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## Self-reported barriers to colorectal cancer screening in a racially diverse, low-income study population

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### Abstract

Colorectal cancer (CRC) screening is underutilized, especially in low income, high minority populations. We examined the effect test-specific barriers have on colonoscopy and fecal immunochemical test (FIT) completion, what rationales are given for non-completion, and what “switch” patterns exist when participants are allowed to switch from one test to another. Low income adults who were not up-to-date with CRC screening guidelines were recruited from safety-net clinics and offered colonoscopy or FIT (n=418). Follow up telephone surveys assessed test-specific barriers. Test completion was determined from patient medical records. For subjects who desired colonoscopy at baseline, finding a time to come in and transportation applied more to non-completers than completers ( $p = 0.001$  and  $p < 0.001$ , respectively). For participants who initially wanted FIT, keeping track of cards, never putting stool on cards, and not remembering to mail cards back applied more to non-completers than completers ( $p = 0.003$ ,  $p = 0.006$ , and  $p < 0.001$ , respectively). The most common rationale given for not completing screening was a desire for the other screening modality: 7% of patients who initially preferred screening by FIT completed colonoscopy, while 8% of patients who initially preferred screening by colonoscopy completed FIT. We conclude that test-specific barriers apply more to subjects who did not complete CRC screening. As a common rationale for test non-completion is a desire to receive a different screening modality, our findings suggest screening rates could be increased by giving patients the opportunity to switch tests after an initial choice is made.

### Keywords

colorectal cancer screening; barriers; FIT; colonoscopy; test preference

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Colorectal cancer is the third leading cause of cancer related deaths in the United States, accounting for nearly 11% of all cancer mortality [1]. Colorectal cancer screening is effective in lowering the incidence and mortality rates of this disease [2, 3]. The U.S. Preventive Services Task Force (USPSTF), the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology agree routine screening for average risk individuals should begin at the age of 50 and end at 75 [4, 5]. A variety of screening methods are recommended: fecal blood test (fecal occult blood test, FOBT, or fecal immunochemical test, FIT) annually, flexible sigmoidoscopy or double

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contrast barium enema (DCBE) every five years, or colonoscopy every 10 years [4, 5]. However, screening remains underutilized in the United States, with only 54.2% of age-eligible adults up-to-date with current guidelines [6].

Due to the benefits that may be achieved by screening and its current underutilization, it is important to understand what factors predict screening adherence and what methods can be used to overcome barriers to, or facilitate completion of, screening. Factors previously associated with screening adherence include age [7-9], gender [10-14], education level [15-18], race/ethnicity [9, 12, 16, 19], income [8, 12, 20], marital status [9, 21-23], fatalistic beliefs about cancer [24-26], and knowledge [8, 24, 27, 28] and fear [12, 24, 27-30] of screening tests. Other factors such as physician involvement [8, 9, 21, 23, 31-33], access to health care [13, 14, 19, 34, 35], geographic location [9, 21, 36], and test-specific barriers [12, 23, 27, 37-40] have also been found to influence screening adherence.

Although colorectal cancer screening predictors, barriers, and facilitators in low income and minority populations have been studied extensively, they are not currently well understood. Past studies have analyzed these populations' perceived barriers to colorectal cancer screening through surveys and focus groups [12, 24, 26, 27, 41, 42]. The present study takes the next step, and correlates these findings with actual test adherence. Specifically, we analyzed the effect certain test-specific barriers have on colonoscopy and FIT completion, what rationales are given by individuals who choose not to complete screening, what screening modality (colonoscopy or FIT) seemed most desirable in a low income, high minority population, and finally what "switch" patterns seemed to emerge when screening eligible individuals were given the option to switch from one test to the other (colonoscopy or FIT) over a 6 month period of time.

## METHODS

### Study Design

This study and all protocols were approved by the University of Kansas Medical Center Human Subjects Committee. Written informed consent was obtained from all study participants.

Study staff recruited 470 study participants in eight Kansas City safety net clinics on a rotating basis between September 2008 and May 2010. Patients in each clinic's waiting room were informed of the study by project staff, and those who were interested were subsequently screened for inclusion requirements. Those who met study eligibility requirements were directed to a touchscreen computer kiosk to complete a survey and receive culturally tailored education and information regarding colorectal cancer screening. Computers were equipped with headphones, and a narrator read survey questions and provided educational information to accompany graphics in each participant's preferred language (English or Spanish).

At the end of each computer session participants were offered the choice of a no cost screening test with either FIT or colonoscopy (Figure 1). Those preferring FIT were given a pre-packaged kit containing stool cards, applicator brushes, and a pre-addressed lab-return envelope. Those preferring a colonoscopy received a colonoscopy scheduling instruction card. The instruction card contained a phone number to call for scheduling, a blank line to write in the date and time of a future test, and the name of the University of Kansas Medical Center (KUMC) endoscopy lab. In some cases (<5%), study staff assisted participants in making an initial call for scheduling a colonoscopy. All testing and laboratory procedures were provided at no financial cost to participants.

### Inclusion/Exclusion Criteria

To be included in the study, participants had to have a household income of less than 150% of the Federal Poverty Level (FPL). Participants were required to be 50 years of age or above and not up-to-date with current U.S. Preventive Services Task Force screening guideline recommendations. Individuals with an acute medical illness, current gastrointestinal bleeding, a history of adenomatous polyps, colorectal cancer, an inherited polyposis/non-polyposis syndrome, a first degree relative with colorectal cancer prior to age 60, or inflammatory bowel disease were excluded. While no formal assessment of dementia or psychiatric illness was performed, any participant demonstrating impaired cognitive function or inappropriate affect or behavior was also excluded. Additionally, only one member from a single household was allowed to enroll in the study.

### Follow Up

No contact was made with participants until follow up phone calls began 90 days after subject enrollment. At 90 days, participants were contacted to complete a standardized telephone survey conducted by study staff. The survey asked about self-reported test completion and assessed barriers subjects may have encountered with either colonoscopy or FIT (Figures 2 and 3). Questions addressing barriers asked participants to respond to a four point Likert scale. Answers ranged from: 1-does not apply at all, 2-applies a little, 3-applies somewhat, and 4-applies very much. Additionally, for those not completing their chosen test (colonoscopy or FIT) at 90 days, comments were gathered on why they did not complete screening. If participants stated they still planned to complete a test, they were given the option to “switch” from colonoscopy to FIT or vice versa. These participants were also scheduled for another follow up phone survey in the future.

While self-reported data on test adherence was obtained, the primary method for measuring test completion adherence was by receipt of mailed and correctly completed FIT cards or receipt of an endoscopy test at KUMC. FIT cards were processed by certified laboratory personnel at Quest Diagnostics Laboratories (Lenexa, KS) with results electronically transmitted to project staff. Medical record data on completed colonoscopies was obtained from the endoscopy lab at KUMC.

### Analysis

Quantitative Likert scale data were used to investigate whether FIT or colonoscopy-specific barriers applied more for those who did not complete their initially chosen screening test as compared to those who did complete their initially chosen screening test. For each barrier question, an answer of 3 or 4 was counted as a negative response and an answer of 1 or 2 was counted as a positive response. Frequencies of negative and positive responses were compared between completers and non-completers for each barrier. Chi-square tests were used to determine if any of these differences were significant. When expected frequencies fell below five, two-sided Fisher's exact tests were used. Because multiple barriers were assessed simultaneously, the Bonferroni correction was used to maintain an overall  $p = 0.05$ .

Qualitative data from participant comments made during phone surveys was used to analyze reasons given for non-adherence for those who initially chose a colonoscopy or FIT at baseline but did not follow through with their preferred test. During follow up, non-completers who initially intended to complete either a colonoscopy or FIT at baseline were asked why they had not completed the respective test. Responses were categorized into common themes such as problems with “scheduling” or “transportation.” Response frequencies were used to discern the main reasons for not completing either a colonoscopy or FIT.

## RESULTS

### Study Population

Demographic characteristics of study participants are shown in Table 1. This study was only concerned with the test completion status of those participants who preferred screening at baseline. Because of this, the subject characteristics in Table 1 do not include the 52 people who initially “preferred no test.” Those included in analysis (N=418) are indicated by the shaded area in Figure 1.

The median age of participants was 55.0 years with a majority of subjects falling below the age of 60 (74.4%). Nearly two thirds of the study participants were female and over 75% had no health insurance (77.3%). The most represented race/ethnicity was non-Hispanic African Americans (42.8%), however, there was considerable representation of non-Hispanic Whites (28.9%) and Hispanics (25.6%). One third of the participants were currently married (32.5%) and there were varying levels of educational attainment, although there was a slight tendency towards less education.

### Colonoscopy-Specific Barriers

For those subjects who initially wanted a colonoscopy at baseline (N = 251), problems finding a time to come in ( $p = 0.001$ ) and problems getting to and from an appointment ( $p < 0.001$ ) applied more to non-completers than completers (Figure 2). Interestingly, the completers’ response rate for answering barrier questions was higher than the non-completers’ response rate; 91 of 96 completers (94.8%) and 75 of 155 non-completers (48.4%) gave responses.

### FIT-Specific Barriers

For those subjects who initially wanted an FIT at baseline (N = 167), problems keeping track of cards ( $p = 0.003$ ), never getting around to putting stool on cards ( $p = 0.006$ ), and not remembering to mail cards back ( $p < 0.001$ ) applied more to non-completers than completers (Figure 3). Again, the completers’ response rate for answering barrier questions was higher than the non-completers’ response rate; 80 of 85 completers (94.1%) and 34 of 82 non-completers (41.5%) gave responses.

### Reasons Given for Non-Adherence

A variety of responses were given by colonoscopy non-completers (N = 97, 62.6% response rate) with regard to their non-adherence (defined as those subjects who did not complete the screening test they preferred at baseline), such as: the desire for completing an FIT instead (39.2%), scheduling problems (34.0%), transportation problems (11.3%), health reasons (9.3%), and being too busy (8.2%) (Note that participants were allowed to respond with more than one rationale).

Fewer reasons (N = 40, 48.8% response rate) were given for FIT non-adherence. However, fewer subjects preferred FIT at baseline (167 FIT vs. 251 colonoscopy) and the FIT non-completer response rate was lower (48.8% vs. 62.6%). The most common rationales given for FIT non-adherence were the desire for completing a colonoscopy instead (35.0%), self-reported FIT completion with no results having been reported to study staff by Quest Laboratories (32.5%), and lost FIT kit (20.0%).

### Test Preference and Completion Rates

Colonoscopy was the most preferred test at baseline when compared to FIT (251 vs. 167 subjects). However, only 38.2% (96 out of 251 subjects) of those who initially wanted a

colonoscopy received one compared to 50.9% (85 out of 167) who initially wanted an FIT. Overall, 107 subjects received screening by colonoscopy and 105 by FIT. Eleven subjects who initially wanted an FIT completed screening by a colonoscopy instead, while 20 subjects who initially wanted a colonoscopy completed screening by an FIT instead (Table 2).

## DISCUSSION

When comparing completers and non-completers for those who initially wanted a colonoscopy at baseline, non-completers tended to have more issues with scheduling a colonoscopy ( $p = 0.001$ ) and finding transportation ( $p < 0.001$ ). Problems with scheduling and transportation were specifically reported by participants as rationales for colonoscopy non-adherence (34.0% and 11.3% of subjects, respectively). The majority of problems reported with scheduling were due to subjects never reaching anyone at the endoscopy clinic, leaving messages and not receiving return calls, or being placed on hold so long that they gave up. It is unclear if completers faced these same barriers but persevered or if they were simply lucky enough to reach someone on their first attempt when scheduling an appointment. Regardless, it seems reasonable that a more effective system for endoscopy scheduling would increase colorectal cancer screening by colonoscopy. Transportation was commonly reported as an issue for subjects who depended on someone else for a ride. Additionally, some noted they would be able to get to the appointment but not back home. Further research is needed on how to overcome issues with transportation.

While many focus groups and surveys suggest fear of embarrassment, pain, and injury are perceived barriers to obtaining a colonoscopy [12, 23, 27, 37-40], this report did not find any of these factors to be significantly linked with non-adherence. However, barriers regarding fear of pain ( $p = 0.013$ ) and injury ( $p = 0.027$ ) did appear to affect non-completers more than completers, although these findings were not significant after adjusting for multiple comparisons (threshold  $p = 0.005$ ).

When comparing completers and non-completers among those who initially wanted an FIT at baseline, non-completers tended to have more problems keeping track of cards ( $p = 0.003$ ), never getting around to putting stool on cards ( $p = 0.006$ ), and not remembering to mail cards back ( $p < 0.001$ ). Nearly 30% of rationales given for FIT non-adherence involved subjects losing FIT kits or being too busy or forgetful to complete the test. Interventions in the literature suggest that patient mailings [43, 44], telephone outreach [45, 46], and patient navigators [47, 48] can all increase colorectal cancer screening rates. However, none of these studies evaluated the effect of these interventions on FIT screening alone. Perhaps one or a mix of these methods could be used to remind patients to complete testing via FIT. This type of outreach could also provide information on how to obtain extra FIT kits for patients who have lost theirs.

A large number of participants self-reported completion of FIT while their medical records reflected non-adherence (32.5%). This could be due to reporting bias. It could also reflect a high number of cards received by Quest that were prepared incorrectly or had been damaged in the mail. In this scenario, subjects who mailed the cards might automatically assume their FIT test was able to be processed. With FIT, patients may assume that no news is good news and develop a false sense of confidence that their tests have been received, processed, and found to contain no occult blood. While it is possible that some participants completed an FIT outside of the study, this is unlikely since the additional cost and effort would have been prohibitive. Future studies may be necessary to insure that informatics systems are in place to follow up with patients who incorrectly prepare a FIT test at home. Practice systems will

need mechanisms to arrange re-testing and possibly education to maximize proper sample collection and submission by patients.

Out of the 418 study participants, 251 (60.0%) initially preferred colonoscopy while 167 (40.0%) initially preferred FIT. Adherence to baseline screening preference was 38.2% (96 out of 251) for colonoscopy and 50.9% (85 out of 167) for FIT. In addition, 11 subjects who preferred FIT at baseline completed screening with a colonoscopy and 20 subjects who preferred a colonoscopy at baseline completed screening with an FIT. Overall, 106 (25.4%) subjects completed screening by colonoscopy and 105 (25.1%) by FIT for an overall completion rate of 55.5%. Thus, while colonoscopy was the most preferred test at baseline, follow up suggests the completion rates for both screening methods are similar in this population.

Because a number of subjects (6-8%) completed screening by a different method than their stated baseline preference, it appears that having the option and knowledge of how to switch tests is important. At baseline, study participants were mostly only given information about their preferred screening test. Switching screening modalities required extra effort by study participants. Many of the subjects switching from colonoscopy to FIT first stated they were interested in a switch when they were contacted for the follow up survey. In contrast, those wishing to switch from FIT to colonoscopy would have had to call the endoscopy lab to schedule an appointment. Perhaps if screening information for both tests was made available to participants throughout the intervention more subjects might have switched and completed screening, rather than giving up because they decided their preferred screening method was undesirable. Indeed, research suggests that only 40% of patients referred for a colonoscopy are even aware of alternative screening options [37]. Future research is needed to determine whether screening rates could be increased by enabling patients to switch tests after an initial choice is made.

The present study has several strengths and limitations. While survey response rates were high for those completing testing, those who did not complete testing tended to have low response rates. This is most likely due to non-responders lack of time, interest, or motivation to participate in the study. Non-completer response rates for the quantitative colonoscopy and FIT barrier data shown in figures 2 and 3 were 48.4% and 42.9%, respectively. Response rates for giving non-adherence rationales for colonoscopy or FIT were 62.6% and 48.8%, respectively. Lower response rates could bias the results if responders held different views than non-responders.

It is also important to note that all information and screening was provided at no financial cost to study participants. This allows for the evaluation of barriers which become significant in the absence of monetary burdens. It is becoming increasingly important to understand these barriers as the Affordable Care Act is estimated to insure an additional 34 million Americans by 2019 [49, 50]. A strength of this study is its high degree of generalizability to those seeking care at safety net clinics, as a large and diverse group of safety net clinics was included in subject recruitment. However, caution must be used when extending these findings to other primary care clinics in the United States as well as other low income, high minority populations who do not use safety net clinics, as the behaviors influencing colorectal cancer screening may differ from the study population. To our knowledge, this is the first study to show test switching as a common rational given for not completing a colonoscopy or FIT. The fact that information on barriers and facilitators to screening was linked with actual test adherence determined by medical records also made this study unique.

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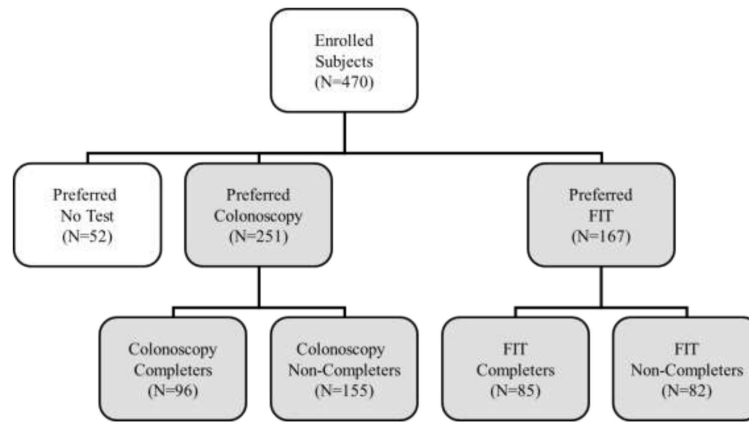
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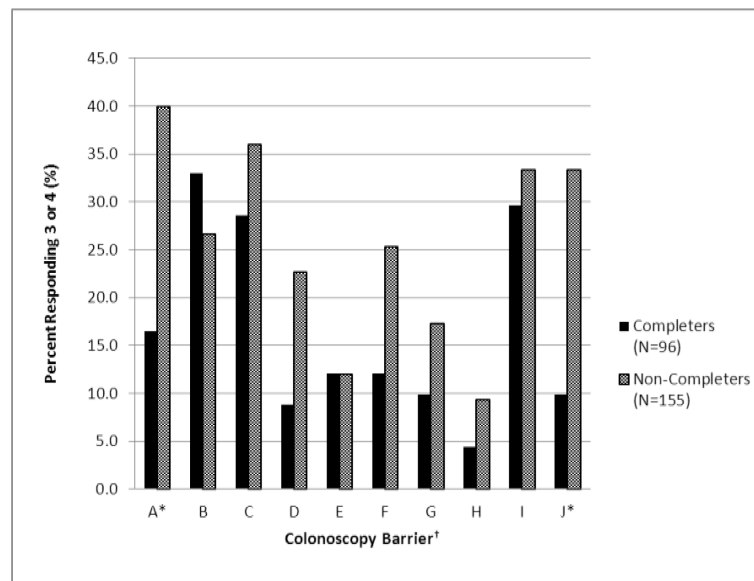


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**Figure 1. Study Diagram**

Shaded area represents participants included in data analysis (N=418).

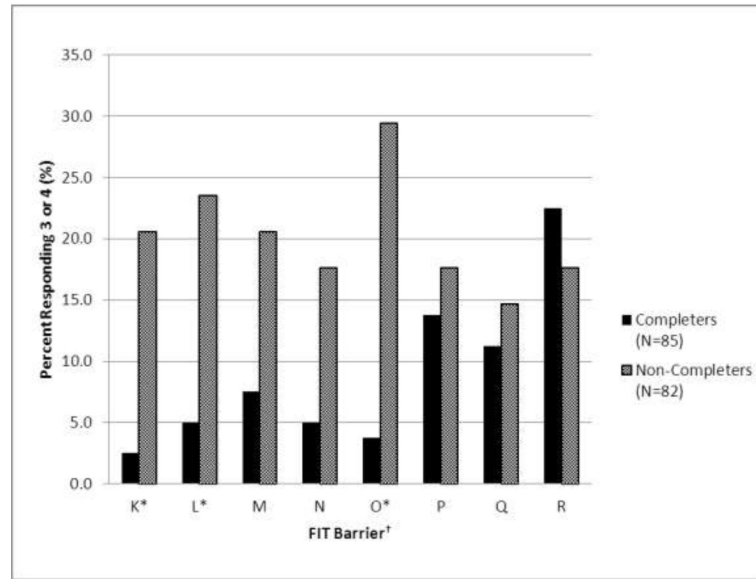


**Figure 2. Comparison of Completers and Non-Completers Negative Responses to Colonoscopy Barrier Questions**

91 of 96 completers (94.8%) and 75 of 155 non-completers (48.4%) gave responses.

\*Statistically significant difference (Bonferroni's procedure for controlling 5% type I error rate).

†A= Problems finding a time you can come in; B= Not liking the large amount of fluid and laxative you have to drink; C= Discomfort from going to the bathroom 10-15 times to clear out the colon; D= Fear of pain; E= Fear of embarrassment; F= Fear of injury to colon; G= Unwilling to have a tube inserted in rectum; H= Too much of an invasion of personal privacy; I= Fear that the test results would show something bad; J= Problems getting to and from appointment.



**Figure 3. Comparison of Completers and Non-Completers Negative Responses to FIT Barrier Questions**

80 of 85 completers (94.1%) and 34 of 82 non-completers (41.5%) gave responses.

\*Statistically significant difference (Bonferroni's procedure for controlling 5% type I error rate).

†K= Problems keeping track of the cards; L= Never getting around to putting the stool on the cards; M= Disgusted by the idea of putting stool and water on the cards; N= Worry about germs or contamination from stool; O= Not remembering to mail the cards back; P= Takes too long to get the test results; Q= Doubt that the test results would be correct or accurate; R= Fear that the test results would show something bad.

**Table 1**

## Subject Characteristics (N = 418)

<b>Characteristic</b>	<b>Value</b>
<i>Age, median (Interquartile Range)</i>	55.0 (52.0-60.0)
<i>Age group, N (%)</i>	
50-59*	311 (74.4)
60-69	95 (22.7)
70-79	12 (2.9)
<i>Sex, N (%)</i>	
Male	152 (36.4)
Female	266 (63.6)
<i>Race/Ethnicity, N (%)</i>	
Hispanic	107 (25.6)
Non-Hispanic White	121 (28.9)
Non-Hispanic Black	179 (42.8)
Non-Hispanic Other	11 (2.6)
<i>Marital Status, N (%)</i>	
Married or Living w/ Partner	136 (32.5)
Divorced or Separated	153 (36.6)
Widowed/never married/other	129 (30.9)
<i>Education Level, N (%)</i>	
Some high school and below	136 (32.5)
High school grad/GED	108 (25.8)
Some college or tech school	118 (28.2)
College grad and above	56 (13.4)
<i>Insurance, N (%)</i>	
Yes	95 (22.7)
No	323 (77.3)

\* 1 subject was 49 at enrollment

**Table 2**

Subjects who switched tests.

<b>Initial Test Preference</b>	<b>Number of Subjects<sup>*</sup></b>	<b>Percent of Subjects who Switched and Completed (%)<sup>†</sup></b>
FIT (N=167)	11	6.6
Colonoscopy (N=251)	20	8.0
<b>Total (N=418)</b>	<b>31</b>	<b>7.4</b>

<sup>\*</sup> Subjects who completed screening by the test opposite of their initial preference (i.e., 11 who initially preferred FIT completed screening by colonoscopy).

<sup>†</sup> By initial test preference (i.e., if initial test was FIT,  $11/167 = 6.6\%$ ).