



Patients' self-reported barriers to colon cancer screening in federally qualified health center settings

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ABSTRACT

Colorectal cancer (CRC) is a leading cause of cancer-related death in the United States. Despite evidence that screening reduces CRC incidence and mortality, only about 60% of age-eligible adults are up-to-date on CRC screening. This analysis aims to identify self-reported barriers to CRC screening among patients in a safety-net healthcare setting.

Participants were recruited from safety-net primary care sites that were participating in a trial to increase CRC screening. At baseline, patients (n = 483) completed self-report surveys that assessed demographics, healthcare and CRC screening. Barriers to CRC screening were assessed through an open-ended question. Using a basic text analysis, data were coded and organized into key topics.

Overall, 65.2% ever had CRC screening; 46.4% were up-to-date. Of those who described barriers (n = 198), 22.9% said they were not due for screening or their provider had not recommended it. Other common barriers included fear or worry about the procedure or outcome, financial challenges such as lack of insurance or cost of testing, and logistic challenges such as transportation and time. Fewer said that screening was of low importance or mentioned discomfort with the procedure or colonoscopy preparation.

In this safety-net setting, CRC screening rates were lower than national rates. These qualitative results are similar to quantitative findings reported in the literature but the qualitative data add to our understanding of patient-reported concerns and challenges faced by safety-net patients. These results may be applied to developing targeting communication or intervention strategies to improve CRC screening rates within safety-net health centers.

1. Introduction

Colorectal cancer (CRC) is the third most common cancer and second leading cause of cancer death in the United States (ACS, 2017). Routine screening and resultant early detection through a range of acceptable strategies (colonoscopy, fecal testing, etc.) are effective and cost-effective in reducing CRC incidence and mortality (ACS, 2017; Pignone et al., 2002). There is a survival benefit to early detection: five-year survival for localized CRC is around 90%, which drops below 20% for patients diagnosed at late stages (ACS, 2017). Despite this, screening rates remain relatively low, only 62.4% of age-eligible adults are “up-to-date” on CRC screening, falling short of national goals for CRC screening (White et al., 2017; CDC, 2012). Further, minority race and ethnicity and socioeconomic challenges such as lack of insurance and low-income are associated with higher CRC mortality (White et al., 2017; Albano et al., 2007; Klabunde et al., 2006; Berkowitz et al., 2015;

Liss and Baker, 2014; James et al., 2008). This is, in part, attributable to screening utilization. These groups show some of the lowest rates of screening, which has been associated with later stages of detection and worse outcomes (White et al., 2017; Klabunde et al., 2006; James et al., 2008).

Prior studies have established several patient-level barriers to CRC screening, including fear, embarrassment, bowel preparation, lack of provider recommendation, and logistical barriers, such as cost and lack of transportation (Nagelhout et al., 2017; Jones et al., 2010; McLachlan et al., 2012). Lack of awareness, low perceived susceptibility, and attitudes about the futility of treatment also affect screening (Honein-AbouHaidar et al., 2016; James et al., 2011).

There are many quantitative studies analyzing CRC screening barriers, but most do not focus on medically underserved populations who may face additional barriers to screening. These patients are often seen in federally qualified health centers (FQHCs), which are community-

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based health care centers that receive federal funds to provide primary services in underserved communities. Given the disparities in screening, it is essential to determine what screening barriers are most important to safety-net patients and “what gets in the way” of CRC screening for lower-income, under- and uninsured patients. Our objective is to describe self-identified barriers to CRC screening in FQHC patients, and to assess the association of these barriers and specific SES challenges (income, education, insurance, employment).

2. Methods

2.1. Study design

Eleven urban and rural FQHCs across two health systems were recruited for a cluster-randomized trial aimed at increasing CRC screening (Muthukrishnan et al., 2018; James et al., 2013). Data were collected through surveys administered in-person, by phone, or mail. All procedures were approved by the University's Institutional Review Board and the administration of each participating health network. This paper describes a secondary cross-sectional analysis that utilizes baseline data from the wider cluster-randomized trial.

2.2. Study population and recruitment

FQHCs were recruited on a rolling basis in metropolitan St. Louis and rural southeastern Missouri. At each FQHC site, we recruited English- or Spanish-speaking adults (age ≥ 50) to complete a baseline paper-based survey (n = 959) that included close-ended questions and one open-ended question. Patients were recruited from waiting rooms or by mailed invitation, depending on the site's preference. The resulting study population consisted of a total of 490 consented participants. Seven participants were excluded from the analysis (4 duplicate enrollments, 2 ineligible due to age, and 1 incomplete enrollment), leaving 483 participants. All participants received a \$20 gift card for completing the survey.

2.3. Participant survey

2.3.1. Demographics

Demographic measures included gender, age, race/ethnicity, monthly income, employment status, and years of education.

2.3.2. Health insurance and utilization

Participants were asked about health insurance, type of insurance, and usual sources of care. We also asked whether they had delayed or not obtained care because of cost, lack of transportation, or because of the way they thought they would be treated.

2.3.3. CRC screening

CRC screening with fecal occult blood test/fecal immunochemical test (FOBT/FIT), sigmoidoscopy, and colonoscopy were assessed with measures based on Vernon et al. (2004). Participants were asked if they had ever had each test and when they completed their most recent test. Up-to-date screening was defined as an FOBT within the last year or sigmoidoscopy/colonoscopy within the last 5 years. Responses were categorized as never screened, screened but not up-to-date, and screened and up-to-date. Barriers to CRC screening were assessed for all participants with an open-ended question: “What barriers/things got in the way of being screened?”

2.4. Data analysis

Descriptive statistics were calculated to summarize participant demographics and CRC screening rates using SPSS v.24. Differences between those who reported barriers and those who did not were determined using chi-square tests. Responses were reviewed by the

Table 1

Comparing characteristics between participants that report barriers to CRC screening and participants who do not. N = 483 (% within reported barriers or not).

Factor, N (%)	Overall (n = 483)	Did not report barriers (n = 285)	Reported barriers (n = 198)	p-Value
Urban network (vs. rural)	327 (67.7)	202 (70.9)	125 (63.1)	0.073
Age (mean, sd)	57.30, 7.03	57.17, 7.22	57.48, 6.77	0.629
Race*				
African American	315 (66.5)	199 (71.3)	116 (59.5)	
White	159 (33.5)	80 (28.7)	79 (40.5)	0.007
Gender — female	296 (61.3)	177 (62.1)	119 (60.1)	0.657
Marital status				
Married, living w/ partner	133 (27.5)	72 (25.3)	61 (30.8)	
Divorced, separated	144 (29.8)	90 (31.6)	54 (27.3)	
Widowed	56 (11.6)	30 (10.5)	26 (13.1)	
Never married	150 (31.1)	93 (32.6)	57 (28.8)	0.352
Income < \$1200 per month	351 (74.2)	205 (73.7)	146 (74.9)	0.782
Education				
Did not finish HS	149 (31.2)	86 (30.4)	63 (32.3)	
HS grad/GED	192 (40.2)	110 (38.9)	82 (42.1)	
More than HS	137 (28.7)	87 (30.7)	50 (25.6)	0.478
Current work status				
Employed	104 (21.8)	50 (17.8)	54 (27.4)	
Unemployed	126 (26.4)	77 (27.4)	49 (24.9)	
Retired	47 (9.8)	28 (10.0)	19 (9.6)	
Disabled	201 (42.1)	126 (44.8)	75 (38.1)	0.091
# of residential moves in the last month (mean, sd)	0.18, 0.82	0.18, 0.85	0.18, 0.77	0.965
Homeless in past year	85 (17.6)	55 (19.3)	30 (15.2)	0.239
Has health insurance	348 (72.0)	204 (71.6)	144 (72.7)	0.782
public insurance only (of those with insurance)	304 (87.4)	177 (86.8)	127 (88.2)	0.693
Has usual doctor/source of health care	381 (80.9)	222 (77.9)	159 (80.3)	0.048
# of visits to doctor's office in the last 12 months (mean, sd)	5.84, 7.47	6.08, 8.03	5.51, 6.61	0.412
Delayed care in the last 12 months due to...				
...Cost	153 (31.8)	82 (28.8)	71 (35.9)	0.139
...Treatment	63 (13.1)	35 (12.3)	28 (14.1)	0.545
...Transportation	98 (20.4)	59 (20.7)	39 (19.7)	0.927
When seeking healthcare, were you...				
...Treated with respect	419 (87.7)	246 (87.2)	173 (88.3)	0.736
...Listened to carefully	397 (82.9)	230 (81.0)	167 (85.6)	0.184
Discuss prevention of illness with doctor in last 12 months				
Usually/always	334 (69.9)	203 (71.7)	131 (67.2)	0.286
Health literacy				
Often/always need help	58 (12.0)	35 (12.3)	23 (11.7)	0.793
Ever had...				
...FOBT	177 (37.7)	100 (35.6)	77 (41.0)	0.240
...Sigmoidoscopy	47 (10.2)	25 (9.3)	22 (11.5)	0.430
...Colonoscopy	241 (50.6)	170 (60.5)	71 (36.4)	0.000
...Any CRC test	315 (65.2)	197 (69.1)	118 (59.6)	0.031
Up-to-date				
...FOBT	45 (9.3)	30 (10.5)	15 (7.6)	0.273
...Sigmoidoscopy	26 (5.4)	15 (5.3)	11 (5.6)	0.889
...Colonoscopy	195 (40.4)	145 (50.9)	50 (25.3)	0.000
...Any CRC test	224 (46.4)	160 (56.1)	64 (32.3)	0.000

* “White” includes Hispanic and non-Hispanic White, “African American” includes Hispanic and non-Hispanic African American; racial/ethnic groups were not further categorized due to small numbers of Hispanics (n = 15) in the study population.

primary coder and organized into topics using a combination of inductive and deductive coding. Pre-determined codes were obtained from the literature (i.e. fear, embarrassment, bowel preparation, lack of provider recommendation, and logistical barriers), and additional codes were added based on preliminary review of the qualitative data. Responses that addressed multiple topics were double coded. A second coder reviewed topics and coding to check agreement; discrepancies were resolved through consensus. We then coded barriers as categorical variables to analyze bivariate associations with socioeconomic variables and CRC screening status using chi-square tests.

3. Results

Overall (n = 483), 65.2% of respondents reported ever having CRC screening, but only 46.4% were up-to-date. The mean age was 57 years (range 49–88), 66.5% were African American, 74.2% reported a monthly income below poverty, 31.2% had not finished high school, and 68.5% were unemployed or disabled. Though 72.0% reported having health insurance, most (87.4%) had solely public insurance (Table 1). More than a third (n = 202) of respondents provided an answer to the barriers question, but 4 of these answered “no” or “none”, leaving 198 responses for this qualitative analysis.

3.1. Self-identified barriers to CRC screening

Of those who described screening barriers, 10.9% said they did not have a provider referral, and 12.0% said they were not due for screening. Nearly a third of responses (29.5%) mentioned fear or worry and a quarter mentioned financial difficulties. Other responses described logistic challenges with screening (19.1%), stated that screening was a low priority for them (15.8%), and described discomfort or disgust with the procedure (11.5%) or the bowel preparation for colonoscopy (6.6%).

3.1.1. Fear or worry

Fear or worry was the most common response when identifying barriers to CRC screening. This manifested in different ways, from expressing anxiety to using words including “fear” and “scary.” These worries ranged from general concerns to different parts of the screening experience. For example, some participants voiced specific concerns related to the procedure and sedation: “I’m afraid of being knocked out or having an allergic reaction to the anesthesia”. Sometimes these concerns were expressed in terms of avoidance of the procedure: “I ducked and dodged the appointment as long as I could.”

Others mentioned concerns about the outcomes of the procedure, and particularly about a cancer diagnosis: “Sometimes you don’t want to hear that anything is wrong with you, especially colon cancer.” Another participant commented, “When you go looking for something, that’s when you find something.” Others commented that there could be

little to do if cancer was found, so there was little reason to screen.

3.1.2. Financial difficulties

The second most common barrier mentioned was financial difficulties. Colonoscopy was described as an “extra.” As one participant said, “I’m not afraid of anything, it’s just the cost.” Others commented that cost kept them from getting additional screening, “Finances are an issue. The last time I got the test, they sent me a bill of \$800.” Within this safety-net population, lack of health insurance, contributed to this concern, summed up by a participant who said that, “I have no insurance and can’t afford the out of pocket expenses.” Lack of access to assistance programs was a challenge even for those who had sought financial help getting screened: “I have no insurance. I have had three family members to die from colon cancer. I do not want to be the fourth. I asked ... if they had any programs or knew some organization that would [cover screening] but they said no.”

Several participants commented on the dynamic on-off nature of health insurance, including temporary coverage (“Insurance is an issue, currently only have insurance for the next 6 months.”), waiting until Medicare-eligibility for screening (“I’ve wanted to have a colonoscopy ever since I turned 50 but don’t have the insurance or money until I get Medicare.”), or the challenges of getting back on one’s feet after gaining coverage (“[I] Didn’t have any insurance for years, before that too busy working, now I have the time, trying to get it done with scheduling”).

3.1.3. Logistical challenges

Logistical challenges included not being able to find the time to do the set-up and completion of a colonoscopy: “Haven’t had time with driving a truck, no appointment set, and been looking for a doctor over a nurse practitioner.” Transportation to the specialist for a colonoscopy was mentioned multiple times, from not having transportation, to not being able to drive the distance to the procedure, and not having someone to go with them (e.g., “I don’t drive long distances and have no one to take me”). Many respondents faced multiple challenges that complicated screening attempts. As one participant commented, “My living situation is too difficult now.”

3.1.4. Lower priority

Fewer participants directly mentioned that CRC screening was not a priority, but some did comment that they had no symptoms or signs that would trigger them to seek screening (“I don’t have any pain, I don’t see a reason to go to the doctor”) or did not see the benefit (“... have to waste all this time and then be told that everything is ok.”). Much like people who said they had too much going in their lives, some participants commented that other health conditions took priority or over-rode the need for attention to CRC screening. One participant commented, “I have too many health complications already.”

Table 2
Differences in patient-reported barriers by CRC screening status and socioeconomic factors (N = 198)**.

Barrier	Ever screened	Not screened	p	Income < \$1200/month	Less than HS degree	Uninsured	Unemployed
	n (%)	n (%)		χ^2 , p	χ^2 , p	χ^2 , p	χ^2 , p
Fear	28 (35.0)	30 (25.4)	0.146	0.323, 0.570	0.061, 0.805	0.976, 0.323	0.008, 0.929
Finances	15 (18.8)	30 (25.4)	0.272	5.511, 0.019	0.038, 0.845	19.940, 0.000	0.217, 0.641
Logistics	28 (35.0)	17 (14.4)	0.001	0.660, 0.417	0.488, 0.485	0.749, 0.387	2.894, 0.089
No recommendation/referral	20 (25.0)	39 (33.1)	0.224	0.043, 0.836	4.399, 0.036	2.037, 0.154	0.001, 0.978
Unnecessary	22 (27.5)	19 (15.3)	0.035	2.607, 0.106	0.532, 0.466	0.188, 0.665	2.044, 0.153
Discomfort/disgust with procedure	16 (20.0)	12 (10.2)	0.051	0.238, 0.626	0.209, 0.648	1.458, 0.227	0.144, 0.704
Discomfort/disgust with prep	6 (7.5)	9 (7.6)	0.974	0.227, 0.634	0.008, 0.930	1.590, 0.207	0.067, 0.796
Other*	9 (11.3)	9 (7.6)	0.384	0.755, 0.385	0.010, 0.922	0.255, 0.614	0.276, 0.599

* Other barriers include medical mistrust (n = 4), lack of information on CRC screening (n = 5), religious reasons (n = 2), or they simply “don’t want to” (n = 7).

** This Table presents the comparison of those reporting each barrier between those who were ever screened for CRC (Column 2) and those who were never screened for CRC (Column 3), in addition to identifying which socioeconomic factors (Columns 5–8) are significantly associated each barrier reported.

3.1.5. Differences in barrier type by CRC screening status and socioeconomic factors

Table 2 describes the associations between patient-reported barriers and CRC screening status. Those who reported logistical difficulties, feeling like screening was a low priority, and discomfort or disgust with the procedure, were more likely to report ever-screening than never-screening (35.0% vs. 14.4% for logistics, 27.5% vs. 15.3% for priority, 20.0% vs. 10.2% for disgust). There were no statistically significant differences in reported barriers between ever-screened and up-to-date for CRC screening.

We examined whether socioeconomic factors were associated with different types of barriers (Table 2). Reporting the barriers of financial difficulties was significantly associated with having an income less than \$1200 per month ($p < 0.05$) and being uninsured ($p < 0.05$). People who had less than a high school diploma were more likely to say their provider had not recommended screening ($p < 0.05$). These socioeconomic factors were not to be found significantly associated with other barrier categories.

4. Discussion

Consistent with other studies that demonstrate screening disparities for underserved populations, we found that rates of being up-to-date on CRC screening among these FQHC patients from rural and urban settings, were below the national and state averages (66.4% and 61.8%, respectively) (Centers for Disease Control et al., 2014; Colditz et al., 2014). In free-text responses to a question about CRC screening barriers, participants most commonly listed fear/worry, financial, and logistical challenges. The qualitative approach adds to our understanding of patient-reported concerns by allowing patients to self-identify their most salient barriers rather than asking them to rate pre-determined barriers.

Our results add depth to understanding how these factors might function for patients served in FQHC settings. For example, though fear and worry are known barriers, the qualitative approach allowed us to identify a wide range of fears, including fears related to sedation and anesthesia, which has been under-reported in the literature (Basch et al., 2016). Different educational messaging is needed to address worries about anesthesia than worries about the procedure or test outcomes.

These findings align with other research suggesting that socioeconomically disadvantaged patients may be especially concerned about the costs and consequences of screening (e.g., complications with anesthesia) and that confidence that treatment can be effective may be low (James et al., 2008). Logistical challenges were expected because of known challenges with transportation to colonoscopy and because the main facility that provided colonoscopy to patients at one health network reduced services and eventually closed during data collection, an event which was mentioned by a few respondents. Additionally, logistical challenges and the belief that screening was not necessary, were reported more often by participants who had ever been screened compared to those who had never been screened, indicating, that perhaps, these might be barriers that could be overcome. That financial challenges reported (e.g. cost, lack of health insurance (including changes to health insurance status), and lack of access to assistance programs) were not surprising in this FQHC setting, especially among those with low income and no insurance. Interestingly, though, fear and worry were mentioned more often than financial barriers, even in this low-income sample. Our previous research, as well as that of others, indicates that socioeconomically disadvantaged patients are more likely to report logistic barriers to completing screening (James et al., 2008).

Of particular concern: 10.9% reported not having a provider referral for CRC screening. Those with lower levels of education had higher odds of reporting no provider referral for CRC screening. Given the evidence-based guidelines for CRC screening, it is not clear why providers would not recommend screening to this population. It is possible

that providers did recommend screening but that individuals did not remember or understand the recommendation. However, further work is needed to understand whether there are systems-level failures to prompt provider recommendation or whether there is a need to address provider-patient communication in this FQHC patient population.

The overall sample size was limited, affecting the ability to generalize findings to other non-FQHC populations. Whether these findings are unique to FQHC settings (or common to all adults eligible for CRC screening) cannot be determined without a non-FQHC comparison group. Low representation of Hispanics ($n = 15$) in our sample means we could not identify barriers unique to that group. Additionally, variability in data collection methods (mailed vs. in-person survey) could affect how and if barriers were reported. Lastly, looking at barriers by type of CRC screening would be valuable but was not possible due to the small sample size in some groups when stratified by type of CRC screening. While this does limit the study in terms of suggesting recommendations to address barriers by screening type, it is still valuable to look at barriers to screening as a whole, and these findings still add to our understanding of how barriers affect CRC screening participation. Focusing on marginalized populations, who current interventions may not address, allows for us to tailor future interventions to the safety-net healthcare setting.

5. Conclusion

Despite cost and lack of insurance being a large barrier to CRC screening, especially in this population, fear still seems to be a more common barrier when participants are asked an open-ended question regarding barriers. Our findings may be applied to developing communication or intervention strategies to improve CRC screening rates within federally qualified health centers.

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Declaration of Competing Interest

The authors do not have any conflicts of interest to declare.

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