "What is Colorectal Cancer?" and "Who gets Colorectal Cancer?" Both brochures also discuss different types of CRC screening modalities, signs and symptoms of CRC and the cost of testing procedures.

The S-M brochures also focus on the critical issues of each stage (see Table 1). We addressed each stage by first creating stage specific intervention strategies to help guide the direction of the brochures by showing what actions should be taken at each stage. The stage specific intervention strategies are based on a model developed by TTM researchers (e.g. 22) and our data from prior studies using Pros and Cons items.

The front panel of each of the five S-M brochures displays specific messages that speak directly to each stage. The wording from the stage characterizations was used. For instance, the contemplation stage characterization is "The person is considering undergoing colonoscopy screening in the next year." Thus, the front panel message reads "Good for you, you're thinking about colorectal cancer screening! Here's what you should know!" Furthermore, Pros and Cons items were also matched to each stage and appropriate statements were incorporated into the brochures. The items were selected based on data analysis from our prior research<sup>1, 19</sup> with African Americans who were

**Table 1. Stages of Change Characteristics and Intervention Strategies**

Stage	Stage Characterization	Stage Specific Intervention Strategies	Front Panel Messages	Brochure Statements
Pre-contemplation 1	The person is unaware of CRC risk.	Provide information on the benefits of screening. Provide information on the procedure. Emphasize risk. Appeal to emotions.	"This brochure was created for you and others like you who have NEVER heard of a colonoscopy."	"Think about colorectal cancer screening/ colonoscopy. Do it for your health and the well being of your family." "You'll feel better about yourself."
Pre-contemplation 2	The person is aware of the CRC risk, but has never considered having a colonoscopy.	Provide information on the benefits of screening. Provide information on the procedure. Review procedure.	"This brochure was created for you and others like you who have NEVER considered having a colonoscopy."	"Think about colorectal cancer screening/ colonoscopy. Do it for your health and the well being of your family." "You'll feel better about yourself."
Pre-contemplation 3	The person is aware of the CRC risk and has considered having a colonoscopy but decided against it.	Tip the decisional balance to LESS cons and MORE Pros. Address the common cons and why person decided against procedure. Show some benefits/common pros associated with screening.	This brochure was created for you and others like you who say they do not want to have a colonoscopy."	"Re-think your decision about colorectal cancer screening/colonoscopy." "Do it for your health and the well-being of your family." "You'll feel better about yourself."
Contemplation	The person is considering undergoing screening in the next year.	Emphasize benefits. Address pros (why to get procedure) and than some common cons – misconceptions.	"Good for you, you're thinking about colorectal cancer screening! Here's what you should know!"	"It's good you're thinking about colorectal cancer screening/colonoscopy." "Make that appointment for your health and the well-being of your family." "You'll feel better about yourself."
Preparation	The person has an appointment scheduled for screening.	Use strategies to enhance commitment.	"Good for you! You've scheduled your colonoscopy. Here's what you should know!"	"Congratulations on scheduling your colorectal cancer screening/colonoscopy appointment." "It's so important to your health and the well-being of your family." "You'll feel better about yourself."
Note. Stage Characteristics have been published previously by Christie et al., In press <sup>27</sup> .				



adherent and non-adherent to CRC screening. For example, using SPSS (version 15.0), the frequency distribution illustrated that individuals who have not had endoscopic screening were more likely to agree with the Cons item, “Colorectal cancer tests are risky, if colorectal cancer tests find a problem, it is too late to do anything about it.” Additionally, those who have had endoscopic screening were more likely to agree with the Pros item, “Having regular colorectal cancer tests would give me peace of mind about my health.” Therefore, to address the Cons items, the Pre-contemplation 1-3 and Contemplation brochures all answer the questions “Are screening tests safe?” and “What if something is found, will it be too late to do something about it?” The brochures also include statements emphasizing the health benefits to getting screened and that one would feel good about oneself if they got tested in order to speak to the Pros items.

Lastly, the S-M brochures included general concepts, such as asymptomatic disease (i.e., not showing or producing indications of a disease or other medical condition), doctor recommendation, fear, pain, and feeling inconvenienced by screening tests. These themes were incorporated into the S-M brochures as previous research by the study team on cancer knowledge and barriers and promoters of cancer screening (i.e., breast, prostate, and colorectal) with African Americans in East Harlem indicated that they were very important issues. For example, the subject of pain was addressed by answering the question “Are screening tests (colonoscopy) painful?”

### **Culturally Sensitive (C-S) Brochure**

Kreuter and colleague’s strategies for developing culturally sensitive educational materials were used to design the C-S brochure. The strategies are as follows: 1) Peripheral strategy; this approach emphasizes the appearance of cultural appropriateness by presenting materials in ways that are most likely to appeal to a particular group, including visual elements, such as colors, layout design, and images; 2) Evidential strategy; which focuses on the relevance of a health issue to a group by showing its impact on that group through data, including rates of incidence, prevalence, mortality or disparity; 3) Linguistic strategy focuses on using the preferred language of a specific group; 4) Constituent involving strategy draws directly upon the experience and expertise of members of the target population, and 5) Sociocultural strategy addresses health-related issues in the context of broader social and cultural values and characteristics of a group <sup>16</sup>.

Regarding peripheral strategy, visual elements were used, such as images of African American men and women and the use of warm earth tone colors in a kente cloth pattern. Additionally, we used a declarative statement on the brochure cover title; “What Black Men and Women need to know about Colorectal Cancer Screening.” For the evidential strategy, data on the relevance of CRC to African Americans was illustrated in a paragraph headlined, “Black adults are more likely to die from colorectal cancer compared to any other racial group.” We talked directly about how African Americans are affected by CRC, presenting statistical data (i.e., mortality rates). Lastly, a CRC survivor’s story that was spiritually based, entitled, “I beat colorectal cancer” incorporated strategies 3 and 4 by drawing directly upon the experiences of African Americans and using language specific to African Americans.

Like the S-M brochures, the C-S brochure also addresses issues such as cost, fear, pain, and feeling inconvenienced by screening tests. However, when dealing with these issues the brochure sections are worded differently in order to reflect the different brochures and methodology. The sociocultural strategy guided the wording in the C-S brochure. For example, to talk about the inconvenience of testing, the S-M brochure section targets the individual and is entitled “Don’t put off getting screened” and in the C-S brochure the section appeals to a cultural value and is entitled “Take care of yourself so you can take care of your family.”

Finally, the constructs of medical mistrust and fatalism were integrated into the C-S brochure. These were found to be significant to the African Americans who participated in past research with the research team and in our focus groups<sup>23</sup>. Fatalism is the belief that death is inevitable when cancer is present. Medical mistrust is defined as a tendency to distrust medical systems and personnel believed to represent the dominant culture (e.g., Thompson et al 2004<sup>23</sup>). To address fatalism a section of the brochure reads, "It seems to me there is nothing you can really do about getting cancer." The section then goes on to discuss the importance of early removal of pre-cancerous polyps. In order to speak to medical mistrust, there is a section "Doctors are always telling me to get one test or another. Is colorectal cancer screening really necessary?" Here we inform our target population that we are aware of their suspicions, nevertheless it is important to be informed about how CRC screening saves lives.

## Focus Groups

Two series of focus groups were completed, with a total of 7 groups and 39 participants. The participant's age ranged from 55 to 78 years with a mean age of 68.21 (SD= 5.69). Sixty-two percent were female and a majority (66.7%) reported an annual income of \$14,999 or less. Forty six percent had less than a High School (or a GED) degree. The majority had health insurance (90.5%) and noted having a primary care physician (76.9%).

All of the focus groups were held in East Harlem, NY between January 2005 and May 2005. An African American Project Coordinator served as facilitator at each focus group. Six different CRC educational brochures (Pre-Contemplation 1, Pre-Contemplation 2, Pre-Contemplation 3, Contemplation, Preparation, and Culturally Sensitive) designed by the research team were compared to the standard CDC brochure entitled Colorectal Cancer Screening Saves Lives, to evaluate the acceptability, understanding, and appropriateness of our materials.

The focus group participants were recruited from neighborhood community and senior centers and the East Harlem community at large. Mount Sinai School of Medicine's IRB approved recruitment fliers, which had tear off sheets with our telephone number on it, and were posted at community sites and health clinics. The fliers had a picture of an African American man and woman. Additionally, an advertisement was placed in a local newspaper, which targets the African American community. The inclusion criteria for the focus groups were as follows: male or female, self-identified as Black or African American, 51 years of age or older (to give participants at least one year after their 50th birthday to undergo screening), at average risk for CRC, must not have undergone an endoscopic screening exam and must have telephone service. HIPAA and IRB consent forms were completed at the beginning of each focus group. Participants were reimbursed \$25 for their participation.

The focus group questions were open-ended and asked about participant's general knowledge of CRC screening, their satisfaction with the educational materials, as well as the cultural relevance and coherence of the brochures. Additionally, we asked for suggestions on ways to improve the educational materials. The questions are listed in Table 2.

Each focus group lasted two hours; was audio taped and transcribed to facilitate qualitative analyses. The purpose of the first series (Set 1) of four focus groups was to refine the educational brochures that were designed by the team. We wanted feedback on the brochure content, layout, color and coherence. Each group viewed the brochures and compared them to the standard CDC brochure. Changes were made to the brochures after the first series of focus groups. The second series (Set 2) of three focus groups were conducted to gather further feedback on the brochures and to consider the content changes that were already made to the brochures. These participants also compared our brochures to the standard brochure.



**Table 2. Focus Group Questions****Participants Prior Knowledge**

- Before today, what did you know about colorectal cancer?
- Before today, what did you know about colorectal cancer screening?

**Evaluation of Brochures****Appearance**

- After reviewing the brochures on colorectal cancer and colorectal cancer screenings, what thoughts come to mind?
- What do you think about the pictures/graphics/colors used in the brochure?

**Ease of Comprehension & Readability**

- Was the information presented in a clear and understandable manner? (What do you think about it?)
- Is there anything you would change about the information? What would you keep the same?

**Knowledge Content**

- Do you think this information in the brochures are useful/applicable to you? Why or why not?
- How could we make this information more useful/applicable to you?

**Attitudes & Perception**

- What impact does this information have on your view of colorectal cancer and screening?
- Has/have your understanding/feelings about colorectal cancer and screenings changed?
- Do you think people similar to you worry about getting colorectal cancer? (If so, do the brochures address this? And how do you think it should be described in the brochures?).

**Testing & Decision Making**

- Would you seek colorectal cancer screening based on the information presented? Why or Why not?
- What information would help you decide whether or not to be screened/tested?
- What are the benefits of getting screened/tested? What are the disadvantages?
- Do you think we should add anything about abnormal findings [to the brochures]? For example, if the doctor finds something wrong, what you should do?

**Group Specific Issues related to CRC**

- Are there things that may be important to Black men/women in general in making the decision to be screened for colorectal cancer?
- What do you think keeps Black men/women from getting screened?
- What myths exist about colorectal cancer and screening?

**RESULTS**

For the first series of focus groups, 4 sessions were completed with a total of 21 participants. There were two all female groups, one all male group, and one mixed gender group. Sixty-two percent (N=13) were female and 38% (N=8) were male. Their ages ranged from 57-78 years. The second series of focus groups included 3 groups with a total of 18 participants. There was one all male group (N=6), one all female group (N=5) and one mixed gender group (N=7). Some of the participants (N=11) had also attended focus group Set 1 and the remainder (N=7) were new participants.

All of the participants reported coherency and understandability of the S-M, C-S, and standard brochures. They thought that all the brochures were informative, however, when compared to the standard brochure, participants thought the S-M brochures had more details and regarding the C-S brochure a participant remarked as follows, "They both are informative, but I'm drawn to the colors in this [C-S] brochure." Additionally, the participants reported that the various font sizes and styles were easy for them to see and that after reading the brochures they felt more encouraged to get tested and/or talk with their health care providers about CRC screening.

The first set of focus group participants recommended revisions to the brochures. They thought that both the S-M and C-S brochures needed more information about the cost and how to pay for the colonoscopy procedure. Accordingly, we added information for governmental and national cancer organizations that may provide assistance to the redesigned brochures. Participants also thought that the picture of the human gastrointestinal system on the standard brochure was larger than those pictured in the other study brochures and recommended that we enlarge our picture. Revisions were made where space permitted.

Regarding the S-M brochures, Set 1 focus group participants felt that all the brochures looked the same except for their colors. This was an important observation because although we wanted the brochures to look similar we also wanted them to be distinguishable, which was one reason why the stage characterization wording was placed on the front panels. In the redesign we focused on content placement on the inside of the brochures as a way to distinguish the messages at each stage. The brochures immediately address the barriers that were found at the different stages. For example, the Pre-Contemplation 3 stage characterization is that "a person has considered having a colonoscopy but decided against it." A major barrier for patients at this stage is fear of the procedure and the results. On the first inside panel, we discuss doctor recommendation with the heading "Here's what doctors say about screening," discuss fear with the caption "Don't let fear stop you" and we ask patients to reconsider getting tested by arguing the benefits of getting screened.

Two groups from the first set of focus groups felt that the brochures should address the issue of embarrassment, while the other two groups didn't think it needed to be discussed. Here is a response from a male participant from a group that did not think embarrassment should be included in the brochures: "When you reach a certain age, there is no more embarrassment, you need to stay healthy." Moreover, here's the perspective of a male participant that thought embarrassment should be included: "Men are very conscious of tests in the rectum." The research team addressed embarrassment in the revision of the brochures as it is documented in the literature that embarrassment is a barrier to CRC screening<sup>24,25</sup>.

Participants were asked to respond to the question – "Do you think we should add anything about abnormal findings [to the brochures]? For example, if the doctor finds something wrong, what you should do?" There were mixed opinions on the topic; some participants thought it was a good idea while others did not. The following are some responses:

"[Yes] it should say something like seek treatment/go for treatment if something is found because people get scared and may not do anything." and "Yes, you are briefed before you meet with the doctor – you are more prepared when you talk with the doctor." Other responses included: "[No] I don't think so, because brochures can be scary and we should talk with our doctors after the procedure to find out what's going on." and "No, it will scare people." From the study team's perspective it was thought that the brochures in their current format were not the appropriate condition to address issues such as advanced cancer or colostomies, therefore abnormal findings were not included in the brochures. All of the brochures do, however, have a cartoon picture of a

colon with a polyp on it, which was thought more suitable for a brochure targeting average risk individuals who had never undergone a colonoscopy.

The second set of focus group participants confirmed the brochure revisions that were made after the first set of focus groups. They too, thought the brochures were very informative and encouraged them to talk with their health care providers about CRC screening. Furthermore, they thought the brochures addressed many of their concerns about the colonoscopy procedure, including cost, pain and fear.

Fear and pain of the colonoscopy procedure were constant themes throughout both sets of focus groups. When participants were asked, “Before today, what did you know about colorectal cancer?” and “Before today, what did you know about colorectal cancer screening?” the concerns of fear and pain were immediately raised. The participants had very strong feelings about these issues. The following are examples of what participants said regarding these concerns: “[Colorectal cancer] is very scary-it’s a dangerous disease.” “[Screening] is painful, so I try to avoid it; I want to know if there is an easier way to get screened.” “I’ve heard it’s [screening] very painful, they put a tube in your rectum.” Issues of fear and pain were addressed in all of the S-M and C-S educational brochures.

All of the participants from both sets of focus groups who viewed the C-S brochure felt that it taught them more about their risk as African Americans for developing CRC. Many stated that the “survivor’s story” touched them and would motivate African Americans to get screened. Lastly, the C-S educational brochure was initially intended to be a four sheet educational booklet, however; the participants thought it was too long, thus it was shortened to two-pages.

The subject of medical mistrust was broached in a majority (six out of seven) of the focus groups. This issue was specifically addressed in the C-S brochure by speaking directly to the issue with the following statement and question “Doctors are always telling me to get one test or another. Is colorectal cancer screening really necessary?” As one of the male focus group participants said: “Black men were used as guinea pigs with syphilis, so when we have a colonoscopy or anything like that (things concerning cancer, a virus or bacteria) we have major concerns. Are we going to be used as guinea pigs? This is still embedded in our minds. It makes us very fearful. In reality it’s not happening but we have it in our minds.”

Examples of the resulting, final brochures are illustrated in Figure 1 (S-M, Contemplation) and Figure 2 (C-S).

It’s important to again point out that both the S-M and C-S brochures included mainstream subject matter that was also found in the standard CDC brochure. However, through use of the TTM stages of change, the culturally sensitive model for educational materials development and data from previous research, the study brochures were more distinct at addressing barriers to CRC screening specifically for African Americans and they appealed more to the focus group participants. When comparing the S-M Preparation brochure to the standard brochure participants said the following: “If they were side by side in a rack I would pick this one [S-M brochure] as opposed to the other [standard] because of the colors, and the way it’s formulated, it grabs my attention.” “It also rewards me and congratulates me for even thinking about looking at this.” “It is a feel good with the colors and another feel good because it says Good for you.” “It makes me want to look inside.” Furthermore, a group comparing the C-S brochure to the standard brochure made the following comments: “the [standard brochure] doesn’t seem geared toward African-Americans,” “the huge diagram [colon] is scary” and “It has a lot of good information in it.” Participants also pointed out regarding the C-S brochure “the colors are good and I like the kente cloth pattern.” “The size [font] is good,” “the diagram isn’t scary,” “the Q & A section is good” and “it’s excellent.”



Figure 1. S-M, Contemplation)

### Who gets colorectal cancer?

Colorectal cancer is the second leading cancer killer in the United States. Over 147,000 new cases are diagnosed, and more than 57,000 people die from this disease each year. You should know:

- Both **men and women** get colorectal cancer.
- Colorectal cancer occurs most often after **age 50**.
- Your **risk is higher** if you or a close relative have had polyps or cancer.

If everyone 50 or older had regular screening tests, more than half of all deaths from this cancer could be avoided.

### You can have colorectal cancer and not know

People who have polyps or colorectal cancer don't always have symptoms.

*Listed below are the signs and symptoms of colorectal cancer.*

- **NONE**, because there are no clear signs or symptoms, such as stomach problems, especially in the beginning. Later, there may be:
- Blood in or on your stool (bowel movement).
- Stomach aches, pains, or cramps that happen a lot and you don't know why.
- A change in bowel habits, such as having stools that are narrower than usual.
- Losing weight and you don't know why.

If you have any of these symptoms, talk to your doctor. They may be caused by something other than cancer. The only way to know is to see a doctor.

### Common Questions and Answers about colorectal cancer screening

*Why should I get screened for colorectal cancer when I don't have any signs or symptoms?*

A person can have colorectal cancer and not have any signs or symptoms, like stomach problems, especially in the beginning. That's why screening is so important; it can find polyps or cancer very early while a person still feels healthy.

*I don't have a family history of colorectal cancer— Am I still at risk?*

Yes, you are at risk for getting colorectal cancer if you are 50 or older. As you get older your risk gets higher.

*Are screening tests safe?*

Yes, and the chance of any problems are extremely rare.

*Can I trust the results?*

Yes, and you should know that colonoscopy is over 90% correct.

*What if something is found, will it be too late to do something about it?*

During most screening tests, the doctor can find and remove nearly all colon polyps and some cancers. Also, when colorectal cancer is found at an early stage, cure rates are very high.

*Are screening tests painful?*

Generally screening tests are painless but there may be some discomfort. Also, during a colonoscopy your doctor gives you a sedative, which is medication to calm and relax you.

### Other types of screening tests for colorectal cancer

There are other tests that can be used to check for polyps or colorectal cancer.

- **Flexible Sigmoidoscopy (Flex Sig)** - This test is similar to colonoscopy except that it uses a shorter flexible tube with a camera at one end. This test checks for polyps or cancer only in the rectum and lower part of the colon.
- **Fecal Occult Blood Test (FOBT) or Stool Test**—a test you do at home using a test kit you get from your health care provider. You put stool samples on test cards and then return the cards to the doctor or a lab. This test checks for hidden blood in the stool.

### How will I cover the cost?

Many insurance plans and Medicare help pay for colorectal cancer screening. Check your insurance plan to find out which screening tests are covered for you. If you do not have insurance, financial assistance is also available to help pay for screening.

For more information, contact The National Cancer Institute at 1-800-4-CANCER, or the American Cancer Society at 1-800-ACS-2345.

## Colorectal Cancer Screening



*Good for you, you're thinking about colorectal cancer screening! Here's what you should know!*

### Don't put off getting screened

Some people feel that colorectal cancer screening will get in the way of other things that they have to do, like working or helping their families. Some may also think the tests are embarrassing. You should know that during every procedure your privacy and dignity is maintained by a staff of professionals. Also, most tests only take about 30 minutes or less and some screening tests are needed only once every 5 to 10 years. **It's worth your TIME.**

### Don't let fear be a factor

Many people don't want to get screened for colorectal cancer because they are afraid that the test will find something wrong. The truth is that for every 200 people screened only 1 person is likely to have cancer. And remember, if cancer is found at an early stage, treatment is very successful and there is a greater chance of surviving. **You'll have peace of mind!**

### Here's what doctors say about screening

- **Screening** is the single most important thing you can do to lower your risk of colorectal cancer. So, talk with your doctor.
- Talk with your doctor to determine the best screening method for you.
- Colorectal cancer is **preventable**.
- When colorectal cancer is **found early**, treatment is most effective.
- Talk about colorectal cancer screening with family and friends.

### What is a colonoscopy?

A colonoscopy is a test that checks for cancer of the colon or rectum. It uses a flexible tube with a camera at one end to look at the entire colon. During the test, the doctor can find and remove most polyps and some cancers. Colon polyps are abnormal growths (that may become cancer) that should not be there. **Also,**



- Colonoscopy is **FAST**. The test usually lasts about 30 minutes.
- Colonoscopy is **SAFE**. The chances of any problems are extremely rare.
- Colonoscopy is **USEFUL**. The test can detect more than 95% of early colorectal cancer.
- Colonoscopy is usually needed **ONLY** once every 5 to 10 years.

### What is colorectal cancer?

**Colorectal** cancer is cancer that occurs in the colon or rectum. The colon is the large intestine or large bowel. The rectum is the passageway connecting the colon to the anus (the part of the body that releases stool).

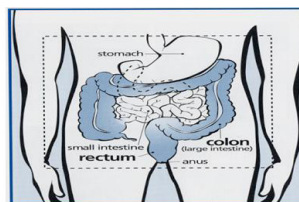


Figure 2. C-S

### What Black Men and Women need to know about Colorectal Cancer Screening



#### Types of screening tests for colorectal cancer

Several different screening tests can be used to test for polyps or colorectal cancer. Each can be used alone. Sometimes they are used in combination with each other.

- Colonoscopy**—A test that checks for cancer of the colon or rectum. It uses a flexible tube with a camera at one end to look at the entire colon.
- Flexible Sigmoidoscopy (Flex Sig)**—This test is similar to colonoscopy except that it uses a shorter flexible tube with a camera at one end. This test checks for polyps or cancer in the rectum and lower part of the colon.
- Fecal Occult Blood Test (FOBT) or Stool Test**—a test you do at home using a test kit you get from your health care provider. You put stool samples on test cards, then return the cards to the doctor or a lab. This test checks for hidden blood in the stool.

#### Take care of yourself so you can take care of your family.

It's easy to put off getting screened for colorectal cancer. Sometimes it's hard to get to a doctor because you're busy doing things for your family and the people you love. There can be problems scheduling an appointment. But remember that colorectal cancer screening can help you to stay healthy and live longer so you can continue to be there for your family.

#### How will I cover the cost?

Many insurance plans and Medicare help pay for colorectal cancer screening. Check your insurance plan to find out which screening tests are covered for you. If you do not have insurance, financial assistance is also available to help pay for screening. **For more information, contact The National Cancer Institute at 1-800-4-CANCER, or the American Cancer Society at 1-800-ACS-2345.**

#### What is colorectal cancer?

**Colorectal cancer** is cancer that occurs in the colon or rectum. The colon is the large intestine. The rectum is the passageway connecting the colon to the anus. (The anus is the part of the body that releases stool).



#### Black adults are more likely to die from colorectal cancer compared to any other racial group.

Colorectal cancer is the second leading cancer killer in the U.S. However, Black men and women are more likely to get and die from colorectal cancer than any other racial and ethnic group in the United States. You should also know:

- Both men and women get colorectal cancer.
- Colorectal cancer occurs most often after age 50.
- Your risk is higher if you or a close relative have had polyps or cancer.

If everyone 50 or older had regular screening tests, more than half of all deaths from this cancer could be avoided.

#### Screening saves lives !

Screening test for colorectal cancer could save your life. Here's how:

- Colorectal cancer usually starts from polyps in the colon or rectum. A colon polyp is a growth that should not be there and overtime, some polyps can turn into cancer.
- Screening tests can find and remove polyps at a point before they turn into cancer.
- Screening tests can also find cancer early, when the chance of being cured is good.



#### Questions about colorectal cancer screening

**It seems to me that there is nothing you can really do about getting cancer.** Some people believe that there is nothing you can do to prevent cancer and if you get cancer, you will probably die from it. **This is not true for colorectal cancer.** If colorectal cancer screening finds a polyp, the polyp can be removed **before** it turns into cancer.

**Aren't screening tests for colorectal cancer painful?** Generally screening tests are painless but there may be some discomfort. Also, during a colonoscopy your doctor gives you a sedative, which is medication to calm and relax you.

**Doctors are always telling me to get one test or another. Is colorectal cancer screening really necessary?** **Yes!** Some people are suspicious of doctors and medical tests because they often aren't given enough information about what a test is for. As you learn more about colorectal cancer screening, you'll see that it can save your life

**Don't let fear be a factor**—Among people who found and had their colorectal cancer treated at an early stage, more than 90% survived.

#### "I beat colorectal cancer": A survivor's story



I put off getting screened for colon cancer until I was 57 years old. I had heard a little bit about screening but, to be honest, I was scared and didn't want to know if I had a problem. The screening test also sounded embarrassing, so I let my manhood get in the way.

Well, one Sunday, my pastor told the church that he had been screened for colorectal cancer and how important it was, especially for Black people. He reminded us that it's God's desire that we live healthy lives. That's when I decided to turn my fear into faith. I talked to my doctor and got screened. Yes, I was diagnosed with colorectal cancer. I worked with my doctor and took all the steps to be treated, knowing that God would see me through. I'm thankful that I finally saw the light, got screened, and survived!



## DISCUSSION

This study employed focus groups as a method to inform the development of print educational materials designed to increase CRC screening among African Americans at average risk for CRC. The focus groups provided important information about low-income urban African Americans' knowledge of CRC and CRC screening as well as identified attitudinal, interpersonal, and practical factors that may influence their screening behaviors. In addition, the focus groups also provided us with detailed suggestions for refinement of the educational materials to make them more relevant and motivational for African Americans. Each of these points is discussed in detail below.

Regarding knowledge of CRC and CRC screening, an overwhelming number of participants had misconceptions about the colonoscopy procedure, although 59% had heard of a colonoscopy. These misconceptions included believing that colonoscopy was a surgical procedure requiring an overnight stay in the hospital and thinking that developing CRC was linked to having diabetes. Additionally, over half of the participants were unaware of their personal risk of developing CRC. These findings suggest that more education and increased awareness of CRC and CRC screening modalities are needed in this community. The results also suggested that fear, pain, embarrassment, and medical mistrust are major themes associated with CRC screening for African Americans.

Each of these themes had salience for the participants; however, fear, pain, and medical mistrust were cited most often, which suggest that they may be key barriers to CRC screening among African Americans and need to be addressed in intervention materials designed to increase screening in this population.

In addition to attitudinal and interpersonal factors, cost and concerns about income and insurance coverage were also identified as barriers to screening. This result suggests that in addition to information on attitudinal barriers and the importance of communication with one's doctor, educational materials need to also address practical barriers such as cost and provide clear guidance on how to obtain free or low-cost screening and/or information about Medicare and insurance policies.

While this study has many strengths such as its focus on an underserved population for which colonoscopy may be critically important, there are study limitations. First, our focus groups were conducted with a patient population and did not include physicians. Conducting focus groups with physicians would have given us the opportunity to learn more about the factors that encourage and/or discourage physicians to recommend and encourage CRC screening and may be an important focus in future research. Our reasons for concentrating on educational materials for patients include the fact that they are easily distributed and commonly used<sup>26</sup>. Moreover, there is a growing trend towards shifting the responsibility of organizing health care to the patient. Further, health promotion theories such as the Transtheoretical Model (TTM) propose that individuals bear some responsibility for their healthy or unhealthy behaviors. Although we focused on individuals, we recognize that CRC screening is a complex problem that involves the health care system, as well as health care providers, and the patients. In future research it would be important to investigate health care system barriers such as the lack of a computer CRC screening reminder system as well as patient and physician barriers.

The second limitation is that the inter-relations of the factors that were associated with CRC screening in this population were not addressed. In future research it would be important to address the relations of these factors such as the relation of medical mistrust and, patient doctor communication. Such relations may be investigated by in-depth interviews addressing these concepts.



A final limitation is the focus on urban, English speaking African Americans. The barriers and promoters of CRC screening for African Americans needs to be addressed in additional geographic locations as well as in other languages to more adequately represent the diversity of this population.

## CONCLUSIONS

Despite the study limitations, this study provides support for the use of focus group methodology to inform the development of educational materials to increase CRC screening among African Americans. The focus groups provided valuable information about barriers to screening among low income, urban African Americans including cost, pain, fear, medical mistrust and low physician recommendation, suggesting that these are important issues to address when designing interventions to increase CRC screening for this population. The focus groups also informed the brochures' content, layout and color suggesting that focus groups are a useful methodology for ensuring that interventions are appealing and relevant to the target population. Thus, the educational brochures were developed to increase colonoscopy among African American with the goal to increase the prevention and early detection of CRC and reduce health disparities with regard to CRC. We are currently investigating the impact of the materials we developed on CRC screening in a randomized clinical trial with African Americans.

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