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Race and gender differences in awareness of colorectal cancer screening tests and guidelines among recently diagnosed colon cancer patients in an urban setting.

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Abstract

The purpose of this study was to first characterize the prevalence of recall, recognition, and knowledge of colon cancer screening tests and guidelines (collectively, “awareness”) among non-Hispanic Black (NHB) and NH white (NHW) urban colon cancer patients. Second, we sought to examine whether awareness was associated with mode of cancer detection. Low awareness regarding colon cancer screening tests and guidelines may explain low screening rates and high prevalence of symptomatic detection. We examined recall, recognition, and knowledge of colorectal cancer (CRC) screening tests and guidelines, and their associations with mode of cancer detection (symptomatic versus screen-detected) in 374 newly diagnosed NHB and NHW patients aged 45–79. Patients were asked to name or describe any test to screen for colon cancer (recall);

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Ethical Approval. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee at the lead study site (University of Illinois at Chicago Institutional Review Board, Protocol #2010-0785) and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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next, they were given descriptions of stool testing and colonoscopy and asked if they recognized each test (recognition). Lastly, patients were asked if they knew the screening guidelines (knowledge). Overall, awareness of CRC screening guidelines was low; just 20% and 13% of patients knew colonoscopy and fecal test guidelines, respectively. Awareness of CRC screening tests and guidelines was especially low among NHB males, socioeconomically disadvantaged individuals, and those diagnosed at public healthcare facilities. Inability to name or recall a single test was associated with reduced screen-detected cancer compared with recall of at least one test (36% vs. 22%, $p=0.01$). Low awareness of CRC screening tests is a risk factor for symptomatic detection of colon cancer.

Keywords

colon cancer; screening; racial disparities; awareness; gender

BACKGROUND

Despite its effectiveness in increasing detection of early-stage tumors and reducing colorectal cancer (CRC) mortality,^{1,2} self-reports of on-schedule screening through fecal test or endoscopy among US adults 50 years and older are well below the Healthy People 2020 goal of 71%, as well as the National Colorectal Cancer Roundtable Initiative of 80% screened for CRC by 2018.^{3–5} Although screening adherence has improved in recent years, differences in CRC screening across racial and sociodemographic characteristics persist.^{3,6} These differences in screening rates may contribute to survival and mortality disparities.

Barriers to CRC screening are multifaceted, involving factors related to socioeconomic status, healthcare access and utilization of preventive care, individuals' beliefs and knowledge about cancer, and screening tests and guidelines.^{7,8} Lack of knowledge or recognition of CRC symptoms are associated with poor health outcomes, including symptomatic mode of cancer detection (versus a screen detection) and delayed diagnosis of CRC.⁹ In the present study, we examined the prevalence of colon cancer patient awareness (recall, recognition, and knowledge) of the major types of CRC screening tests and guidelines for average-risk adults. In addition, we examined whether recall, recognition and guideline knowledge were associated with mode of colon cancer detection (screen-detected versus symptomatic presentation).

METHODS

Setting and Participants.

The parent study, Colon Cancer Patterns of Care in Chicago (CCPCC), has been described in detail elsewhere.¹⁰ Briefly, this was a multi-site study that examined socioeconomic and racial disparities in colon cancer screening, initiation of care, stage at diagnosis, and subsequent treatment.¹⁰ Patients were recently diagnosed with a first primary colon cancer and recruited from nine facilities representing a mix of public, private academic and private non-academic institutions. Patients were eligible if they self-identified as non-Hispanic white (NHW) or non-Hispanic black (NHB), were between 30 and 79 years of age, were

diagnosed between October 2011 and January 2014, and resided in Cook, DuPage, Lake or Will counties in Illinois, or Lake County, Indiana. All participants provided written informed consent and received \$100 for completing a 90-minute interview and consenting to medical record abstraction for a final sample of 407 patients. Colon cancer screening guidelines recommend starting screening at age 45 for NHB and age 50 for NHW patients; therefore, the present sample was restricted to 374 patients ages 45 and older.^{11,12}

Measures.

The main study measures were awareness of CRC screening tests (recall, recognition and guideline knowledge) and mode of colon cancer detection.

Outcome measure: Mode of colon cancer detection.—Interview questions related to mode of detection were developed through cognitive interviews which revealed multiple ways in which patients could report what might otherwise be called a screen-detected or symptomatic detection. For the main study, patients were asked “Please tell me which statement best represents how you became aware, for the very first time, of the problem that was later diagnosed as colon cancer.” Next, they were given a card with four response options summarized as: (1) colon symptoms, (2) non-colon symptoms, (3) routine screening, or (4) surveillance screening. Mode of detection was defined as symptomatic for those who responded with colon or non-colon symptoms and screen detected for those who responded with routine or surveillance screening.

CRC Screening Test Recall.—Patients were asked “Do you know if there are any tests that check to see if a person has colon cancer?” Patients responding affirmatively were asked, “What are some of the tests you have heard of?” Responses that identified or described colonoscopy, fecal occult blood testing, and sigmoidoscopy, were coded to create a score with a range of 0 to three for the number and type of tests that each patient could recall without being prompted with a test name or description.

CRC Screening Test Recognition.—Patients were asked the following questions: (1) “Have you ever heard of a colonoscopy, or have you never heard of a colonoscopy?” (2) “Have you ever heard of a fecal occult blood test, or FOBT, or have you never heard of a fecal occult blood test? This test is sometimes called a stool blood test.” (3) “Have you ever heard of a sigmoidoscopy or “flex sig”, or have you never heard of this procedure?” Responses that indicated recognition of colonoscopy, fecal occult blood testing, and sigmoidoscopy, were coded to create a score with a range of 0 to three for the number and type of tests that each patient could recognize once prompted with a test name or description.

Screening guideline knowledge.—Patients were asked how frequently they believed each of the three CRC tests was recommended for average risk adults who are 50 years and older (every 10 years, every 5 years, every year, or not sure). Correct answers (10 years for colonoscopy, every year for stool testing, and five years for sigmoidoscopy) were recorded and summed to create a score with a range of 0 to three for knowledge of colon cancer screening guidelines.

Sociodemographic and healthcare access.—Patient age at diagnosis, marital status, educational attainment, annual household income, family history of colorectal cancer and personal history of non-cancerous colon conditions were reported at interview. Facilities at recruitment were categorized as public, private (non-academic) and private (academic). Type of health insurance at diagnosis was dichotomized as private insurance versus public or no insurance. Patients responded to Likert scale questions from the Habits of Healthcare Utilization, Health Care Access, and Patient Provider Communication scales.^{13–15} Inter-item reliability (Cronbach’s alpha) were 0.82, 0.88 and 0.82, respectively.

Statistical Analysis.

We tabulated the distribution of selected sociodemographic and health care-related characteristics overall and by race and gender and associations between race and gender with screening test recall, recognition, and knowledge. We calculated p-values from Pearson’s Chi-squared test for nominal variables and Wald-tests for trend from crude logistic regression models for ordinal variables. Next, we also compared a series of nested models for inability to name or recall any of the three colon cancer screening tests as the dependent variable, henceforth referred to as absence of recall. Compared to the baseline model including independent variables for race, gender, and age, likelihood ratio tests were conducted (Type 1 analysis) for models with facility type, healthcare access and utilization, and SES. Conversely, compared to the full model with all covariates, likelihood ratio tests were conducted (Type 3 analysis) for models excluding facility type, healthcare access and utilization, and SES. Lastly, logistic regression was used to model the association between recall, recognition, and knowledge with colon cancer mode of detection (symptomatic versus screen detection) while incorporating non-response weights to account for differences in response rate by facility, age, race and gender. All models controlled for age, race, gender and socioeconomic status (SES).

RESULTS

Compared to NHW men and women, NHB men and women were less likely to be married, and had lower educational attainment and household income, were less likely to have private insurance at diagnosis, or a regular health care provider, more likely to report lower patient-provider communication scores and lower healthcare utilization and access scores than (Table 1). However, there were no differences by race or gender in self-reported prior CRC screening history (Table 2).

Recall, Recognition and Knowledge.

When asked to recall tests that check to see if a person has colon cancer, few named FOBT as a screening test (19%) while a majority of patients could name a colonoscopy (76%) (Table 2). When prompted with names for these tests, recognition of FOBT increased but remained lower than a nearly universal recognition of colonoscopy (60% vs. 97%). Knowledge of colon cancer screening guidelines was low (13% and 20% for FOBT and colonoscopy respectively). Generally, recall, recognition, and guideline knowledge was lowest among NHB patients, in particular NHB males (Table 2).

Inability to name a single test (absence of recall).

Absence of recall was positively associated with absence vs. presence of any prior colon cancer screening history (28% vs. 18%, respectively, $p=0.04$). Nearly half (41%) of NHB men and a quarter (27%) of NHB women were unable to name a single test, compared to just 13% and 11% of NHW men and women, respectively (Table 3). Absence of recall was higher for patients who were not married, had less than a high school education, and who had an income less than \$20,000 (Table 3). Receipt of care at a public facility, not having private insurance or a regular provider, low patient provider communication, and lower healthcare utilization and access were all associated with absence of recall (Table 3).

Compared to a “baseline” logistic regression model for absence of recall regressed on age and race (Type 1 analysis), the addition of facility type, SES variables, and healthcare access/utilization variables, each improved model fit (Table 4). Compared to a full model including all covariates (Type 3 analysis), removal of socioeconomic status variables decreased model fit ($p=0.0003$), whereas removal of healthcare access/utilization variables marginally decreased model fit ($p=0.14$) and removal of facility type did not affect model fit (Table 4).

Mode of colon cancer detection.

Screen-detection, versus symptomatic, was higher for patients with a prior colon cancer screening history vs. patients without any prior screening (39% vs. 22%, $p=0.001$). Prior colon cancer screening was associated with screen-detection, whereas prior screening via stool testing was marginally associated with screen-detection (Table 5). Absence of recall was associated with lower prevalence of screen-detection compared with patients who could name at least one of the three tests (36% vs. 22%, $p=0.01$) and for patients who could name a colonoscopy (36% vs. 22%, $p=0.01$), as well as for patients that knew the screening guidelines for colonoscopy (44% vs. 30%, $p=0.02$) (Table 5).

DISCUSSION

Findings from the present study indicate that recall, recognition, and guideline knowledge (collectively, “awareness”) of CRC screening tests was low in this sample of recently diagnosed NHW and NHB colon cancer patients. Awareness was lowest among NHB males, socioeconomically disadvantaged patients and those diagnosed at public facilities. Low awareness of colon cancer screening tests is likely to indicate lack of readiness to initiate screening, which could explain the associations observed in this study between lack of recall, recognition and knowledge with symptomatic detection. Individuals with low colon cancer knowledge may only seek consultation from a physician about their colon if they suspect a problem.^{16,17} Awareness and knowledge are essential components of multiple individual-level health behavior theories and models and are consistently found to be predictors of colon cancer screening and initiation.^{18–20} For example, the Integrated Theory of Behavior Change posits that engagement in health behaviors (e.g., screenings) can be fostered by enhancing condition-specific knowledge.²¹ Knowledge, a modifying factor of an individual’s health-related beliefs, can initiate cues to engage in health-related actions, such as colon cancer screenings.

As in the present study, prior studies have also shown low knowledge of screening guidelines overall, especially among NHB populations.^{19,22} In the Health Information National Trends Survey, a national probability based sample in the US, 74% overall reported having heard of a FOBT and 40% knew the frequency of screening to be annual.²² Regarding colonoscopy and sigmoidoscopy (asked together), 84% overall reported having heard of these procedures but only 13% knew the frequency (every 5–10 years) and screening knowledge was lower for NHB compared to NHW respondents.²²

There were limitations to this analysis. We interviewed patients who had recently been diagnosed with colon cancer (most of whom had recently undergone a colonoscopy as part of their diagnosis), so our prevalence estimates for awareness and knowledge of colonoscopy substantially overestimate the awareness and knowledge they may have had prior to diagnosis, which could not be directly assessed in this study. Further, this sample was not population-based; however, the nine recruitment facilities represented a range of hospital types (public, academic and non-academic) with diverse patient populations. Patients may have been distracted by their diagnosis and treatment, which could have affected recall, recognition and guideline knowledge, perhaps producing an underestimate of actual awareness. Despite these potential limitations, this study reveals that, even among recently diagnosed patients, awareness is low.

Our results can be translated to health education practice in that they may help identify target populations for enhanced education to increase knowledge and awareness of colon cancer screening. In particular, our results suggest that NHB and socioeconomically disadvantaged patients, as well as those diagnosed at public facilities may need extra attention and engagement with healthcare professionals to increase awareness. Providers can engage patients in shared decision making strategies about their colon cancer screening, a strategy with demonstrated potential to increase screening rates.^{23,24} Additional prompting on the part of health care providers may ensure that they obtain the necessary surveillance for colon cancer over the long term. More generally, regardless of sociodemographic characteristics, far too many patients were unable to recall, recognize or state correct guidelines in this study, despite having recently gone through a CRC diagnosis, suggesting that more work needs to be done to train providers to engage patients about the importance and high value of colon cancer screening.

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Table 1.

Patient characteristics by race and gender, among recently diagnosed colon cancer patients aged 45+ in the Colon Cancer Patterns of Care in Chicago study (2010–2014).

	Overall (N=374)		White Male (n=89)	White Female (n=84)	Black Male (n=96)	Black Female (n=105)	P-Value
	N	%	%	%	%	%	
Age							
45–59	147	39	30	38	43	45	
60–69	133	36	44	27	34	36	
70–79	94	26	26	34	23	19	
Married							<0.001
No	206	55	28	51	64	73	
Yes	168	45	72	49	36	27	
Education							<0.001
<12	54	14	8	7	27	14	
12	95	25	18	24	29	30	
>12	225	60	74	69	44	56	
Income							<0.001
≤20K	128	36	9	26	54	48	
20–50k	98	27	17	23	29	37	
>50K	134	37	73	51	17	16	
History of non-cancerous condition							<0.001
No	286	76	66	65	85	86	
Yes	88	24	34	35	15	14	
Family history colon cancer							0.006
No	297	80	84	67	87	82	
Yes	72	20	16	33	13	18	
Facility							<0.001
Public	79	21	10	7	34	30	
Private, non-academic	133	36	28	48	32	35	
Private, medical center	162	43	62	45	33	35	
Private Insurance at Diagnosis							<0.001
No	133	36	10	24	53	50	
Yes	241	64	90	76	47	50	
Regular Provider							0.011
No	66	18	10	15	28	16	
Yes	308	82	90	85	72	84	
Patient Provider Communication							0.09
Low (<20 out of 25)	134	36	29	33	45	35	
Moderate (21–24 out of 25)	126	34	44	38	23	31	
High (25 out of 25)	114	30	27	29	32	33	
Habits of Healthcare Utilization							<0.001

	Overall (N=374)		White Male (n=89)	White Female (n=84)	Black Male (n=96)	Black Female (n=105)	P-Value
	N	%	%	%	%	%	
Lowest third	128	34	44	42	36	18	<0.001
Middle third	128	34	27	21	42	44	
Highest third	118	32	29	37	22	38	
Healthcare Access Score							
Lowest third	143	38	28	23	58	41	
Middle third	120	32	33	32	28	35	
Highest third	111	30	39	45	14	24	

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Table 2.

Awareness and knowledge of colon cancer screening and guidelines, and prior screening history, among recently diagnosed colon cancer patients aged 45+ in the Colon Cancer Patterns of Care in Chicago study (2010–2014).

	Overall (N=374)		White Male (n=89)	White Female (n=84)	Black Male (n=96)	Black Female (n=105)	P-Value
	N	%	%	%	%	%	
Prior screening history (ever had)							
Any prior CRC screening							
No	148	42	40	40	45	42	
Yes	206	58	60	60	55	58	
Prior Colonoscopy							
No	252	67	66	61	73	69	
Yes	122	33	34	39	27	31	
Prior FOBT							
No	226	60	58	61	66	57	
Yes	148	40	42	39	34	43	
Prior Sigmoidoscopy							
No	340	91	91	90	86	95	0.2
Yes	34	9	9	10	14	5	
Tests named or described (recall)							
Colonoscopy							
No	91	24	15	12	41	28	<0.001
Yes	283	76	85	88	59	72	
FOBT							
No	302	81	83	60	93	85	<0.001
Yes	72	19	17	40	7	15	
Sigmoidoscopy							
No	351	94	92	85	99	98	<0.001
Yes	23	6	8	15	1	2	
Number of tests named							
None	88	24	13	11	41	27	<0.001
One	207	55	67	44	52	57	
Two	66	18	15	36	6	16	
All Three	13	3	4	10	1	0	
Heard of test (recognition)							
Colonoscopy							
No	11	3	0	2	9	0	<0.001
Yes	363	97	100	98	91	100	
FOBT							
No	151	40	37	21	54	46	<0.001
Yes	223	60	63	79	46	54	

	Overall (N=374)		White Male (n=89)	White Female (n=84)	Black Male (n=96)	Black Female (n=105)	P-Value
	N	%	%	%	%	%	
Sigmoidoscopy							<0.001
No	264	71	63	51	86	78	
Yes	110	29	37	49	14	22	
Number of tests recognized							<0.001
None	8	2	0	2	6	0	
One	130	35	29	14	48	44	
Two	142	38	42	39	35	36	
All Three	94	25	29	44	10	20	
Knowledge of guidelines							
Colonoscopy							<0.001
No	299	80	73	68	92	85	
Yes	75	20	27	32	8	15	
FOBT							0.07
No	325	87	87	79	91	90	
Yes	49	13	13	21	9	10	
Sigmoidoscopy							
No	351	94	91	93	96	95	
Yes	23	6	9	7	4	5	
Number correctly identified (relaxed)							<0.001
None	146	39	20	27	56	49	
One	181	48	62	50	40	44	
Two	40	11	16	18	3	8	
All Three	7	2	2	5	1	0	

P-values >0.20 are suppressed

Table 3.

Patient characteristics and associations with lack of recall of colon cancer screening tests, among recently diagnosed colon cancer patients aged 45+ in the Colon Cancer Patterns of Care in Chicago study (2010–2014).

Overall (N=374)			
	N	%	P-Value
Any prior CRC screening			0.04
No	148	28	
Yes	206	18	
Race & Gender			<0.001
White Male	89	13	
White Female	84	11	
Black Male	96	41	
Black Female	105	27	
Age			
45–59	147	22	
60–69	133	19	
70–79	94	33	
Married			<0.001
No	206	31	
Yes	168	15	
Education			<0.001
<12	54	54	
12	95	25	
>12	225	16	
Income			<0.001
<=20K	128	39	
20–50k	98	24	
>50K	134	7	
History of non-cancerous condition			
No	286	27	
Yes	88	13	
Family history colon cancer			
No	297	24	
Yes	72	22	
Facility			<0.001
Public	79	42	
Private, non-academic	133	23	
Private, medical center	162	15	
Private Insurance at Diagnosis			<0.001
No	133	35	
Yes	241	17	

Overall (N=374)			
	N	%	P-Value
Uninsured at any point prior 5 years			0.001
No	301	20	
Yes	73	38	
Regular Provider			0.007
No	66	36	
Yes	308	21	
Patient Provider Communication			0.004
Low (<20 out of 25)	134	33	
Moderate (21–24 out of 25)	126	21	
High (25 out of 25)	114	16	
Habits of Healthcare Utilization			0.014
Lowest third	128	33	
Middle third	128	21	
Highest third	118	16	
Healthcare Access Score			0.004
Lowest third	143	26	
Middle third	120	30	
Highest third	111	14	

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Table 4.

Comparison of nested model for lack of recall of any colon cancer screening tests.

	P (Likelihood Ratio test)
Versus Baseline Model ¹	
Add Facility Type ²	0.004
Add HealthCare Access & Utilization ³	0.001
Add Socioeconomic Status ⁴	<0.0001
Versus Full Model ⁵	
Remove Facility Type ²	0.46
Remove HealthCare Access & Utilization ³	0.14
Remove Socioeconomic Status ⁴	0.0003

¹Logistic regression model of lack of recall of any colon cancer screening tests (dependent variable) regressed on age and a common referent variable for race and gender.

²Public, private, non-academic, academic.

³Insurance status, regular provider, health care access, utilization and patient provider communication scales.

⁴Income, education tract disadvantage and tract affluence. Full model contains baseline predictors and all predictors from the three variable domains.

Table 5.

Awareness and knowledge of colon cancer screening tests and associations with screen-detection of their colon cancer (as opposed to detection through symptoms) among 374 recently diagnosed colon cancer patients aged 45+ in the Colon Cancer Patterns of Care in Chicago study (2010–2014).

	Screen-Detection		P-Value
	Overall (N=374)	%	
Prior screening history (ever had)			
Any prior CRC screening			0.001
No	148	22	
Yes	206	39	
Prior Colonoscopy			0.01
No	252	28	
Yes	122	43	
Prior FOBT			0.1
No	226	30	
Yes	148	38	
Prior Sigmoidoscopy			0.03
No	340	31	
Yes	34	50	
Tests named or described without prompting (recall)			
Colonoscopy			0.01
No	91	22	
Yes	283	36	
FOBT			
No	302	33	
Yes	72	31	
Sigmoidoscopy			
No	351	32	
Yes	23	43	
Number of tests named			0.01
None	88	22	
One or more	286	36	
Heard of test when prompted (recognition)			
Colonoscopy			
No	11	27	
Yes	363	33	
FOBT			
No	151	32	
Yes	223	33	
Sigmoidoscopy			
No	264	33	
Yes	110	32	

	Screen-Detection		P-Value
	Overall (N=374)	%	
Number of tests recognized			
None	8	38	
One or more	366	33	
Knowledge of guidelines			
Colonoscopy			0.02
No	299	30	
Yes	75	44	
FOBT			
No	325	34	
Yes	49	27	
Sigmoidoscopy			0.09
No	351	34	
Yes	23	17	
Number correctly identified (relaxed)			0.18
None	146	29	
One or more	228	36	

P-values > 0.20 are suppressed

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