



Research Article

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Barriers and Facilitators to Colorectal Cancer Screening Among Rural Women in Community Clinics by Health Literacy

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Abstract

Background: Rural women lag rural men and urban women in colon cancer (CRC) screening completion.

Objective: To identify rural female patients' knowledge, beliefs, barriers, self-efficacy, prior recommendation and completion of CRC screening using an FOBT and to compare these factors by health literacy (HL) level.

Methods: This descriptive study was conducted between 2015 and 2016 in 4 rural community clinics in South Louisiana. Patients overdue for screening were given a structured interview by a research assistant.

Results: 339 women were enrolled, mean age 58.5, 32% had limited HL, 66% were African American. Most (91.7%) had heard of CRC, yet only 71% knew of any CRC screening tests. Women with adequate HL had greater knowledge of specific tests than those with limited HL (78.4% vs 56.6%, $p < 0.001$). Only 25.7% had been given information on CRC testing; those with adequate HL were more likely to have received information (30.1% vs 16.8%; $p = 0.017$). Most women (93.2%) indicated they would want to know if they had CRC, while 72.2% reported a provider had recommended CRC screening. Only 24.9% said a healthcare provider had ever given them an FOBT or that they had ever completed an FOBT (22.7%). There were no differences in women's report of recommendation or completion by HL level. Self-efficacy for completing an FOBT was high; over 90% indicated they could get an FOBT, complete it and mail results to the lab. Level of confidence did not vary by literacy. Three of the four barrier items varied by HL with women with low HL being more likely to fear doing an FOBT because they thought FOBT instructions would be confusing ($p = 0.002$), doing the test would be embarrassing ($p = 0.025$) or messy ($p = 0.057$).

Conclusion: Rural women are receptive to CRC screening and view FOBTs as effective. Rural community clinics need to provide low cost FOBTs with literacy, gender and culturally appropriate information.

Keywords

Colorectal cancer screening; Rural women's knowledge; Beliefs and behavior

Introduction

Colorectal cancer (CRC) is the third most common cancer in women and the third leading cause of women's cancer deaths in the United States [1]. Recent increases in use of cancer screening is reducing CRC death rates but disparities persist among low income women, those with less education, minorities and those living in rural areas [2,3]. Rural women continue to lag behind both rural men and urban women in CRC screening completion [4-6]. Knowledge about cancer screening, perceived susceptibility, and physician recommendation have been found to be positively correlated with CRC screening [7-12].

Previous research has identified barriers to CRC screening among low income populations including, limited knowledge, misinformed perceptions of screening, lack of motivation, lower self-efficacy, inadequate transportation, and lack of access to screening tests [2,8,13,14]. However most of these studies took place in urban settings and did not focus specifically on women [2,15-22]. Low income rural residents face additional system barriers including, lack of public transportation, convenient colonoscopy facilities and persistent shortages of healthcare providers [4,5,23].

To address barriers for vulnerable populations the National CRC Roundtable recommends collaborating with community clinics to improve rates of CRC screening using cost-effective, convenient fecal occult blood test (FOBTs) [24]. To develop effective strategies to promote CRC screening using FOBTs among low income rural women more information is needed about their understanding, beliefs, prior experience and perceived barriers to CRC screening using FOBTs.

The objective of this report is to identify rural female patients' knowledge, beliefs, barriers, self-efficacy, prior recommendation and completion of CRC screening using an FOBT and compare these factors by health literacy level.

Methods

Study design

This descriptive study is part of a larger clinical trial evaluating the effectiveness of approaches to improve annual CRC screening in community clinics in isolated rural areas in South Louisiana. Enrollment was conducted February 2015 - October 2016. According to clinic electronic health records (EHRs) CRC screening completion rates pre-intervention ranged from 1% to 3%.

Participants

Clinic staff in four rural community clinics asked consecutive patients aged 50 to 75 presenting to the clinic for a scheduled routine primary care visit if they were interested in participating in a CRC screening study. If a patient agreed a clinic based research assistant (RA) prescreened them for eligibility using a structured interview, went through the consent process using a simplified consent form and administered a structured baseline interview. The inclusion criteria included: 1) a patient of the identified clinics, 2) age 50 to 75 (based on ACS guidelines), and 3) English speaking. Exclusion criteria include: 1) previous history of cancer other than non-

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melanoma skin cancer, 2) up-to-date with CRC screening according to ACS guidelines [1] (FOBT every year, sigmoidoscopy every 5 years, or colonoscopy every 10 years), 3) a first relative family history that requires a more complete history and possible colonoscopy because of their risk factor (these patients will be referred to their provider for follow-up), 4) an uncorrectable hearing or visual impairment, or 5) too ill to participate.

The entire process of screening, consenting, and administering the structured interviews took approximately 15 minutes. Patients commonly had at least a 45-minute wait, so clinic flow was not disrupted. The Louisiana State University Health Sciences Center – Shreveport Institutional Review Board approved the study. Patients were compensated \$15 for their time.

Structured survey

The structured interview included 46 demographic and CRC screening items. It was written on a 4th grade level and administered orally. Questions about cancer screening knowledge, beliefs prior recommendation and education, self-efficacy and barriers were designed utilizing the Health Belief Model and Social Cognitive Theory [25,26]. Items were modified for use with colon cancer screening from validated questionnaires used in previous studies by the authors [27].

Response options for knowledge, prior recommendation and education items were ‘yes’, ‘no’, ‘don’t know’ or open ended. Beliefs, barriers and self-efficacy questions used a 5-point Likert scale to assess intensity of agreement. Health literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM) [28]. Raw REALM scores (0-66) can be converted into reading grade levels that correlate with health literacy levels. Scoring 60 or below indicates below 9th grade reading level and is considered limited health literacy [28].

Statistical analysis

Data are presented as means and standard errors for continuous variables, and as frequencies and percentages for categorical variables. Continuous variables were compared between health literacy groups using a t-test accounting for different group standard deviations. Categorical variables were compared using Fisher’s exact test. A self-efficacy scale was calculated from the three self-efficacy questions and ranges from 3 to 15 with higher values indicating greater self-efficacy. A barrier scale was calculated from the four barrier questions and ranges from 4 to 205 with higher values indicating greater barriers to doing an FOBT [29].

Results

Patient characteristics are compared by health literacy in Table 1. Patients ranged in age from 50-75, all were female. Of 339 women, the majority (66%) were African American. Approximately one third (32%) had less than a high school education and 32% had limited health literacy. Rural African American female patients were significantly more likely to have limited health literacy compared to their white counterparts (81% vs 19%, p<0.0001).

Awareness of CRC was high with almost all women (91.7%) reporting they had heard of CRC. Fewer (71%) had ever heard of any test to find CRC (Table 2); women with adequate health literacy were significantly more likely to have heard of a test than those with limited health literacy (78.4% vs 56.6%, p<0.001). Of those who had heard of a test almost all (93.8%) had heard of colonoscopy, much fewer had heard of an FOBT, stool test or fecal immunochemical test (FIT) as it was described (17.8%). The majority had seen or heard an advertisement that encouraged colon cancer testing. Women with adequate health literacy were much more likely to report seeing an ad (83.1% vs 65.5%). Few women had been given information/education on CRC testing (25.7%), however those with adequate

Table 1: Characteristics stratified by literacy.

Variables	Total (n=339)	Limited HL (n=113)	Adq. HL (n=226)	p-value
Age, Mean (sd)	58.5 (6.1)	59.4 (6.3)	58.1 (5.9)	0.066
Self-Efficacy, Mean (sd)	12.7 (1.3)	12.6 (1.3)	12.8 (1.3)	0.25
Barrier, Mean (sd)	9.2 (2.5)	9.7 (2.7)	8.9 (2.3)	0.01
Age Categories	N (%)	N (%)	N (%)	
50-59	194 (58)	59 (53)	135 (61)	0.18
60-69	122 (37)	44 (39)	78 (35)	
70-85	18 (5)	9 (8)	9 (4)	
Years of Education				
Less than high school	107 (32)	61 (54)	46 (21)	<0.001
High school grad	167 (50)	43 (38)	124 (56)	
Some College	35 (10)	5 (4)	30 (13)	
≥ College Graduate	21 (6)	1 (1)	20 (9)	
Refused or Don't know	6 (2)	3 (3)	3 (1)	
Race				
African-American	224 (66)	92 (81)	132 (59)	<0.0001
Caucasian/Hispanic	113 (34)	21 (19)	92 (41)	
Marital Status				
Single	100 (30)	36 (32)	64 (29)	0.066
Married	114 (34)	35 (31)	79 (35)	
Separated	23 (7)	10 (9)	13 (6)	
Divorced	48 (14)	9 (8)	39 (17)	
Widowed	51 (15)	22 (20)	29 (13)	

Table 2: Knowledge, attitude, self-efficacy, and barriers stratified by literacy.

	Total (n=339)	Limited HL (n=113)	Adq. HL (n=226)	p-value
Knowledge				
Have you ever heard of CRC?				
Yes	311 (91.7)	103 (91.2)	208 (92.0)	0.99
No	26 (7.7)	9 (8.0)	17 (7.5)	
Don't Know	2 (0.6)	1 (0.9)	1 (0.4)	
Have you ever heard of any tests to find CRC?				
Yes	241 (71.1)	64 (56.6)	177 (78.3)	<0.001
No	89 (26.3)	47 (41.6)	42 (18.6)	
Don't Know	8 (2.4)	2 (1.8)	6 (2.7)	
No answer	1 (0.3)	0	1 (0.4)	
What tests have you heard of?				
(More than one answer possible. Percentages are out of those answering 'Yes' to the question above)				
FOBT	43 (17.8)	14 (21.9)	29 (16.4)	0.34
Colonoscopy	216 (93.8)	60 (93.8)	166 (93.8)	0.99
Sigmoidoscopy	3 (1.2)	0	3 (1.7)	0.57
No answer	4 (1.7)	0	4 (2.3)	0.58
Recommendation/Behavior/ Education				
Have you ever seen or heard an advertisement that encouraged you to get tested for colon cancer?				
Yes	261 (77.2)	74 (65.5)	187 (83.1)	0.001
No	74 (21.9)	38 (33.6)	36 (16.0)	
Don't Know	3 (0.9)	1 (0.9)	2 (0.9)	
Have you ever been given information or education on CRC testing?				
Yes	87 (25.7)	19 (16.8)	68 (30.1)	0.010
No	249 (73.4)	92 (81.4)	157 (69.5)	
Don't Know	3 (0.9)	2 (1.8)	1 (0.4)	
What kind of information/education?				
(More than one answer possible Percentages are out of those answering 'Yes' to the question above)				
Pamphlet	55 (63.2)	12 (63.2)	43 (63.2)	0.99
Discussion	19 (21.8)	6 (31.6)	13 (19.1)	0.35
Health Fair	5 (5.7)	0	5 (7.4)	0.58
Community church programs	1 (1.1)	0	1 (1.5)	0.99
Don't know	13 (14.9)	2 (10.5)	11 (16.2)	0.72
Has a doctor ever recommended you get screened for CRC?				
Yes	244 (72.2)	80 (70.8)	164 (72.9)	0.34
No	90 (26.6)	33 (29.2)	57 (25.3)	
Don't Know	4 (1.2)	0	4 (1.8)	
Has a doctor ever given you an FOBT to do?				
Yes	84 (24.9)	26 (23.0)	58 (25.8)	0.54
No	251 (74.3)	87 (77.0)	164 (72.9)	
Don't Know	3 (0.9)	0	3 (1.3)	
Have you ever done an FOBT?				
Yes	76 (22.7)	25 (22.1)	51 (23.0)	.77
No	255 (76.1)	86 (76.1)	169 (76.1)	
Don't Know	4 (1.2)	2 (1.8)	2 (0.9)	
Beliefs				
If you had CRC would you want to know about it?				
Yes	315 (93.2)	103 (92.0)	212 (93.8)	0.73
No	14 (4.1)	6 (5.4)	8 (3.5)	
Don't Know	9 (2.7)	3 (2.7)	6 (2.7)	

How helpful do you think it is to find CRC early?	Total (n=339)	Limited HL (n=113)	Adq. HL(n=226)	p-value
Very Helpful	292 (86.4)	91 (81.3)	201 (88.9)	0.13
Helpful	37 (11.0)	16 (14.3)	21 (9.3)	
Don't Know	5 (4.5)	5 (4.5)	4 (1.8)	
How worried are you that you might find out you have CRC?				
Very Worried	23 (6.9)	11 (9.7)	12 (5.4)	0.059
Somewhat Worried	50 (14.9)	19 (16.8)	31 (13.9)	
Not Worried	143 (42.6)	49 (43.4)	94 (42.1)	
Not Worried at All	110 (32.7)	28 (24.8)	82 (36.8)	
Don't Know	10 (3.0)	6 (5.3)	4 (1.8)	
I feel I will get CRC sometime in my life				
Strongly Agree	8 (2.4)	2 (1.8)	6 (2.7)	0.007
Agree	17 (5.0)	8 (7.1)	9 (4.0)	
Disagree	167 (49.4)	50 (44.6)	117 (51.8)	
Strongly Disagree	47 (13.9)	8 (7.1)	39 (17.3)	
Don't Know	99 (29.3)	44 (39.3)	55 (24.3)	
Having an FOBT will help me find CRC problems early.				
Strongly Agree	98 (29.0)	27 (24.1)	71 (31.4)	0.12
Agree	223 (66.0)	76 (67.9)	147 (65.0)	
Disagree	4 (1.2)	3 (2.7)	1 (0.4)	
Strongly Disagree	1(0.3)	0	1 (0.4)	
Don't Know	12 (3.6)	6 (5.4)	6 (2.7)	
Having an FOBT will decrease my chances of dying from CRC.				
Strongly Agree	79 (23.4)	29 (25.9)	50 (22.1)	0.89
Agree	193 (57.1)	62 (55.4)	131 (58.0)	
Disagree	26 (7.7)	7 (6.3)	19 (8.4)	
Strongly Disagree	4 (1.2)	1 (0.9)	3 (1.3)	
Don't Know	36 (10.7)	13 (11.6)	23 (10.2)	
I am afraid of doing an FOBT test because I might find something wrong.				
Strongly Agree	14 (4.1)	3 (2.7)	11 (4.9)	0.002
Agree	39 (11.5)	16 (14.2)	23 (10.2)	
Disagree	206 (60.8)	69 (61.1)	137 (60.6)	
Strongly Disagree	53 (15.6)	9 (8.0)	44 (19.5)	
Don't Know	27 (8.0)	16 (14.2)	11 (4.9)	
Self-Efficacy Scale				
	Total (n=339)	Limited HL (n=113)	Adq. HL (n=226)	p-value
I know for sure I can get an FOBT				
Strongly Agree	70 (20.7)	22 (19.5)	48 (21.3)	0.97
Agree	238 (70.4)	81 (71.7)	157 (69.8)	
Disagree	4 (1.2)	1 (0.9)	3 (1.3)	
Strongly Disagree	1 (0.3)	0	1 (0.4)	
Don't Know	25 (7.4)	9 (8.0)	16 (7.1)	
I know for sure I can find out how to correctly do an FOBT.				
Strongly Agree	79 (23.3)	20 (17.7)	59 (26.1)	0.23
Agree	251 (74.0)	91 (80.5)	160 (70.8)	
Disagree	1 (0.3)	0	1 (0.4)	
Don't Know	2 (1.8)	2 (1.8)	6 (2.7)	
I know for sure I will mail my results back.				
Strongly Agree	155 (46.0)	45 (40.5)	110 (48.7)	0.25
Agree	177 (52.5)	63 (56.8)	114 (50.4)	
Disagree	2 (0.6)	1 (0.9)	1 (0.4)	
Strongly Disagree	1 (0.3)	1 (0.9)	0	
Don't Know	2 (0.6)	1 (0.9)	1 (0.4)	
Self-Efficacy Scale (mean, sem)	12.74 (0.07)	12.62 (0.12)	12.80 (0.09)	0.25

Barrier Scale	Total (n=339)	Limited HL (n=113)	Adq. HL (n=226)	p-value
I am afraid the FOBT instructions will be confusing				
Strongly Agree	7 (2.1)	3 (2.7)	4 (1.8)	0.002
Agree	17 (5.0)	9 (8.0)	8 (3.5)	
Disagree	231 (68.1)	69 (61.1)	162 (71.7)	
Strongly Disagree	40 (11.8)	8 (7.1)	32 (14.2)	
Don't Know	44 (13.0)	24 (21.2)	20 (8.9)	
Doing an FOBT is embarrassing				
Strongly Agree	9 (2.7)	4 (3.6)	5 (2.2)	0.02
Agree	30 (8.9)	10 (8.9)	20 (8.9)	
Disagree	234 (69.2)	78 (69.6)	156 (69.0)	
Strongly Disagree	39 (11.5)	6 (5.4)	33 (14.6)	
Don't Know	26 (7.7)	14 (12.5)	12 (5.3)	
Doing an FOBT is a lot of trouble				
Strongly Agree	5 (1.5)	4 (3.5)	1 (0.4)	0.057
Agree	16 (4.7)	4 (3.5)	12 (5.3)	
Disagree	240 (70.8)	82 (72.6)	158 (69.9)	
Strongly Disagree	33 (9.7)	6 (5.3)	27 (12.0)	
Don't Know	45 (13.3)	17 (15.0)	28 (12.4)	
Doing an FOBT is messy				
Strongly Agree	10 (3.0)	3 (2.7)	7 (3.1)	0.42
Agree	57 (16.8)	18 (15.9)	39 (17.3)	
Disagree	164 (48.4)	52 (46.0)	112 (49.6)	
Strongly Disagree	23 (6.8)	5 (4.4)	18 (8.0)	
Don't Know	85 (25.1)	35 (31.0)	50 (22.1)	
Barrier Scale (mean, sem)	9.17 (0.13)	9.68 (0.25)	8.92 (0.15)	0.01

health literacy more likely to report they had been given information (30.1% vs 16.8%; p=0.017).

Although none of the rural female patients were up-to-date with CRC screening, the majority (72.2%) reported a primary care provider (PCP) had previously recommended they get screened for CRC. Yet only about a fourth (24.9%) said a PCP had ever given them an FOBT kit or that they had ever completed an FOBT (22.7%). There were no differences in women's report of recommendation or completion by health literacy level.

Most women (93.2%) indicated they would want to know if they had CRC and 86.4% said it would be helpful to find CRC early. Only 6.9% were very worried that they might find out they had CRC. Women viewed FOBTs as effective; 95% agreed that an FOBT would be helpful in finding CRC problems early and 80.5% agreed that an FOBT would decrease their chances of dying from CRC. There were no differences in these any of these beliefs by health literacy level.

Three of the four barrier items varied by health literacy with women with limited health literacy being more likely to fear doing an FOBT because they thought the instructions would be confusing (p=0.002), doing the test would be embarrassing (p=0.025) or messy (p=0.057). When barrier items were scored as a scale, patients with limited health literacy were more likely to report they strongly agreed with most of the barriers questions (p=0.01) indicating they perceived greater barriers to screening. Self-efficacy for obtaining and completing an FOBT was high with over 90% of female patients indicating they agreed that they could get an FOBT, complete it and mail results to the lab. Level of confidence measured by the self-efficacy index did not vary by health literacy.

Discussion

Although almost all low income rural women in the study had heard of CRC, and the majority reported they had been given a physician recommendation, all were overdue for screening. A significant barrier was that less than one fourth had ever been given information or education on CRC screening or given an FOBT by a provider. The test most women had heard of was colonoscopy. Given that a third of patients had limited health literacy and were more likely to perceive FOBT completion as a barrier is an indication that rural clinics need to consider providing literacy and culturally appropriate screening information and simplified FOBT instructions as part of standard practice for eligible patients. In addition, that most women felt confident they could complete an FOBT indicates they would be receptive to using the low cost, convenient test if given useful information about the test.

Recent studies of low income individuals and those living in rural areas indicate a continuing lack of clear understanding of CRC screening. A common misconception was that women are less likely to get CRC than men and that the cancer screenings that are important for women are breast and cervical cancer tests. In a recent CRC screening study of rural women in Appalachia "key players" in women's rural social networks suggested information / education needs to specifically target rural women with messages and pictures that are applicable to them [4,23].

CRC screening completion is influenced not only by patients' knowledge but their beliefs about screening and their confidence in being able to obtain and complete the test [12,30,31]. Our finding that rural women wanted to know if they have CRC and have positive beliefs about FOBT suggests strengths that need to be utilized in

future approaches to improve screening. These findings coupled with studies pointing out women's more common experiences with cervical and breast cancer screening and its benefits indicate they would be receptive to strategies to increase women's CRC screening using FOBTs [4].

In a 2007 study by the authors in urban and rural community clinics, eligible male and female patients who were given a screening recommendation, illustrated information about screening written on a 4th grade level and a demonstration of how to complete an FOBT by a clinic based research assistant were significantly more likely to complete an FOBT within six months than those who were only given a recommendation and FOBT kit [27]. Those that additionally received personal phone reminders were even more likely to complete the test. These findings provide evidence of the value of clinic-based education and provision of an FOBT kit.

Implications for practice and policy

Strategies to increase CRC screening among women in rural areas need to consider rural culture, gender and literacy. Recent CRC prevention studies in rural Appalachia and Pennsylvania found rural self-reliance leads people to prefer to take care of problems on their own and be less likely to seek medical care [4,23]. In rural areas residents tend to be less focused on preventive services than in urban areas. Rural women tend not to prioritize their own health, instead they prioritize the well-being of their families [4,23].

Health literacy is an over looked barrier in CRC screening completion [32,33]. Unlike other cancer screening tests, FOBTs and colonoscopy require patients to have clear understanding and confidence to prepare for or complete screening [27,34]. In busy primary care practices providers commonly assume patients can follow the instructions. Patients are rarely instructed on how to prepare for or complete CRC test or asked to confirm their understanding [34]. Improvement in our previous studies was most pronounced when patients were given simplified FOBT instructions and a demonstration with "teach back" to confirm their understanding [27].

An unrecognized barrier in rural areas may be the providers. A recent study of primary care physicians in rural Pennsylvania found the doctors strongly supported CRC screening but were not clear about current guidelines [14]. These PCPs universally recommended colonoscopy and tended to believe FOBTs were substandard screening tools. None offered patients an FOBT kit.

With renewed national focus on the cost and access benefits of FOBTs along with the recommendation of the FIT by the ACS and GI Society FIT [35-37], rural physicians may need easily accessible current guidelines for CRC screening. Given that PCPs often mention time as a barrier, community clinics may consider use of health coaches or patient educators to provide education on CRC screening options. Health coaches, patient educators or navigators are increasingly common and are required in community clinics that receive a level three designation of Patient Centered Medical Home [38]. Clinics having standing orders to provide eligible patients with FIT kits with literacy, cultural and gender appropriate information might help address barriers in rural areas.

Limitations

Our study has limitations. We focused only on female community clinic patients in one state and our sample included predominantly

African Americans. However, this is generally representative of rural community clinic populations in the southern United States.

Conclusion

Low income rural women who were not up-to-date with screening had positive attitudes toward CRC screening and use of FOBTs. Strategies to promote CRC screening using FOBTs need to specifically address rural women beliefs, barriers and confidence in completing the test. Information needs need to be easy to understand and tailored to rural women.

Future studies to improve CRC screening among female rural community clinic patients should investigate the feasibility and cost effectiveness of clinic-based health coaches / patient educators to provide literacy, culture and gender appropriate screening information as part of standard practice. The coaches could also query the EHR to send a letter as well as call or text patients to give recommendations and FOBT kit with simplified instructions.

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