



Engaging the Community on Colorectal Cancer Screening Education: Focus Group Discussions Among African Americans

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Abstract

Colorectal cancer (CRC) is the third most diagnosed cancer in the USA, and African Americans experience disproportionate CRC diagnosis and mortality. Early detection could reduce CRC incidence and mortality, and reduce CRC health disparities, which may be due in part to lower screening adherence and later stage diagnosis among African Americans compared to whites. Culturally tailored interventions to increase access to and uptake of CRC stool-based tests are one effective strategy to increase benefits of screening among African Americans. The objectives of this study were to obtain feedback from African Americans on CRC educational materials being developed for a subsequent behavioral clinical trial and explore participants' knowledge, attitudes, and beliefs about CRC and CRC screening. Seven focus groups were conducted between February and November 2020. Participants were African Americans recruited through community contacts. Four focus groups were held in-person and three were conducted virtually due to Covid-19 restrictions. Participants ranked CRC educational text messages and provided feedback on a culturally tailored educational brochure. A focus group guide with scripted probes was used to elicit discussion and transcripts were analyzed using traditional content analysis. Forty-two African Americans participated. Four themes were identified from focus group discussions: (1) knowledge, attitudes, and beliefs on CRC and CRC screening; (2) reliable sources of cancer education information; (3) cultural factors affecting perspectives on health; and (4) community insights into cancer education. Participant input on the brochure was incorporated in content creation. Engaging African American community members to qualitatively examine cancer prevention has value in improving implementation strategy and planning for behavioral clinical trials.

Keywords Colorectal cancer · Cancer screening · Stool blood tests · Colonoscopy · African Americans

Introduction

Colorectal cancer (CRC) is the third most common cancer detected and the third leading cause of cancer-related deaths in the USA, with approximately 147,950 new cases diagnosed annually and 53,000 deaths [1]. While CRC incidence has declined in patients over 50 years old over the last two decades, the rates have increased in younger aged patients [2], prompting the US Preventive Services Task Force (USPSTF) to issue a draft statement lowering the screening age to 45 [3]. Model-based approaches estimate that over 50% of CRC deaths in the USA could be prevented with better adherence to screening recommendations [4, 5]. Evidence-based and cost-effective CRC screening includes colonoscopy, flexible sigmoidoscopy, and stool-based tests [6]. Because of the high survival rate of CRC when detected early, groups like the National Colorectal Cancer Roundtable

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have championed sustained efforts to increase awareness of the importance of screening and early detection to achieve the national screening goal of “80% in every community” [7].

African Americans compared to whites have higher incidence and mortality from CRC and are diagnosed at earlier ages but later stage of disease, leading most medical organizations to recommend CRC screening for African Americans beginning at age 40 to 45 [8, 9]. Despite steady overall declines in CRC incidence and mortality rates across racial and ethnic groups in the USA, the disproportionate burden among African Americans has persisted albeit shrinking, compared to their white counterparts. For example, the CRC incidence rate is approximately 20% higher for African Americans compared to whites [10, 11]. These cancer health disparities may be partially accounted for by different and insurmountable levels or rates of obesity, physical activity, dietary habits, smoking, environmental factors, genetic factors, and access to care (screening, diagnostic, and treatment) [12, 13]. In Florida, where the current study was conducted, Whites reported greater adherence to screening with colonoscopy (69%) compared to African Americans (53%) in 2018 [14]. It is noted however that Florida is non-Medicaid expansion state, and Medicaid expansion has been associated with improvements in colorectal cancer screening for low-income residents and African Americans [15]. According to clinician colleagues at the community health centers in the area, there is a shortage of gastroenterologists who will provide colonoscopy screening to uninsured patients. In addition, in 2020, because of the Covid-19 pandemic, adults are delaying any screening or avoiding diagnostic screening procedures like colonoscopy, and this negative trend is affecting medically underserved populations disproportionately [16]. The 5-year relative survival rate for colon cancer from 2009 to 2015 was 65.4% for African Americans compared to 71.7% for Whites [17]. African American CRC patients have lower survival rates and less localized disease compared to White patients, in part due to later stage at diagnosis, which could be partially addressed with better adherence to screening guidelines and improvements in health care coverage [10]. While CRC death rates across the USA have declined, in southern states, where there are larger populations of African Americans, the decline has been slower compared to Whites [1].

In the USA, colonoscopy is the most thorough test and is often referred to as the “gold standard” for CRC screening. However, because of a shortage of gastroenterologists—especially in rural areas, lack of health care coverage to cover the diagnostic procedure or excess copays and deductibles, and other barriers such as transportation or fear of the test—participation in colonoscopy screening can be challenging for some communities. There have been several studies to examine the potential impact of stool-based testing

interventions to increase screening rates among low-income and minority populations since this testing modality is more easily administered and costs less than other tests [18–20]. A Cochrane review estimated that the reduction in CRC deaths associated with stool-based testing was approximately 14% [21]. To address CRC health disparities, there needs to be increased outreach and education on the necessity of timely CRC screening for African Americans regardless of the modality. Lowering the screening age may increase uptake but adherence remains a major factor for the annual stool blood test and requires successful intervention approaches [19, 22].

Culturally tailored/targeted interventions to increase annual stool blood tests in African Americans are one strategy to potentially improve adherence to CRC screening according to the US Preventive Services Task Force (USPSTF) guidelines [23, 24]. According to a systematic review on interventions to increase stool blood testing in African American communities, tailored navigation approaches such as using a patient navigator to contact patients by telephone or in person have resulted in a range of 6 to 36% increases in CRC screening compared to usual care [25]. In another study performed in a large health care system to understand screening uptake in younger populations, a prospective study of fecal immunochemical test (FIT)-mailed screening resulted in a 33% return rate among African Americans between 45 and 50 years old [26]. The objective of this focus group study was to collect feedback on educational components of a planned behavioral research study that will employ community health advisors to increase stool-based testing in African Americans in north Florida. Additionally, we explored the knowledge, attitudes, and beliefs of focus group participants toward CRC and CRC screening. This study reports the analysis of these focus group discussions among African American community members in two north Florida counties with large proportions of African Americans compared to other counties in the state.

Methods

The data reported in this focus group study are part of a larger behavioral trial that will test the effectiveness of a community health advisor intervention to increase stool-based testing in African Americans between 45 and 64 years of age who are not up-to-date with USPSTF CRC screening guidelines [3]. This would include individuals who have never been screened but are recommended to begin stool-based screening at age 45. The rationale for the upper age limit of 64 for the planned intervention study was to recruit pre-Medicare eligible patients to potentially capture more of the uninsured population. Formative research was conducted with African Americans in this approximate age range to

explore knowledge, attitudes, and beliefs about CRC and CRC screening, elicit feedback on draft versions of a CRC educational tri-fold brochure, and identify preferred CRC screening educational text messages.

Recruitment

The study team recruited participants for seven focus groups of African Americans in northern Florida: rural Gadsden County, Florida's only majority African American county and neighboring Leon County, location of the state's capital, Tallahassee, a mid-size Florida city. Eligible participants could be either male or female and needed to identify as African American. The first four groups were held in person, and the last three groups were held online because of Covid-19 mitigation precautions. Focus group recruitment was facilitated through contacts with church and community leaders, and the in-person groups were held at three different African American churches in two counties from February to early March 2020. The fourth group was conducted in mid-March 2020 and subsequently university Covid-19 restrictions on staff travel and society-wide communicable disease prevention efforts essentially precluded further in-person meetings. The study team submitted an amendment to the Institutional Review Board (IRB) and proceeded to recruit individuals to participate in Zoom meetings for three additional focus groups. After conducting seven focus groups, the content of the discussions reached thematic saturation [27].

All participants provided informed consent to join in the focus group discussions. Twenty-nine participants joined the four in-person focus groups, and an additional

13 participants joined the online focus groups. The research project was approved by the Florida A&M University IRB.

Data Collection

The study team developed a focus group guide with questions and scripted probes composed of approximately 21 questions (Table 1). In addition, participants completed demographic questions (including place of birth) and a rating form with a series of 13 educational text messages on colon cancer using a 5-point Likert scale to measure agreement. The term "colon cancer" was a more familiar term than "colorectal cancer," so we primarily used "colon cancer" in the focus group questions. The opening questions focused on sources of health information, knowledge and awareness of colon cancer, colon cancer prevention, and whether they thought colon cancer was a problem in their community. The focused set of questions asked participants to discuss whether colon cancer screening could be improved by education on the disease, whether they were familiar with any specific symptoms and screening methods, and what types of prevention and screening methods such as colonoscopy and stool-based tests they had heard about.

The next set of questions asked participants to review the draft version of the educational brochure. Learner verification for the educational brochure was used to obtain feedback about the materials to ensure they resonated with the target audience. The considerations of learner verification, culture, and literacy used in our study was informed by the recommendations of Meade and colleagues [28] to positively impact patient education and outreach through accessible materials. It involves

Table 1 Examples of focus group questions

Domain	Questions
Sources of health information	Where do you get most of your general health information? How do you know what sources to trust for health information?
Sources of CRC information	Tell me about any health topics involving colon cancer that you have heard about? Tell me about what you have heard in the news or media about colon or colorectal cancer?
CRC prevention knowledge	What are your thoughts about ways to reduce colon cancer? To increase screening? What are the roles of exercise or diet in preventing colon cancer?
CRC prevention education	Do you think colon cancer screening can be improved with education?
CRC knowledge	What types of symptoms have you heard about from colon cancer? Do you self-diagnose or are others involved in determining if someone has symptoms of colon cancer?
CRC screening knowledge	What have you heard about screening for colon cancer? Have you heard about stool-based tests?
Feedback on brochure	Attraction: Is the information in the brochure attractive and call your attention? Comprehension: Do you understand the words that are used to convey the information? Have you ever received information about colon cancer screening before? Cultural acceptance: Do you think these brochures would be culturally appropriate in your community? Persuasion: Do you think these brochures would be persuasive to get someone to think about screening?
Learning preference	What is the best way to present information about colon cancer to individuals/community? Who would you prefer to deliver the message about colon cancer screening? Who are you most likely to trust? (e.g., family, friend, doctor, nurse)

verifying or reviewing the materials with the audience on several elements: acceptability, attraction, understanding, self-efficacy, and persuasion. Learner verification is especially helpful during the development phase of educational materials/media and offers multiple feedback loops for improvement and revision to ensure content is understood and culturally appropriate for the intended audience. Participants were asked about the attractiveness and content of the brochure. They were also asked to comment on comprehension, cultural appropriateness, and persuasion characteristics, as well as to provide suggestions on improving the content. The focus group concluded with questions about who they were likely to trust delivering health messages, most important points discussed in the focus group, and any final questions or concerns. The co-moderator presented a summary of the discussion at the end.

The focus groups were led by a skilled facilitator and a co-moderator to handle the recording equipment and the forms. Interviews were digitally recorded and transcribed by a transcription company. The only difference in procedure for the online focus groups was that participants completed demographic forms online rather than paper and pencil, and the transcription was created automatically by the videoconference platform. The co-moderator's role was the same in terms of taking notes and summarizing the discussion at the end. All focus group participants received a retail grocery gift card in the amount of \$20 either in person or through the mail and an educational infographic handout from the American Cancer Society.

Data Analysis

First, an internal report summarizing each focus group was prepared by the co-moderator. Interview transcripts were analyzed using MAXQDA® (Marburg, Germany) computer software. The lead author (JL) employed a traditional content analysis approach to develop a coding scheme to attach meaningful codes to blocks of text [29, 30]. A codebook was developed in MAXQDA® to operationalize and define the code categories. The lead author (JL) and one co-author (MV) then recoded the transcripts using the codebook to reach agreement on coding procedures and coding accuracy. The lead author and two co-authors (MV, OM) then convened to resolve any coding discrepancies and collaboratively agree on the overarching themes and subthemes from the focus groups. Qualitative feedback on the brochures and quantitative ratings of the text message preferences were analyzed and incorporated to improve these educational materials for use in the subsequent behavioral clinical trial.

Results

Participants

The study recruited a total of 42 African Americans who participated in seven focus groups. Table 2 provides the demographic characteristics of participants, and only two participants listed a foreign country of birth. A majority of participants were female (81%), between the ages of 50 and 59 years (55%) and most had completed at least some college (67%). There was one participant aged 41 and one participant aged 70. All other participants were in the age range 45–64 as was requested of community partners by the research team to aid with recruitment efforts. Half of the participants lived in Tallahassee, and the other half lived in neighboring Gadsden County. Focus groups ranged in size from three to nine participants, with fewer participants per group in the online focus groups than the in-person focus groups. The length of the focus group discussions ranged from 36 to 82 min, with an average of approximately 52 min. Table 3 summarizes the participant ratings for possible text messages intended for use in the intervention phase. Shorter text messages about the benefits of screening were rated slightly higher over text messages which pointed to health disparities or CRC rates among African Americans. Out of 13 text messages, participants rated “Screening for colon cancer saves lives” the highest.

Summary of Findings

After analyzing the focus group transcripts, four major themes emerged from the coding categories: (1) knowledge, attitudes, and beliefs on CRC and CRC screening; (2) reliable sources of cancer education information; (3) cultural factors affecting perspectives on health; and (4) community insight on cancer education materials. The results presented here are organized around these themes. Direct quotes from participants illustrate the themes and sub-themes in the following section.

Knowledge, Attitudes, and Beliefs About CRC and CRC Screening

The theme around knowledge, attitudes, and beliefs about CRC and CRC screening encompassed codes on CRC family history, CRC screening, CRC symptoms, diet and exercise to prevent cancer, and perceived causes of CRC. There were varying levels of knowledge about CRC (Table 4). Participants were familiar with various symptoms they had heard about such as blood in the stool and rectal bleeding. Conversations frequently mentioned older family members or

Table 2 Demographic characteristics of focus group participants and by format

Characteristics	Total (<i>N</i> =42)*	%	Face to face (<i>N</i> =29)	Online (<i>N</i> =13)
Sex				
Male	8	19	8	0
Female	34	81	21	13
Age group**				
40–49 years	6	15	5	1
50–59 years	23	55	16	7
60–70 years	11	30	7	4
Place of birth				
Florida	27	71	20	7
Georgia	1	2	1	0
Mississippi	1	2	1	0
New York	3	8	1	2
Other US	4	11	4	0
Jamaica (country)	1	2	1	0
Guyana (country)	1	2	0	1
Marital status				
Single/divorced	22	52	12	10
Married	18	43	15	3
Domestic partner	2	5	2	0
Education				
< 11 years	1	2	1	0
12 years or high school	13	31	12	1
Some college	12	29	9	3
Completed college	16	38	7	9
Employed				
Yes	33	79	22	11
No	9	21	7	2
Housing				
Apartment	4	10	2	2
House	32	78	21	11
Mobile home	5	12	5	0
Reads English				
Very well	36	86	23	13
Fairly well	6	14	6	0
Residence				
Urban	21	50	10	11
Rural	21	50	19	2
Have a regular provider				
Yes	38	91	25	13
No	4	9	4	0

*If total number (*N*) does not equal 42, there were missing data for that question and percentages may not add to 100% due to rounding

**There was one participant aged 41 and one participant aged 70 who attended the focus groups. All other participants were in the age range 45–64 as requested in communications with community partners

celebrities—e.g., the actor Chadwick Boseman had recently passed from CRC at the age of 43—in the context of their

knowledge about the disease. In terms of explanatory models of the disease, there was the belief that diet, stress, family history, and environmental factors were possible causes for someone to receive a CRC diagnosis. Because there were tobacco fields in the area, some participants discussed the history of farm work in their family as being a cause of cancer in the community. Eating a “Southern food” diet was viewed as unhealthy because these foods could be high in fat resulting from how they were prepared. Some participants stated that a diet high in red meat was related to CRC and that a diet high in vegetables/fiber was beneficial. Also, there were frequent discussions about concerns with modern industrial food production, in particular “chemicals” and “hormones” in the processed foods. Regarding CRC incidence, several groups discussed that African American men were more likely to receive a CRC diagnosis than women. Four participants stated that they had no knowledge about CRC and CRC screening.

Many participants were familiar with the age to begin screening, either 50 or earlier at 40 or 45. Some participants wanted to have more information about the recommended age if CRC was more common in African Americans, and why they were not being told to start screening at age 45. There was no reported knowledge of the upper limit of age 75 for CRC screening. There were more frequent discussions of the colonoscopy procedure than other types of CRC screening, and the common aversion to the bowel preparation prior to colonoscopy, but there was acknowledgement that removing precancerous polyps was a positive outcome. Regarding colonoscopy, there also was discussion about concerns surrounding the decision to undergo the exam with or without anesthesia. There was also some aversion indicated for the stool-based test, which might lead some to delay completing the home test. Some participants described their own or their family members’ or friends’ awkwardness or embarrassment about completing the stool-based test, sometimes using words like “gross” or “nasty” to describe it. Another reason cited for not completing CRC screening was the absence of symptoms, signaling a lack of urgency to get the CRC screening scheduled and completed. It was expressed across groups that there was a lack of awareness about CRC and CRC screening in the community. Many participants stated that there was much greater promotion and awareness about breast cancer than CRC.

Reliable Sources of Cancer Education Information

The theme of reliable sources of cancer education information included discussions of both one’s personal network and media sources of information. Participants mostly preferred and trusted cancer education information from their doctors whom they believed would be in the best position to answer their questions (Table 5). Some participants also believed

Table 3 Ratings of text messages by focus group participants by level of agreement

Text message	Mean*	SD
Screening for colon cancer saves lives	1.17	0.49
Seven out of ten people diagnosed with colorectal cancer often have no obvious signs and symptoms, regular screening is the key to early detection	1.24	0.53
Colorectal cancer screening is one of the most important things you can do for yourself and your loved ones	1.29	0.55
Get tested! It is the single best thing you can do to prevent colorectal cancer	1.29	0.55
Don't let fear of diagnosis stop you from getting tested, early detection is key to prevent colon cancer. Get tested today	1.29	0.55
Preventing colorectal cancer by finding it early is possible with regular screening. There are many test options, including simple, affordable tests	1.31	0.56
Screening tests can help prevent colorectal cancer or find it early, when treatment works best. Colorectal cancer screening saves lives!	1.36	0.53
Did you know that colorectal cancer is one of the leading causes of cancer among blacks?	1.41	0.63
Did you know that colorectal cancer rates are higher for blacks than whites in both men and women?	1.45	0.67
Colorectal cancer is the second leading cause of cancer-related deaths	1.48	0.70
Did you know that colorectal cancer is the third most common cancer in both black men and women?	1.49	0.74
The National Medical Association and the American Cancer Society have collaborated to develop materials specific to African Americans that focus on prevention, early detection, and treatment of colorectal cancer	1.56	0.89
According to the Centers for Disease Control (CDC), you should start receiving colorectal cancer screening after the age of 50	1.76	1.10

Lower mean scores indicate higher preference

SD standard deviation

*Based on Likert scale responses: 1 = strongly agree; 2 = somewhat agree; 3 = somewhat disagree; 4 = strongly disagree

and trusted information from family or friends, survivors of colorectal cancer whom they knew, and from cancer advocacy organizations. Other sources of information included trusted websites, television programs, magazines, and social media posts from their social network. When sources of information such as magazine articles specifically addressed the needs of African Americans, participants highlighted these examples in their responses.

Cultural Factors Affecting Perspectives Toward Health

Several topics discussed were grouped into a category labeled “cultural factors” which included codes relating to fear of cancer, African American perspectives, and religious beliefs (Table 6). One topic discussed in several groups was fear of a cancer diagnosis. Fear of receiving a diagnosis was listed as a reason for not completing or for delaying CRC screening; one participant described her fear of learning of a CRC diagnosis through screening as well as her fear about not knowing (i.e., not completing her screening). Some participants valued screening to help them have peace of mind; however, other participants pointed out that sometimes it was better not to know if someone had cancer because that could lead to a negative mindset or catastrophic thinking. Moreover, among men, there were some statements which indicated perceived stigma around the colonoscopy procedure alluding to threats to masculinity. Because the in-person focus groups were conducted in Christian churches, many discussions around health and illness addressed religious

beliefs and the importance of faith in God. Because of challenges with health care access and awareness of persistent health disparities, several participants expressed the dual importance of both praying to ask God for healing and seeking timely medical care when confronted by a cancer diagnosis. These sentiments may not necessarily be unique to this faith community, however.

Community Insights on Cancer Education

The focus groups generated additional qualitative data about CRC screening educational resources which consisted of a draft version and subsequently modified educational tri-fold brochure. For the original draft version of the brochure, participants read through the entire brochure to ensure comprehension of the material in terms of health literacy. Participants liked the colors and the graphics of the human anatomy and the colon showing polyps. Some said that they wanted a short testimonial and liked the photos featuring famous African Americans who had died from CRC (e.g., Eartha Kitt). Focus group participants also indicated a preference for pictures of well-known community members rather than stock photos. Due to copyright restrictions, the final version did not feature photos of celebrities, but had two photos of couples; one photo was of a couple people knew in the community and the other was a stock photo.

Following the brochure revisions from the earlier focus groups, one online focus group participant commented: “I

Table 4 Knowledge, attitudes, and beliefs about CRC and CRC screening

Theme/sub-theme	Example quote
CRC knowledge, attitudes, and beliefs	
Symptoms	<p>I think usually of bleeding – blood in the stool is usually maybe a possible indicator. – <i>Male participant, FG 1</i></p> <p>I've heard of pain, stomach pains, and blood in the stool. – <i>Female participant, FG 5</i></p> <p>I've heard that, you know, having gastrointestinal issues as well as blood in the stool is a symptom. So, that's, you know, my understanding of that. – <i>Female participant, FG 5</i></p>
Lack of knowledge	I've never really heard of colon cancer until recently. One of my brothers-in-law, he was telling me that he had colon cancer. But that's about it. – <i>Female participant, FG 6</i>
More prevalent in men	<p>I don't know if it's rumors or if it's truth to it – that it's very hard to be diagnosed in women ... But even in me seeing patients throughout the hospital, I've seen more men with the diagnosis than I have women. – <i>Female participant, FG 1</i></p> <p>I heard that black men – it was higher in black men than other races. – <i>Male participant, FG 1</i></p>
Etiology of cancer	<p>And I know lots of people in the African American community who are working two jobs. They're working extra hours. And so, we have to talk about self-care in terms of exercise, taking a few, you know, like three days a week or something to de-stress ... As well as the diet, encouraging you know those two things, stress, and diet. – <i>Female participant, FG 7</i></p> <p>Environmental. Because I know people working at different areas of healthcare field. I mean the whole county. It's one thing that I noticed that we was [sic] focusing on one time. Nine time out of ten if you look at the population of people that are think about this disease, either their momma, their dad, their grandmomma or great grandmomma, somebody work in the tobacco field here. – <i>Female participant, FG 4</i></p> <p>I think that, first off was: African Americans – maybe their diet – I was raised on a lot of pork and fat. And every vegetable we had had to have seasoning in it. We didn't have plain old sweet peas ... So, I think maybe that fat got something to do with it. – <i>Female participant, FG 3</i></p>
Family history	If it runs in your family, I think you should get it earlier because my son had large polyps and he has a history of cancer. So, he had to get them removed. So, it just depends on your family history, as well as your age. – <i>Female participant, FG 6</i>
Ways to prevent cancer	<p>You need to be careful with—we need to eat more green vegetables, basically. It's important to make sure you're eating foods where you're having regular bowel movements. Because you need to be concerned if you're going for, you know, days and days and days or even weeks and you're having problems with your bowels. So, any diet high in fiber ... I've heard that those are some of the positives to us. – <i>Female participant, FG 5</i></p> <p>Positive you know, lifestyle changes, whether it's walking 30 min a day or eating more fruits and vegetables or adding fiber, to your diet, just healthier, making healthy food choices. – <i>Female participant, FG 6</i></p>
CRC screening knowledge, attitudes, and beliefs	
Screening age	<p>You're not looking for colon cancer until you reach 50 because that's the current age that they say, unless you have someone in the family who's had it, or they've had polyp, then you don't even start, the doctors don't recommend you taking them until you're 50. But, you know, you can get it at 45, even earlier. So, the sooner you detect it, the better off you will be, and the cure rate will be higher, if you had tested sooner. – <i>Female participant, FG 7</i></p> <p>If it's suggested in African Americans that we start at age 45, what is the reason for our medical professionals not making the referrals for us to get those colon screenings, or mammograms and all that if the research suggests that we do it five years earlier? To me, again, if there are procedures and markers put in place, why aren't the medical professionals making those recommendations at 45, 46, 47, you know? – <i>Female participant, FG 4</i></p>
Colonoscopy experience	<p>I've had like two colonoscopies within the past, you know, couple years because my dad used to have polyps. So, people usually say if you have a relative who has had problems with polyps, that you should go and get tested. So that's why I went and got it done. – <i>Female participant, FG 7</i></p> <p>Well, me, myself is working with the community. I've never heard so many men said, "Lord, I've been violated." They don't like the procedures. – <i>Female participant, FG 4</i></p>

Table 4 (continued)

Theme/sub-theme	Example quote
Stool blood test	<p>I don't understand because it don't bother me, but did them with other people. Some people have a problem with dealing with bowel. They can't just – like for example, I had nieces that was nursing that had to put on a mask to help change the colostomy bag when I just go in there and do what I've got to do. – <i>Female participant, FG 4</i></p> <p>I just heard a cousin the other day make the statement, “I have one of those things to do, those stool samples. I can't stand doing those things. Those things get on my nerves.” And so, my first thing, my statement to her was, “yeah, it is, it seems like it's cumbersome sometimes but,” I said, “think about it, if they're giving it to us to do, it is for a reason. They're checking.” So, you know, I mean, I learn to even appreciate the fact that this is something I don't like to do but I find it necessary. – <i>Female participant, FG 5</i></p>
Reasons for screening delay	<p>And like I said, that's when I turned 45 and then that's when the COVID outbreak just hit. So, I know I need to go and get it done— the year's almost over, whatever. So, you know, I still can get it done at the beginning next year, something like that. But it's just all of those, factors or whatever. And it's still early because, like, some of the studies say 45, some say 50, some say other ages. But I do believe that early detection is the best protection. And then for me, I don't have any blood in my stool, and I don't really have any stomach pains or anything kind of going wrong in that area. So, just those kind of things just helped me to keep kind of like pushing it back. – <i>Female participant, FG 6</i></p> <p>My insurance is through [blinded] Care just like this. They monthly send me information about have you done this, or have you done that. And they sent me the stool sample. I did that through that, and when I needed to – they wanted to setup a colonoscopy for me but they told me it was not time, so my insurance would keep me up to date, and they say something every month on information like this. – <i>Female participant, FG 4</i></p>

like the brochure. I love the photos, you're showing a couple, not just men and not just women, a couple, and at different ages as well, which is great.” Another online participant in a different focus group also commented on the pictures and colors: “I think what you have is good with the pastor and his wife, you know, local people. People can identify and

know that they are just everyday people. And, I like the fact that it's very colorful and eye catching.” The final version highlighted statistics about African Americans and CRC and featured clear and colorful graphics showing the anatomy of the colon, the digestive system, and descriptions of colonoscopy and the stool-based test. The back cover of the brochure

Table 5 Reliable sources of health information on cancer

Information channels	Example quote
Information from doctor	Well, I got it from my, from my doctor. My husband just had a colon screening, and we got a lot of information from the physician in reference to that. Especially dealing with African Americans. So that was really a help. You know, and we've had some experience with colon cancer. – <i>Female participant, FG 7</i>
Television	Well, with the advertisements, there's a lot of advertisements for people to do the Cologuard. And I've been seeing that, you know, quite a bit. But... I think I've seen different shows, where people talk about, you know, African Americans and colon cancer. – <i>Female participant, FG 7</i> Just TV news. 'Cause you don't call the doctor unless you need to. Otherwise, you get your information from social media, TV. – <i>Female participant, FG 2</i>
Internet	For me, it's usually the web. Like WebMD. But I usually cross-reference. I don't check just one source, to make sure that the information is correct. And usually my doctor's office – I'll pick up information when I go. – <i>Male participant, FG 1</i>
Social media	I turned 45 this year. And I know that I'm supposed to go and get a screening done. I'm of age now. And I saw that on some reading on social media, as well as I saw a news clip. – <i>Female participant, FG 6</i>
Advocacy organizations	I was about to say my doctor's office. You know, I have regular check-ups and things like that from the doctor's office, but I also work with the Relay for Life Team as one of the team captains and so that's a piece of information that is usually shared when we have meetings looking at the various cancers that are out there because I think they color code them. So, between the doctor's office and the cancer Relay for Life association. – <i>Female participant, FG 5</i>
Magazines	We get the AARP magazines. They send out a lot of information referencing, talking about colon cancer and the need for being tested. But also, as a part of AARP, there's a sub-publication called Sisters for AARP that specifically targets African Americans, and it speaks about that specifically as to males versus females. So, they talk a lot about those issues, too. – <i>Female participant, FG 7</i>

Table 6 Cultural factors affecting perspectives on health

Theme/sub-theme	Example quote
Cultural factors related to a cancer diagnosis	
Fear of cancer	I think also beyond the accessibility, the lack of insurance, I think another thing is fear. I know some people that – they just fearful to find out. But I have a totally different philosophy. I say, “If something’s killing me, I wanna know what it is. Maybe I can do something about it.” And so, I think we need to educate people to change their mindset. Because we know if you catch it early, great chance that you can remediate it. But if you wait ‘til it’s too late then you’re gone. – <i>Male participant, FG 1</i> But, you know, sometimes it’s just we look, and we see someone else that has had it and, the fear and we see what they’ve gone through and sometimes, you know—sometimes, people feel like, I’d rather not know. I mean, I know that’s not a good thing for us to say but there are times when you talk with people and you’ve heard say, I’ve heard statements like that. But then, you know, like if you do know, maybe you catch it in time so that you can do something about it. – <i>Female participant, FG 5</i>
Religious beliefs	What he’s saying is very relevant to the black community. We do have a lot of us who totally solely depend on a word from God. And feel like even if they are sick, “Oh, he gonna heal me; God gonna heal me. I don’t need to go to the doctor. I’m gonna give it to God.” And all that kinda stuff. So, I think that it needs to be a balance. I feel like we still need to go to the doctor. You know what I’m saying? And still trust God at the same time, but don’t neglect the fact that we live in a world that ... medicine and doctors are here to help. – <i>Female participant, FG 2</i>
Issues discussed through an African American lens	
Access to health care	Having access to affordable health care, I think, makes a big difference, whether or not you have the screenings. I mean, given, you know, I think about my situation, and I’ve always had great health care. I’ve never been without health care, but that’s not really the norm for the average African American person. So, I think that’s one way, is having access to affordable health care. And maybe having a healthier diet would not hurt either. – <i>Female participant, FG 7</i> A lotta African Americans don’t have the funds to pay for the insurance. Don’t have the insurance, they don’t have the medical treatment. – <i>Female participant, FG 1</i>
Health disparities	I think that if it’s more prevalent in our race then there should be some standards in place for us so that we get the proper treatment, and screening, and everything that’s available for us to help fight this thing. I know prayer definitely will help fight it, but if it’s medical as well we should have something in place for us. – <i>Female participant, FG 4</i>
Injustice	I just want to make sure that nobody is getting rich off our people. – <i>Female participant, FG 4</i>

listed information for accessing resources from the American Cancer Society and the National Cancer Institute. On the inside panel, relating to questions on cancer screening, there was a testimonial called *Earl’s Story*, which read, “*It’s a test no one looks forward to, but it’s important to talk about it. I feel like I dodged a bullet.*” There was also a short section above the testimonial about not letting fear be a factor, stating the fact that those who found CRC early had a greater than 90% survival outcome.

Discussion

This qualitative study adds to the literature on knowledge, beliefs, and attitudes of CRC and CRC screening among African American community members in northern Florida and how such community participation may help to inform content and strategies for a cancer education intervention. While the bulk of the focus group discussions were in response to questions specifically about CRC, several other related topics were discussed including access to health care, health challenges specific to African Americans, quality of health care, and sources of reliable health information.

These discussions provided the facilitators an opportunity to share CRC educational materials with participants on a topic rarely discussed in the community. In addition, the engagement prompted valuable input and feedback for the creation of the intervention brochure and preferences for a series of educational text messages to influence behavior toward CRC screening. During the online focus groups, participants confirmed that the brochure and its contents were understandable and culturally appropriate. Collecting qualitative feedback on materials and strategies prior to refinement of a behavioral intervention has been associated with increased community engagement and improved effectiveness of planned intervention strategies [31]. Discussion of CRC, and cancer in general, can be an uncomfortable topic which might elicit fear or have stigma attached to it, especially around the topic of screening, so incorporating community health advisors into cancer screening intervention programs is a promising approach to address concerns community members may have about screening [32–34].

Participants expressed limited communication with providers on the topic of CRC and CRC screening. For many women who participated in the groups, there was the perception that there were less discussions about CRC, with more

emphasis usually placed on breast cancer education and screening mammography. Focus group participants opined that “everything costs,” suggesting the perception that even the effort to obtain accurate health information, during a doctor visit for example, had a monetary cost attached to it. Participants mostly relied on accurate health information coming from their health care providers in terms of health information seeking. Moreover, some believed that to receive recommended preventive health care required patients to be advocates for themselves in the health system. One participant specifically mentioned an African American gastroenterologist as providing personalized care. In a focus group study with African Americans who had a first-degree relative with CRC, a strong physician recommendation served as a cue to action for completing CRC screening [35]. Therefore, it is important for patients to discuss CRC and CRC screening with their primary care physician to ensure that they receive timely screening based on their risk profile.

The focus group discussions revealed several barriers to screening. Participants stated that many community members, especially those who are uninsured and lack a medical home, may not receive CRC home screening mailings and may be unaware of the availability of no-cost or low-cost stool blood screening through community clinics, and consequently, participants indicated the need for more effective communication of the availability of CRC home screening. There were some negative attitudes to CRC screening because of lack of insurance, lack of symptoms, fear, and embarrassment; however, this was more pronounced among men than women. Reasons for delaying screening, such as the belief that CRC was more common in men than women and the absence of symptoms, among other individual and systematic barriers, align with findings from other qualitative studies conducted with African Americans on this topic [31, 34, 36–38]. Although the brochure did not address cancer risk in men explicitly, the testimonial in the brochure was titled *Earl’s Story* and described how CRC screening was a test no one looks forward to, but is important to talk about, emphasizing social norms.

There were some limitations to the focus groups in terms of difficulties recruiting enough men to participate in the focus groups and challenges relating to the discontinuation of in-person focus groups following the institution of Covid-19 protocols in mid-March 2020. The research team had to adjust their recruitment strategy and recruit an additional three focus groups to participate in Zoom meetings which delayed focus group scheduling. The major advantage of holding Zoom meetings is the technological feature of producing transcripts and recording videos that could be reviewed later. The disadvantages of virtual rooms include the lack of visual cues used in focus groups to indicate who is ready to speak next. However, no differences were

detected in terms of the information participants were willing to share. Demographic surveys were completed using an online survey tool instead of paper surveys and did not present barriers for participants. The only technical challenge for focus group participants who joined virtual rooms consisted of not being able to turn on their videos and view the brochure. However, the brochure file was emailed to them prior to the meeting. Based upon their feedback, most had reviewed it before the meeting.

Conclusions

The qualitative methods used to gather data in the focus group discussions allowed participants to express their knowledge, attitudes, and beliefs about CRC and CRC screening, offer insight into risk factors and concerns present in their community, and provide perspectives from their own personal experiences and interactions with the health care system. The limited availability of easily accessible cancer education information was a concern raised across focus groups, with many suggestions provided on how to increase community awareness, both in terms of general information on CRC and the availability of affordable stool-based screening. These concerns were addressed in the intervention materials. Engaging African American community members to qualitatively examine cancer prevention educational strategies was valuable for improving our program implementation and planning for the behavioral clinical trial. The planned intervention has the anticipated impact of improving the quality of CRC screening education and of changing negative attitudes leading to enhanced uptake of CRC screening among African Americans and thus reducing disparities in cancer health outcomes.

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