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Barriers and Facilitators to Stool-Based Screening for Colorectal Cancer Among Black Louisville Residents

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Abstract

Knowledge of colorectal cancer (CRC) screening options remains suboptimal in Black populations, contributing to screening disparities. Guided by community-based participatory research (CBPR) principles, we partnered with five Black churches in Louisville, a region of Kentucky with high Black-white CRC screening disparities, to explore screening barriers and facilitators for CRC education and outreach. Project champions ($n = 5$) served as primary points of contact, developed project support within their churches, and were trained to recruit church and community members ($n = 39$) to participate in five semi-structured focus groups. Interview questions probed actual and perceived barriers to CRC screening, focusing on knowledge and perceptions of stool-based tests. Subsequent questions explored perceptions of different screening tests, CRC knowledge and beliefs, and trusted community locations for screening outreach. Transcripts were analyzed iteratively, and codes were derived inductively and refined to develop overarching themes. Participants experienced multilevel barriers to completing CRC screening. Primary themes about CRC screening included acknowledgment of importance, positive and negative personal experiences, need for increased outreach, and desire for greater cultural representation in educational materials. Participants frequently discussed perceptions of inadequate medical care, with most having only ever been offered colonoscopy; subsequently, knowledge of stool-based tests was low. To address this knowledge gap, participants stressed interpersonal communication from trusted individuals, such as local Black medical providers and CRC survivors. Given the low knowledge of stool-based testing among participants and identified

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inequities in receipt of clinical care, community-based CRC screening interventions are warranted to reduce Black-white CRC screening disparities.

Keywords

Colorectal cancer; Screening; Stool-based screening; African Americans

Nearly half of Kentucky's Black population—about 170,000 of Kentucky's nearly 365,000 Black residents—lives in Jefferson County, where Black residents experience worse outcomes for colorectal cancer (CRC) incidence and mortality than white residents (54.3 vs. 43.3 for overall incidence, and 14.8 vs. 11.2 for mortality, for Black vs. white residents of Jefferson county, per 100,000 population [age-adjusted]) [1]. Disparities in CRC incidence in Black populations are largely explained by lower screening rates, which are, in turn, related to a number of social-ecological barriers [2]. Black patients cite perceptions of test invasiveness, fatalism, and lack of knowledge about screening importance as individual barriers [3, 4], and living in segregated, impoverished neighborhoods with low perceived social capital [5] as systemic barriers to screening. In Jefferson County, the highest CRC incidence is found in census tracts with high proportions of Black residents [6], low educational attainment, and high poverty, necessitating increased screening outreach in these areas.

Multiple randomized clinical trials have demonstrated the efficacy of stool-based screening, such as the fecal immunochemical test (FIT) [7]. As such, FIT is included by the US Preventive Services Task Force (USPSTF) as a recommended screening modality for individuals at average risk for CRC [7]. Stool-based tests reduce many individual-level barriers to screening and are broadly preferred by patients nationwide [8], yet knowledge of screening options [4, 9]—and subsequently, stool-based testing rates—remains suboptimal in Black populations [9] despite clinical trials showing increased screening rates among Black patients when offered screening options beyond colonoscopy [10, 11]. Furthermore, although primary care settings are ideal for CRC screening promotion, Black patients are more likely to use the emergency department as a usual source of care, particularly when they report higher levels of medical mistrust [12]. To fill this care gap, faith-based organizations in minority communities have a long history of developing and implementing health promotion programs in trusted local settings and, specifically, they have increased community CRC screening rates by implementing evidence-based interventions (EBIs) that educate about CRC and promote stool-based testing [13].

To better understand the multifactorial reasons for CRC disparities among Black Kentuckians, researchers from [blinded university cancer center] and [blinded regional organization] conducted qualitative focus groups with project support and guidance from leaders of five Black churches in Louisville who had interest in colorectal cancer prevention and capacity to partner on research projects. This pilot study was designed to explore facilitators and barriers to stool-based screening and perceptions of church-based CRC education and outreach, with the ultimate goal of using these findings to select and adapt a

community-based EBI to address CRC disparities in Louisville in a future study. Herein, we present the thematic findings from our qualitative research.

Methods

Community Partners and Study Setting

Five Louisville churches were chosen purposively to partner with project co-investigators and regional [blinded regional organization] team members based on their history of community/health promotion outreach activities and their capacity to participate in research. Our approach to developing these partnerships was guided by community-based participatory research (CBPR) principles, wherein church members led study recruitment efforts and encouraged participation via existing channels of communication (e.g., sermons, social media outreach, small group worship activities). Project investigators relied on both established cancer advocacy networks focused on Black populations and snowball recruitment approaches through personal and professional networks to identify and approach churches, as well as to determine their respective interest and ability for partnership. Churches were each provided a \$1000 incentive to offset time and resource commitments for recruitment and focus group administration.

We identified one primary project champion (including both health ministry leaders and clergy members) from each church ($n = 5$) and provided them with IRB-approved training on best practices for recruiting church and community members for focus group participation in cancer education research. Project champions recruited participants primarily from within their own church settings but also from community and familial associations using the aforementioned recruitment techniques. Inclusion criteria for recruitment included ensuring participants were (a) of screening age (i.e., 45–74 years old, per USPSTF recommendations) [7], (b) Black or African American-identified, and (c) willing and comfortable to discuss issues surrounding CRC screening, as explained in one-on-one interactions with project champions and on simple-language recruitment flyers (prepared by project investigators) that explained the purpose, time commitment, and topic of the focus groups. All methods, materials, and research plans were approved by the [blinded academic institution] Institutional Review Board.

Data Collection

Data were collected between April and June 2021 via a series of five focus groups (one per church) that were conducted both with in-person (3 focus groups) and teleconferencing (2 focus groups) formats chosen based on the churches' contemporaneous health safety protocols and comfort levels. Focus group questions (18 questions, with probes used when necessary) were guided by semi-structured interview guides probing facilitators and barriers to CRC screening, with primary emphasis on knowledge and perceptions of stool-based tests (i.e., FIT). Additional questions explored perceptions of community CRC screening needs, knowledge and beliefs regarding CRC and different screening tests, and ideas for trusted community locations to conduct screening interventions. Upon conclusion of each focus group, participants completed a simple 11-question demographic survey with questions

about gender, education, insurance coverage, previous CRC screening experiences, and self-reported health literacy.

Data Analysis

Focus groups were facilitated by one researcher with significant qualitative methods training and practice (AK-D) and a community partner with substantial experience providing community education and outreach (EH). Sessions were audio recorded and sent to a professional transcription service, where they were transcribed verbatim. The project senior investigator (AK-D) compared random audio samples to the transcribed documents to ensure general transcription accuracy and did not find any significant deviations. Two members of the research team (CC, RW) coded transcripts using a thematic analysis approach as outlined in Braun and Clarke [14], and met regularly with the senior investigator (AK-D) to ensure consistency and resolve any coding discrepancies that arose to reach consensus. Codes were derived both deductively (i.e., based on focus group question topics) and inductively (i.e., from discussions that diverged from thematic topics) and were compiled in a template-based codebook that operationalized codes and provided exemplar quotes. The codebook was refined iteratively throughout the coding process as new data expanded, refined, or otherwise changed the operationalization of codes. Ultimately, codes were described via broad, overarching themes representative of the major findings from the study. To ensure trustworthiness, we employed “member checking” by presenting our initial thematic findings to project champions and a subset of community member participants. This process is critical in qualitative research to minimize bias and validate data interpretations. Ultimately, no substantive changes to our interpretations were recommended from the member checking process.

Results

Description of Participants

Focus group participants ($N=39$) were mostly female (61.6%) and over 65 years old (66.6%). A plurality (46.2%) had a bachelor’s degree or higher, and different income levels were well-represented across the sample. Most (71.8%) had at least one person as a primary medical care provider, and 64.1% listed Medicare as an insurance source. Regarding CRC screening, 87.2% had received a screening recommendation from a provider in their lifetime; however, over half (51.3%) had not had a CRC screening examination of any sort in the last year, and nearly three-fourths (74.4%) had never been offered a stool-based test by their medical provider. Consequently, basic knowledge of stool-based screening modalities was low. Self-reported health literacy was generally high, with only seven participants reporting rarely (12.8%) or sometimes (5.1%) requiring assistance reading written materials from their doctor or pharmacist (Table 1). Participants reported on four major themes related to both CRC screening behaviors and CRC in general: (1) acknowledgement of screening importance; (2) personal experiences, and how they shaped either positive or negative perceptions of screening tests; (3) need for increased education about stool-based testing and CRC in general, particularly in community settings; and (4) the importance of cultural representation in educational materials to motivate screening adherence. Table 2

operationalizes each theme and lists additional exemplar quotes for each (beyond what is described in the text herein).

Acknowledgement of Screening Importance

Overwhelmingly, participants recognized the importance of CRC screening to one's health, both in terms of their own personal health and the health of friends and family, as exemplified by one individual who noted that they "...know that these tests... are important for everybody." Participants also felt that this importance should be acknowledged more by other people within their community, and they underscored the importance of interpersonal communication to help disseminate information about screening importance. As one individual stated, "[I]t's all about providing information, sharing information that will save somebody's life. And once we get it... we don't want to just hold it ourselves. You want to share it."

Perceptions of CRC screening importance were frequently influenced by participants' personal exposures to CRC. Often, before expressly acknowledging the importance of screening, participants described how someone close to them had CRC or how people around them talked about CRC. As one person explained, "I think we often listen to people's horror stories to how [colonoscopy] is done... [but] you have to remember [not to] listen to people's horror stories... [By] not doing anything in the next five or six, 10 years, you [can] end up with colon cancer." In general, word of mouth throughout social networks had a noticeable effect on how participants perceived CRC screening and their own comfort levels with discussing screening. A participant summed it up in the following manner: "Just like people have a mystery about the stock market, people have a mystery about a lot of things [related to cancer]. Obviously, you don't bring it up [i.e., CRC screening] at the Thanksgiving dinner, but it's something that people should feel comfortable talking about." Overall, both acknowledgement of the importance of screening and the need to discuss screening more often were strongly endorsed by participants.

Effects of Personal Experiences

Focus groups discussed their first-hand experiences with CRC screening that were often shaped either positively or negatively based on both individual perceptions and interpersonal communication. For example, anecdotes about friends and family often motivated members to pursue colonoscopy. As one member stated "... several persons that I know have succumb[ed] to [CRC]. And now I get a test regularly just so that I can know in my mind that I have done what the medical profession has asked me to do. And that is get a colonoscopy..." Another commented similarly, "My dad died of colon cancer and so [I] have to have screening more often." Perceptions of colonoscopy, however, were not always positive. For example, one focus group participant mentioned that "the preparation is worse than the cancer cell," and another concurred, describing it as "messy." Other factors associated with negative perceptions of colonoscopy included test invasiveness and "horror stories" as told by family and friends.

Despite a number of concerns about colonoscopy, participants had very little knowledge or experience with stool-based screening modalities, such as FIT. Only a handful of

participants had ever heard of FIT, and most of those individuals were either medical professionals or had previously received a FIT kit in the mail from their insurer or the Veterans Administration. Participants widely stated that the reason they did not know about FIT was that their provider had never mentioned it to them (“My doctor has never said anything like that to me, like a FIT test”) though they were much familiar with FIT-DNA due to commercials they had seen on television, even if they did not fully understand its purpose; for example, one participant commented that they did not realize that the commercial was advertising an alternative to colonoscopy. Some individuals also noted perceptions of disgust with completing stool-based tests, just as they did with colonoscopy (or, more specifically, colonoscopy preparation). For example, one focus group member noted, “Some people are just germophobic...and they won’t mess with it.” Nevertheless, participants were largely very interested in FIT and often interjected during focus groups to ask additional questions about the test, its purpose, and how it is self-administered. In particular, they reacted positively to the ease of FIT and lower time commitment as compared with colonoscopy.

Need for Increased Education and Outreach

Generally speaking, focus group members also underscored the need for better screening education, highlighting the lack of education received in health care settings. One participant noted how their provider gave them very little information about screening beyond simply recommending them to complete colonoscopy: “My doctor scheduled the appointment and I went in had it done, and that was it. So the lack of education is my concern.” Another individual noted that during a previous colonoscopy, their doctor had removed polyps but never explained that polyps could develop into CRC over time; the focus group session was the first time that individual had ever received that particular piece of information. Participants overwhelmingly expressed a desire for increased education; as one participant noted, “I think that if more people really understood and had more knowledge, maybe, maybe they would do the testing that’s necessary.”

Resulting from some of these perceived deficiencies in traditional health care environments, participants were extremely receptive to the idea of receiving CRC screening education in trusted community settings. Some individuals mentioned that they had received education at church about other illnesses and health conditions: “We had education. It was part of our announcements... [W]e educated our congregation and some other congregations, and they [were] willing to receive [education] that way.” Because the church was a relatively common venue for receiving health information, participants were positive about receiving CRC there as well. As one participant stated, “I think a church setting (of some type) where people will have an opportunity to receive the information and then some type of follow up...would be important. Follow up to what we talked about. ‘You attended this session last week, have you had an opportunity to do the FIT test yet?’” Other community settings’ participants endorsed for receiving CRC screening education included barbershops and beauty shops, regional African American civic organizations, and Greek societies.

Importance of Cultural Representation in Educational Materials

Lastly, focus group participants widely noted the importance of cultural representation in CRC screening educational materials, something they perceived as generally lacking. Participants expressed a desire to have greater representation of Black culture in educational materials, including photos of Black individuals, so that members of their community would be more likely to be receptive to the materials. One participant detailed, “I get older, I hear more, I’m trying to educate myself more... to be frank with you, sometimes in our culture, sometimes in our community, the understanding, the educational aspect, and all of the importance has been limited [in the Black community] for some reason.”

Specifically, they mentioned numerous types of individuals they would want to see on educational materials for CRC screening. For example, citing the recent death of a younger Black male celebrity, participants mentioned the importance of having education materials feature pictures of younger Black men to address what they viewed as a common perception among young Black men that they are less susceptible to CRC. Other individuals that participants wished to see on educational materials included trusted Black community members, such as local newscasters, pastors, doctors, and well-known former regional athletes. Finally, participants emphasized the need for educational materials to be written in a conversational, comfortable tone so as not to be frightening or intimidating. One individual specifically stated materials should be “very conversational. And that’s part of ‘the thing’ in the Black community and among men, among people in general.”

Discussion

The present study identified four main themes to stool-based screenings for CRC among Black Louisville residents: (1) acknowledgement of screening importance, (2) effects of personal experiences, (3) need for increased education and outreach, and (4) the importance of cultural representation in educational materials. These themes add to the extant literature about CRC screenings within Black communities, and while this study shares similarities to other studies about CRC screening in Black communities, our findings highlight the lived experiences of a subset of Black patients in Louisville; specifically, they underscore that despite acknowledging the importance of CRC screening and expressing desire to learn more information about FIT, many Black patients continue to receive inequitable CRC screening guidance in health care settings.

Our findings suggest that simply acknowledging the importance of CRC screening among family and friends can facilitate screening uptake. Participants in this study expressed the importance of disseminating information about CRC screening, often describing how someone close to them had previously discussed CRC with them. Within the Black community, one common motivator for health decision making is sharing information that could save the life of a family member or friend [15]. Interpersonal discussion about health issues such as CRC can help mitigate stigma regarding the screening process. Historically, Black families have used various interpersonal communication methods, such as storytelling and testimonies that offer an opportunity to communicate about personal and family health histories [16]. Screening interventions utilizing these communication styles to motivate CRC

screening are likely to increase screening knowledge (and adherence) among Black families and community members.

Our study also revealed that individuals reported both positive and negative experiences with CRC screening. For example, in some cases, participants reported that conversations with friends or family members motivated them to seek a colonoscopy. In other cases, however, a number of participants expressed concern that colonoscopies are messy and invasive, perceptions aligned with the previous research showing a correlation between disgust and CRC screening avoidance [17]. Other concerns such as lack of CRC knowledge, cost of screening procedures, transportation issues, lack of provider recommendation, and medical mistrust are also associated with CRC screening avoidance [18, 19]. To mitigate those barriers, screening modalities such as FIT are available for individuals at average risk for CRC. At-home testing does not require time off work, an additional individual for transportation purposes, or any preparation the day before the test; additionally, stool-based tests are often free or low cost, and while they may not necessarily completely remove feelings of disgust, they are far less invasive.

One way of reducing racial and ethnic health disparities related to CRC screening is for health care providers to increase outreach to Black individuals and communities, including promoting stool-based screening modalities as an available option for those at average risk for CRC. The majority of participants in the present study reported that doctors had only recommended colonoscopy as an available screening option despite the USPSTF's inclusion of three stool-based tests as recommended CRC screening strategies for average risk individuals [7]. This sole focus on direct visualization tests might possibly stem from providers relying on outdated research suggesting a preference for colonoscopy among Black individuals or from inadequate provider documentation of family histories, limiting the ability to stratify patients by risk. It is also possible that health care providers require additional information about the efficacy of FIT or training on how to engage their patients in shared decision making about screening preference, a strategy endorsed by the USPSTF [20]. Nevertheless, recent research indicates that individuals of all racial and ethnic groups prefer [8] and are likelier to complete [10, 11] stool-based screening vs. colonoscopy when presented with all available screening options. By not offering Black patients a choice of available screening options when appropriate, health care providers can inadvertently exacerbate medical mistrust within the Black community, possibly contributing to disparate CRC screening rates among their Black patients [19].

US Census Bureau projections have suggested that the USA will become a "majority-minority" nation by 2044, yet as of 2018, only 5% of active physicians are Black or African American [21], suggesting the medical profession has a steep uphill climb to achieve equitable racial representation in the field. In the meantime, to fill the outreach gap, public health educators can increase knowledge and awareness of other CRC screening modalities within the Black community by leveraging trusted regional resources, organizations, and businesses. Individuals from this study reported receiving information in churches, barbershops/beauty shops, and African American civic organizations. Health educators can partner, and collaborate, with these trusted community settings to provide education and outreach necessary to promote CRC screenings. Furthermore, participants expressed

the importance of having trusted Black community members represented on educational materials. The use of culturally tailored materials is empirically proven to increase stool-based CRC screening in Black communities [22] and is aligned with the National Colorectal Cancer Roundtable's CRC messaging recommendations for Black and African American people [23]. By partnering with trusted individuals and organizations in Black communities to co-develop CRC screening interventions, public health researchers and practitioners can ensure that materials and methods are representative of local culture, thereby increasing their likelihood of contributing to intervention success.

Limitations

This study has a number of strengths, including strong representation of individuals in different annual household income categories but must also be interpreted in light of a few limitations. First, our sample skewed generally older (i.e., over 65% were 65 years of age or older), and their views might not be representative of younger Black Louisville residents of screening age for CRC (i.e., those between 45 and 64 years old); although 15% of our sample was comprised of individuals 45–55 years of age, it is possible that their perceptions were not as well represented as those of older participants. Second, we purposively recruited five Black churches in the region based on existing partnerships and willingness to participate. If the views of participants from these churches and their surrounding communities were to differ significantly from other non-participating churches, conclusions and implications derived from our data might not be generalizable to all regions of Louisville. Similarly, individuals in this study participated willingly and were at least somewhat comfortable discussing CRC; it is critical for researchers to capture the perspectives of individuals who are less comfortable with these sorts of conversations as well. Third, as is common with many church-based studies, our study skewed toward higher educational attainment (i.e., nearly 90% of participants had at least some college education), though our participants nonetheless reported a diverse range of reported annual incomes. Fourth, as with most qualitative studies, data represent solely the perspectives of the individuals who were interviewed and cannot be generalized to extend to other regions or populations. Last, although focus groups were facilitated by an experienced team consisting of a skilled qualitative researcher and community outreach partner, data interpretation is always subject to potential researcher and participant biases. We made every attempt to mitigate these concerns through the use of regular member checking, including in data analysis members of the research team who did not facilitate focus groups, and participating in regular team debriefing meetings to discuss possible biases and ensure consensus among coders.

Conclusion

Multiple barriers spanning different social ecological levels influence Black Louisville residents' knowledge of CRC screening and, subsequently, their decision-making and ability to complete screening. Participants expressed issues of perceived inequities in health care, including medical providers not adequately determining CRC risk and thus not providing all available options of screening modalities, leading to low participant knowledge of stool-based tests. Given these clinical care inequities and the overall knowledge gap, community-

based CRC screening interventions may be feasible to reduce Black-White CRC screening disparities among Louisville residents.

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Table 1

Participant demographics

	n	%
Age		
45–50	2	5.1
51–55	4	10.3
56–60	4	10.3
61–65	3	7.7
66–70	13	33.3
71–75	8	20.5
76 +	5	12.8
Gender		
Female	24	61.6
Male	13	33.3
No response	2	5.1
Highest level of education		
Some high school (did not complete)	0	0
High school or GED	4	10.3
Some college (did not complete)	17	43.6
Bachelor’s degree or higher	18	46.2
Total household annual income		
Less than 25,000	7	17.9
25,000 to 34,999	6	15.4
35,000 to 49,999	4	10.3
50,000 to 74,999	6	15.4
75,000 to 99,999	7	17.9
100,000 or more	8	20.5
No answer	1	2.6
Type of medical insurance ^a		
Medicare	25	64.1
Employer plan (mine or my spouse’s)	17	43.6

	n	%
Plan I purchased myself	8	20.5
Medicaid	3	7.7
Plan through VA	2	5.1
I do not have medical insurance	0	0
Has one or more people considered primary medical care provider		
Yes	28	71.8
No	10	25.6
No answer	1	2.6
Any type of colorectal cancer screening recommended by medical care provider, ever		
Yes	34	87.2
No	5	12.8
Don't know/not sure	0	0
Stool-based test recommended by medical care provider, past year		
Yes	9	23.1
No	29	74.4
Don't know/not sure	1	2.6
Type of colorectal cancer screening tests taken, past year ^a		
None	20	51.3
Colonoscopy or sigmoidoscopy	10	25.6
Stool blood test like (FIT or Cologuard)	6	15.4
Other type of colon exam	1	2.6
No answer	2	5.1
Help needed reading written material from doctor or pharmacy		
Never	32	82.1
Rarely	5	12.8
Sometimes	2	5.1
Often	0	0
Always	0	0

^a Percentages do not equal 100% because participants selected all applicable response options

Table 2

Themes and representative quotes

Acknowledgement of screening importance	When you do get [CRC], you're presenting already with signs and symptoms, bloaty-ness, nausea, vomiting. A lot of times you're writing it off as something that's, "Oh, something that I ate, or this or that." And it might go on for a couple of years, and then when you do get a colonoscopy or when you do see the first blood passing, it's an emergency. So, a screening is very important
Effects of personal experiences	I would say that the screening is extremely important because I had a close relative who subsequently died of colon cancer and complications thereof. The location of the cancer was one of the factors that contributed to the difficulty of operations and would have made the outcome better for that person. But there is a need to be screened and to be screened frequently, and they told every member of the family after that, okay, every five years at least, that we needed to have colonoscopies [People] can often be confused...that [CRC screening is] uncomfortable, like prostate screening. So that turned off a lot of people I know
Need for increased education and outreach	I had a colonoscopy probably about 12 years ago, and I've been scheduled for another one, and it was such a horrible experience for me that I swore I didn't want to go back for the other
Importance of cultural representation	I had [a colonoscopy] last year, and they did take some polyps...and I didn't really realize that the polyps led to cancer, possibly led to cancer, until I was...going over the information with you. So that's when I said, oh, my goodness, I had those things [Cancer is] scary, and I think that if more people really understood and had more knowledge, maybe, maybe they would do the testing that's necessary I think for African Americans, we'd want to see a person of color [on educational materials]. And that goes for any diverse group of individuals
	A Black medical doctor could...be suggested to be one of the candidates for [screening materials], because they will speak from their profession [which] we care a lot about