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Cancer and Colorectal Cancer: Knowledge, Beliefs, and Screening Preferences of a Diverse Patient Population

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Background: Colorectal cancer (CRC) is the second leading cause of cancer-related deaths in the United States, with African Americans having the highest incidence and mortality of all racial and ethnic groups. CRC screening is widely recommended but remains underused, especially in minority populations. This study's purpose was to enhance our understanding of factors contributing to low screening rates among patients from a variety of racial and ethnic groups. Methods: We conducted individual interviews with 30 participants, ages 50 or above, with an equal number of African Americans, Hispanics, and whites at a university-based family medicine clinic. We used open-ended interviewing techniques to elicit patient knowledge and beliefs regarding cancer, CRC, screening, and CRC screening. They did not understand the concept of screening, had difficulty listing common cancer and CRC screening tests, and had trouble understanding simplified medical terms and procedure names. Patients were hopeful about the benefit of early cancer diagnosis but remained reluctant to get tested if they are symptom free. Conclusions: Lack of understanding of cancer, screening, and routine terminology is a barrier to CRC screening, especially among minority groups. Effective communication strategies that address these issues may help increase CRC screening rates.

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Colorectal cancer (CRC) is the second leading cause of cancer deaths in the United States,¹ with 56,290 deaths and 145,290 new cases expected in 2005.² African Americans have the highest CRC incidence and mortality rates of all groups.¹

Based on accumulating evidence, screening for CRC in average-risk, asymptomatic individuals is now widely recommended with any of four different screening methods.³⁻⁶ However, despite this, CRC screening rates remain low,⁷⁻¹⁷ are much worse than for other cancers,^{9,10,13,18} and are lowest of all for African Americans and other minority groups.^{8,11,19}

The higher mortality rates observed in African Americans has been attributed to the observed lower screening rate in this group,²⁰ but causal factors for the low screening rate are poorly understood. Although studies have revealed a relationship between CRC screening behavior and sociodemographic and attitudinal factors,^{12,14-16,21-31} these studies involved predominantly white populations or those of unspecified race/ethnicity and have therefore not addressed our understanding of racial/ethnic differences in screening rates. Diverse patients' preferences for the four recommended screening tests are also not known.

If racial/ethnic group differences in CRC mortality are to be addressed, we need to clarify the factors responsible for screening rate differences and to identify patient preferences for the different CRC screening tests. This study's purpose, therefore, was to identify the range of knowledge, attitudes, and beliefs about cancer, CRC, and CRC screening test preferences in three different racial/ethnic groups. The results of the study can then be used to help design CRC screening interventions appropriate for all groups.

Methods

Study Design

We conducted a cross-sectional study using the freerecall listing technique³² to compare CRC knowledge and attitudes among three racial/ethnic groups. The freerecall listing technique determines participants' understanding of the definition and boundaries of a topic or domain of interest. It is an open-ended interviewing

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technique in which participants, as a group, generate a list of responses in their own words.

Free-recall lists have some important cognitive properties. In particular, items that are most salient to participants are mentioned at the beginning of individual lists and also occur more often across interviews. Items that are not mentioned on the lists are not as salient as items that appear on the lists. Interviewing more participants may increase the number of items, but the list itself becomes stable, and the order of items does not change as new items are added by each new person. The interviews generate many items per participant, maximizing the amount of information collected per individual and allowing for a smaller sample size.

Participants

After obtaining institutional review board approval, study participants were recruited from a universitybased family medicine clinic. Participants ages 50–80 years of white, African American, or Hispanic race/ ethnicity were invited to participate. Those with a history of any type of cancer or advanced chronic medical condition were excluded. A convenience sample was obtained to interview participants of both genders from each racial/ethnic group. Interviewing was stopped when no new themes were being identified in each group, and this occurred by the time 10 participants had been interviewed per group.

Materials

Interview materials focused on knowledge, attitudes, and beliefs about cancer and CRC; knowledge of screening; and preferences for the four CRC screening tests (fecal occult blood test [FOBT], flexible sigmoidoscopy, double contrast barium enema, and colonoscopy). We assessed knowledge of cancer and CRC symptoms and causes in open-ended fashion. We also explored knowledge of screening and screening tests. Attitudes and beliefs about cancer and CRC were assessed using the Health Belief Model as a guiding framework.³³ Questions included participants' belief in the benefit of finding cancer early and whether they would agree to do a test to find cancer early. We also asked them how they obtained information about cancer and screening. A summary of these questions without follow-up probes is listed in Table 1.

We also assessed participant preferences for the four different CRC screening tests after presenting test descriptions that we developed. These were adapted from previous studies^{34,35} but were simplified to reduce the reading difficulty to below the seventh-grade level. The descriptions included information on eight different aspects of each test (description, prior preparation, time taken, recommended frequency, discomfort, risks, reduction in CRC deaths, and need for further tests).

Procedures

We identified potential participants from the clinic appointment roster and approached them to confirm eligibility and obtain consent. The participants were interviewed by either the principal investigator, a research associate, or a research assistant, with one other of these individuals present for each interview as an observer. We conducted individual interviews lasting about an hour each, using free-recall listing. We used follow-up probes to aid participants' recall. The CRC screening test descriptions were presented in written format and read aloud. Comprehension of the descriptions was checked by having the participant explain the material back to the interviewer. Participants were asked for the negative and positive aspects of each test and then asked for their final test preference, together with reasons for their choice.

Data Analysis

The interviewer and the observer recorded comments and phrases contemporaneously, in written format using the participant's own words. The free-recall listing technique lends itself particularly well to transcribing verbatim because the responses are in list format and consist of short phrases or brief sentences. If the principal investigator (NKS) was absent for an interview, the other interviewers immediately met with her to go through the interview question by question. The data analysis was done by NKS on an ongoing basis through-

Table 1

Summary of Cancer and Colorectal Cancer **Knowledge and Attitudinal Questions**

- What different kinds of cancers are there? Which are the most common? 1.
- 2. Do you know someone with cancer/colorectal cancer?
- 3. What are the causes of cancer/colorectal cancer? What increases the risk of getting cancer/colorectal cancer?
- 4. Who is more likely to get cancer/colorectal cancer? Are certain groups at more risk?
- What can a person do to prevent cancer/colorectal cancer?
- 6. Are you more or less likely to get cancer/colorectal cancer compared to other people?
- 7. How can a person tell if they have cancer/colorectal cancer? What are some of the warning signs?
- How does cancer/colorectal cancer affect someone's life?
- What are the things that you can do to get rid of colorectal cancer? 9
- 10. Can you have cancer/colorectal cancer without symptoms? What are some of the different ways that you have found out about 11.
- cancer/colorectal cancer? 12
- How successful is treatment for colorectal cancer?
- 13. Have you heard of screening for cancer? What is it?
- 14. Can you name any medical tests for screening for cancer/colorectal cancer?
- Can you name any medical tests to find cancer/colorectal cancer early?
- 16. Would you agree to do a test for cancer if you did not have symptoms?
- 17. Could there be any benefit to finding cancer early?
- 18. What would make you more likely to complete a test that your doctor orders?

out the study; emerging themes were identified by NKS and SW separately, reviewing responses to each question and listing unique themes mentioned by the participant. This procedure also allowed us to check for inter-rater reliability. Points of disagreement were discussed until a consensual coding was reached. We did not infer categories but used those that the participant intended. This was an ongoing process, which led us to add new questions early on in the process. Data for each racial/ethnic group was summarized by tabulating the frequency with which themes were mentioned; this is a method of presenting data obtained from the free-recall listing technique.³²

Results

Table 2 shows the age, gender, and educational level of the participants. The Hispanic and African American groups consisted of more females and individuals with a lower educational level than did the white group.

Knowledge of Cancer and CRC

Our questions revealed that overall knowledge of cancer was poor. When asked to name all the cancers they knew, the whites in our sample listed an average of 9.4 cancers (range 2–17); African Americans listed 5.3 (range 0–12), and Hispanics listed 3.9 (range 2–6). Only half of African Americans and one third of Hispanics mentioned CRC of their own accord.

Table 3 shows that participant awareness of cancer warning signs or symptoms was also poor. Although participants listed many general symptoms, whites and African Americans listed one third of the American Cancer Society's (ACS) Seven Warning Signs of Cancer, whereas Hispanics listed one fifth. Only three participants mentioned a change in bladder or bowel habits as possible symptoms. No participant spontaneously mentioned that cancer could occur without symptoms.

Table 4 reveals a similar lack of awareness of cancer risk factors. Only two of our 30 participants mentioned increasing age, the strongest risk factor for adult cancers, and although the most frequently listed causes of cancer were similar across groups, minority participants mentioned them less frequently. We also observed that each racial/ethnic group emphasized different aspects. For example, although all groups mentioned diet as risk for cancer, Hispanics made general comments about "eating well," and African Americans stated that eating certain types of foods and certain dietary practices were possible causes of cancer, eg: "high fat intake," "heavy meat eating," "hot peppers," and "lack of fiber." Whites were more likely to mention the protective effects of supplements such as "flax seed oil," "garlic," "green tea," and "beta carotene."

Table 2

Demographic Characteristics of Patients, by Race/Ethnicity

		African	
	White	American	Hispanic
	n=10	n=10	n=10
Mean age* (years)	65.0	65.3	63.1
Males	5	3	4
< high school education	2	5	4
High school graduate	1	1	2
Some college or vocational training	2	4	4
College graduate or above	5	0	0
* Age range 51–80 years			

The different groups also mentioned some unique causes. For instance, whites were the only group to mention stress as a cause, and African Americans mentioned race as a risk factor more frequently than the other groups. Some factors were mentioned less frequently but by more than one group (eg, hormones, injury, lack of exercise, and passive smoking).

The only CRC risk factor listed by more than one Hispanic participant was diet, and only whites mentioned polyps and lack of exercise (Table 5). Similarly, questions about CRC symptoms and signs revealed that although all groups mentioned bleeding as an early sign, only whites were able to correctly identify any other sign (change in bowel habits). It is interesting that although pain is not considered an early sign of cancer, all groups mentioned this symptom frequently.

Knowledge of Screening

Our questions also revealed poor understanding about screening. When asked to define screening, most participants had difficulty explaining what it meant; half

Table 3

Number of Patients Listing the American Cancer Society's Seven Warning Signs, by Race/Ethnicity

	Number Mentioning Item			
	White n=10	African American n=10	Hispanic n=10	Total
Warning signs				
Unusual bleeding or discharge	5	6	4	15
Lump in breast or elsewhere	5	8	4	17
Indigestion or difficulty swallowing	2	1	3	6
Change in wart or mole	6	0	2	8
Persistent cough or hoarseness	5	5	1	11
Change in bladder or bowel habits	3	0	0	3
Non-healing sore	2	2	2	6

Table 4

Cancer Causes and Risk Factors Mentioned by More Than 10% of Participants, by Race/Ethnicity

	Perc	Percent Mentioning Item			
		African			
	White	American	Hispanic		
	n=10	n=10	n=10		
Environment	90	50	40		
Smoking	60	80	70		
Diet	70	40	60		
Sun	70	30	40		
Alcohol	20	20	20		
Infection	30		_		
Increasing age	20		_		
Stress	20		_		
Black race	_	40	20		
Lack of exercise	_		30		
Male gender	_		20		
Passive smoking	_		20		
-					

or more of African Americans and Hispanics could not give any definition. None of the subjects realized that the purpose of screening is to detect disease in the absence of symptoms.

Table 6 shows the frequency with which subjects mentioned established cancer screening tests. Participants infrequently listed Pap smear or mammogram, no one mentioned breast self-exam, and only white participants mentioned any kind of prostate cancer

Table 6

Number of Cancer Screening Tests Named or Described, by Race/Ethnicity

	African			
	White	American	Hispanic	
	n=10	n=10	n=10	
Screening tests				
Pap smear	1	4	3	
Mammogram	4	3	4	
Prostate screen	5*	0	0	
Rectal exam	1	0	1	
Well woman exam	1	0	0	
Annual exam	1	0	0	
Skin inspection	2	1	1	
Colonoscopy	6^{\dagger}	2	2**	
Stool test	5‡	1	2	
Barium enema	1	1	0	

In response to general question asking patients to list all the cancer screening tests they could think of (number of responses):

* Prostate-specific antigen test (1), prostate blood test (3), prostate digital test (1)

[†] Colonoscopy (4), scope for colon (1), endoscopy (1)

[‡] Hemoccult (1), rectal blood test (1), stool blood test (2), occult blood (1)

** Colon test (1), endoscope (1)

Table 5

Colorectal Cancer Risk Factors Mentioned by More Than 10% of Participants, by Race/Ethnicity

		African			
White		American		Hispanic	
(n=10)		(<i>n</i> =10)		(n=10)	
Cause	#	Cause	#	Cause	#
Diet	9	Increasing age	3	Diet	2
Increasing age	4	Family history	3		
Family history	3	Black race	2		
Lack of exercise	3	Diet	2		
Polyps	3	Lack of preventive care	2		
Constipation	2	_			

screening. Rephrasing the question to ask them to list "tests to find cancer early" or to "name tests recommended according to age" had little effect on the responses. Many participants went on to tell us that they had previously undergone a test such as mammogram or Pap test without realizing that these are actually cancer screening tests.

Participant knowledge about CRC screening was also poor, especially among minority participants. African Americans could only correctly name colonoscopy, and no Hispanic correctly named a test. Even when they were familiar with the tests, all groups had difficulty remembering test names and used terms such as "finger test," "tube with air," "light in rectum" (Hispanics); "square thing you put poop on," "liquid then X ray" (African Americans); "tube with light"(whites).

Attitudes and Beliefs About Cancer and CRC

Although most participants were pessimistic about the outcome of a diagnosis of cancer, they did believe that it would be beneficial to find cancer early because of better treatment prospects. Despite a belief in the benefit of early diagnosis, however, participants were reluctant to get tested if they felt well. There was uncertainty about whether CRC could be present without symptoms; only half of African Americans and a third of the whites and Hispanics thought this could happen. Some minority participants felt very strongly and said that they would not get tested at all if they did not have symptoms. However, the overriding feeling among the rest was that if the doctor was insistent that they would probably agree, but it would be conditional on getting more information about the test, with some minority participants placing more emphasis on the doctor's recommendation.

CRC Screening Test Preferences

Knowledge and familiarity with the tests was low. Many participants did not understand simple medical terms such as "enema," "stool," or "polyps," and they lacked comprehension of numerical concepts such as percentages or proportions. Participants did, however, report strong feelings about CRC tests, using emotive words to describe their feelings, eg, "prep is awful" (a white commenting on colonoscopy), "scary" (an African American commenting on flexible sigmoidoscopy), "messy" (all three groups commenting on fecal occult blood testing), "demeaning, humiliating" (a white commenting on barium enema).

When asked to state a test preference, participants focused on only one or two aspects of each test. Although all groups made varying choices, some patterns of preference did seem to emerge. For instance, the most popular test choice for whites was colonoscopy, while for African Americans it was fecal occult blood testing; the Hispanic group was more divided (Table 7).

As a group, participants identified 30 different reasons for their preferences. Discomfort associated with the prep or with the procedure itself was the most frequently cited concern in all groups. Whites were the only group that cited cost, embarrassment, stress, and inconvenience of delivering the FOBT to the doctor. Minority groups were more concerned about the risk of perforation, having to get stool from the toilet, and having to do the FOBT at home. Different participants cited the same reason as a positive or negative influence on decision making—eg, need for sedation for colonoscopy, partial colonic exam by flexible sigmoidoscopy, and the need to perform the FOBT themselves were in some cases perceived positively and in other cases perceived negatively.

We also discovered that participants most frequently attributed their knowledge of cancer to friends and acquaintances with cancer. Participants less commonly attributed knowledge to magazine articles and only rarely reported their physicians as their source of information.

Discussion

Our study revealed deficits in knowledge about can-

cer, CRC, and screening among our participants. Participants have difficulty comprehending terms routinely used in practice. These findings underline the challenges that providers face in effectively discussing cancer and CRC screening with their patients.

Our findings of poor knowledge of cancer warning signs and risk factors have also been reported by other studies of minority populations.^{36,37} Lack of knowledge of CRC risk factors and warning signs in a diverse population are also in keeping with the findings of other studies of more homogenous populations.^{21,23,38,39} Unfortunately, our results reveal little improvement over the last decade,^{14,15,40} despite the evolution of screening recommendations for CRC over this period. One of our most significant findings was participants' lack of understanding about screening. They did not comprehend the purpose of screening for cancer, were not able to distinguish screening tests from any other kind of test, and did not realize that screening is performed when a person feels well. We found only one other study that has explored and reported this lack of understanding about screening.⁴¹ Further, it is worrying that even when our participants had previously undergone a screening test, they often failed to recognize it as such, thus suggesting that patients may be having tests without understanding why.

Our study is unique because we directly compared cancer knowledge, attitudes, and beliefs of different racial/ethnic groups attending the same clinic. The only previous study that directly compared cancer knowledge of different racial/ethnic groups²¹ examined populations attending different clinics. Our findings suggest possible racial/ethnic group differences in responses that cannot be attributed to educational differences between groups, since the educational profiles of our two minority groups were similar.

Participants' responses to our questions on beliefs revealed some paradoxical findings in that although participants believe in the benefit of early diagnosis, they still remain reluctant to get tested for cancer if they feel well, even when they understand that cancer can be symptom free. These findings are difficult to reconcile but suggest that there are other barriers to screening that need to be identified. However, we were encouraged to note the absence of a fatalistic attitude toward cancer that has been found to be a particular barrier for screening in elderly African American participants.⁴²

Our study also reveals the complexity of decision making for this unique cancer with four recommended tests for screening. Our participants identified more than 30 reasons for making a particular choice. There was a suggestion that African Americans preferred less invasive tests and that both minority groups were more wary

Table 7

Colorectal Screening Test Preferences by Race/Ethnicity

	African			
	White n=10	American n=10	Hispanic n=10	Total
Colorectal cancer tests				
Colonoscopy	5	1	3	9
Fecal occult blood test	2	4	2	8
Barium enema	1	2	1	4
Any	1	1	2	4
Flexible sigmoidoscopy	0	1	1	2
None	1	0	1	2
Up to doctor	0	1	0	1

of possible complications, but this needs to be examined in more detail in further studies.

Limitations

Our study has several limitations. The first is that our data, collected in one clinical setting, cannot necessarily be generalized to others. Second, although our sample size was appropriate for our qualitative study, it was not large enough for statistical inferences to be made. Third, because the sample was a convenience sample, it is also possible that it was not representative of our population as a whole. Fourth, our sampling strategy meant that we did not necessarily interview patients from each racial/ethnic group with comparable sociodemographic characteristics. Fifth, our use of qualitative methods was appropriate for hypothesis generation for future research but did not permit hypothesis testing. Therefore, it is not possible to say whether the apparent racial/ethnic group differences were the result of cultural factors or sociodemographic differences such as education.

Conclusions

In summary, we found poor knowledge of cancer, CRC, and screening in our racial/ethnically diverse population, and we identified many reasons for miscommunication about cancer screening. It is essential for providers to simplify the language they use to encourage patients to undergo cancer screening.

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