

Screening Recommendation Adherence Among First-Degree Relatives of People With Colorectal Cancer

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Research Article

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Abstract

Purpose: To determine what factors are associated with colorectal cancer (CRC) screening adherence among first-degree relatives (FDRs) of people with CRC.

Methods: The study used data from the 2015 National Health Interview Survey, a nationally representative survey in the US. Self-reported CRC screening rates were compared between FDRs and their peers without a family history of CRC. Participants were considered to be adherent if they had undergone any of the following: fecal immunochemical test within the prior 1 year, sigmoidoscopy or computed tomography colongraphy within 5 years, or colonoscopy within 10 years. Multivariable models of CRC screening adherence were created for both cohorts and the results compared.

Results: The analysis included 11,381 people age 50-75 at time of survey. Overall, 62% of participants were adherent to screening recommendations. FDR of people with CRC were more likely to be adherent (76% compared to 61%, $p < 0.001$). In the multivariable models, a FDR with CRC was associated with an 86% increase in odds of being adherent to recommendations (aOR 1.86; 95% CI 1.59-2.59). Race, ethnicity, and socioeconomic variables were all associated with adherence. Models were largely similar between FDRs of people with CRC and the general public.

Conclusions: Approximately one-quarter of FDRs of people with CRC are not adherent to screening recommendations. Further outreach is needed for members of minority races and the Hispanic community and additional efforts are needed to increase the accessibility of CRC screening for those with more limited finances and the uninsured.

Introduction

A history of colorectal cancer (CRC) among a first-degree relative (FDR), mother, father or sibling, is one of the most important risk factors for the disease. The risk is estimated to be two- to four-fold that of the peers without a family history of CRC [1]. Although colorectal cancer screening is recommended for all people aged 50–75, it is of even greater importance for high-risk individuals, including to those with a family history of CRC [2]. Some professional organizations recommend those with higher risk be screened starting at a younger age and at more frequent intervals [3].

There are several modalities for CRC screening including: computed tomography colongraphy (CTC), also referred to as a “virtual colonoscopy”; fecal immunochemical test (FIT); sigmoidoscopy; and colonoscopy. In the average risk population, CTC, FIT, or sigmoidoscopy may provide similar benefits in reduction of CRC-related mortality as colonoscopy [4]. Among higher-risk individuals, colonoscopy is still the standard because it not only can lead to earlier detection of CRC; removal of precancerous lesions during the procedure can prevent CRC.

Perhaps counterintuitively, the detection of precancerous lesions, often referred to as polyps, during colonoscopy is associated with superior clinical outcomes in terms of reducing CRC risk [5]. However,

polyp detection seems to be associated with a more thorough procedure, a more meticulous inspection and/or for longer duration, and not necessarily related to the disease process [6]. The detection of at least one polyp is a widely used quality indicator [7].

Despite the evidence supporting the benefit of colonoscopy among FDRs of those with CRC, rates in the United States have historically been low; a meta-analysis estimated that only 40% (95% CI 26%-54%) of eligible, those age 50–75, underwent colonoscopy [8]. However, the studies included in the analysis ranged from 1999–2009 and may not reflect current trends. A study using data from the 2009 California Health Interview Survey found that 73% of those with a FDR with CRC reported having a screening colonoscopy [9].

FDRs of people with CRC can encounter a myriad of barriers to screening [10]. They may not even be aware that their status is associated with a higher risk of CRC or that screening colonoscopy may help mitigate that excess risk. Some may abstain due to a fear of being diagnosed with CRC or due to negative attitudes regarding colonoscopy, disputing its effectiveness, or out of consideration on the associated discomfort and complications.

CRC screening, particularly colonoscopy, can also be costly and those without insurance may have more limited access. One study found only 44% of uninsured individuals age 50–64 reported undergoing colonoscopy compared to 57% of those with insurance [11]. Another, found that people reporting difficulty affording healthcare were less than half as likely (aOR 0.41; 95% CI 0.22–0.74) to have had a colonoscopy or sigmoidoscopy [12].

Following approval of the Affordable Care Act in the United States in 2011, CRC screening including colonoscopy is required to be covered by insurance providers without cost sharing, co-pays, coinsurance, and deductibles. However, if performed for surveillance or diagnostic purposes or when a polyp is detected and removed during screening, the procedure may be subject to cost sharing [13].

Other cultural and demographics factors have been associated with CRC screening adherence. Black Americans, who have the highest incidence of and mortality from CRC, have had lower rates of CRC screening than their Caucasian peers [14–15]. Even lower rates of CRC screening have been observed among those of Asian or Hispanic heritage [15]. However, these observations were among the general population and it is unclear if similar trends persist among those who have FDR with CRC. In this study, we sought to determine what factors are associated with CRC screening recommendation adherence among FDRs of patients with CRC.

Methods

Data Source

Data from the 2015 National Health Information Survey (NHIS) Cancer Control Supplement (CCS) was used to compare the self-reported adherence with colorectal screening recommendation guidelines of

FDRs of people with CRC and their peers without a family history of CRC. The NHIS is a cross-sectional, nationally representative, household survey of non-military and non-institutionalized individuals living in the United States. [16] The Census Bureau administers the NHIS survey annually, throughout each year, using computer-assisted personal interviewing. The core questionnaire remains consistent each year and includes demographic characteristics, health insurance, health care access and use, health conditions, tobacco use, and functioning and disability. Additional questionnaires are rotated each year, some with fixed periodicity, some ad hoc. The data are openly available from the Centers for Disease Control and Prevention at <http://www.cdc.gov/nchs/nhis.htm> [16].

The CCS is an additional module that is administered to adult participants of the NHIS covering diet and nutrition, physical activity, cancer screening, genetic testing, and family history of cancer. It is co-sponsored by the National Cancer Institute and the Centers for Disease Control and Prevention. It was first administered in 1987 and subsequently has been administered approximately every 5 years through 2015. Since 2019, the CCS has been integrated into the annual NHIS adult survey with questions rotating each year. The 2015 NHIS CCS was used for this analysis. Although the 2019 NHIS CCS data is available at time of analysis, the survey did not include family history of cancer, which precluded its use.

Participants

In 2015, the NHIS surveyed 33,672 adults. The analysis was limited to the 13,707 who were 50–75, inclusive, at time of survey, consistent with the recommendations for CRC screening at the time. Although some professional organizations recommend earlier screening for higher-risk individuals, [3] the practice is still not universal. Further, 119 participants who reported a personal history of colorectal cancer, and 2,207 where familial history of colorectal was unknown, were excluded leaving a final analysis cohort of 11,381.

Measures

Demographic data, age, sex, race, ethnicity, geographical region of the country, education, marital status, family income relative to poverty threshold, and insurance coverage were extracted from the files. To approximate each participant's affordability of healthcare, a composite variable was created using a series of questions regarding affordability of healthcare including: prescription medicines, mental health care/counseling, dental care, to see a specialist, and follow-up care. The questions are formatted as the following example:

"During the past 12 months, was there any time when you needed any of the following, but didn't get it because you couldn't afford it? ... Prescription medicines."

A positive response to any was coded as the participant reporting issues with the affordability of healthcare.

CRC screening was based on self-report. Participants were considered to be adherent to CRC screening guidelines if they had undergone any of the following: FIT within the prior 1 year, sigmoidoscopy or CTC within 5 years, or colonoscopy within 10 years.

Statistical Analysis

The composition of the study cohort and the frequency of CRC screening tests were reported descriptively. The characteristics of the participants with FDR's with CRC were compared to those who did not using bivariate statistics. Multivariable models of colonoscopy recommendation adherence were created for: 1) the entire cohort; 2) for FDR of people with CRC; 3) for those without a family history of CRC. Subsequently, the model results between FDR and their peers without a family history of CRC were compared using interaction variables between each predictor variable and family history of CRC to determine if the relationship between the predictor and colonoscopy adherence was moderated by a family history of CRC.

Results

Of the 11,381 participants included in the analysis, 9% (n = 1,074) reported a history of CRC among a FDR. Participant characteristics segmented by FDR status is summarized in Table 1. Those who were are FDR of a person with CRC were slightly older on average, more likely to be black, non-Hispanic, reside in the southern region of the United States, have a prior cancer (non-colorectal) diagnosis themselves, and to be insured by Medicare. There was no difference in between the two groups in relation to poverty status, being uninsured, or self-reported difficulty affording healthcare.

Table 1
Study Demographics

	Study Population N = 11,381	First-Degree Relative w/ Colorectal Cancer N = 1,074	No First-Degree Relative w/ Colorectal Cancer N = 10,307	P-Value
Age in years (Mean, SD)	61.5, 7.2	62.6, 7.2	61.4, 7.2	< 0.001
Gender	44.8%	42.8%	45.0%	0.172
Male	55.2%	57.2%	55.0%	
Female				
Race	79.2%	82.6%	78.9%	0.017
Caucasian	13.3%	11.3%	13.5%	
Black	7.5%	6.2%	7.6%	
Other Race				
Ethnicity	12.1%	6.1%	12.7%	< 0.001
Hispanic	87.9%	94.0%	87.3%	
Non-Hispanic				
Region	17.8%	19.6%	17.7%	0.024
Northeast	20.7%	23.3%	20.5%	
Midwest	34.0%	32.1%	34.2%	
South	27.5%	25.1%	27.7%	
West				
Marital Status	64.2%	65.2%	64.0%	0.461
Married	35.9%	34.8%	36.0%	
Not Married				
Education	42.8%	44.9%	42.6%	0.161
College Degree	57.2%	55.1%	57.4%	
No Degree				
Cancer History	13.2%	17.8%	12.8%	< 0.001
Prior Cancer	86.8%	82.2%	87.2%	
No Cancer				

	Study Population	First-Degree Relative w/ Colorectal Cancer	No First-Degree Relative w/ Colorectal Cancer	P-Value
	N = 11,381	N = 1,074	N = 10,307	
Family Income	12.3%	10.7%	12.5%	0.111
Below Poverty	87.7%	89.3%	87.5%	
Above Poverty				
Insurance Provider	6.5%	5.4%	6.6%	< 0.001
Uninsured	45.1%	41.2%	45.5%	
Private	6.7%	4.9%	6.9%	
Medicaid	41.7%	48.6%	41.0%	
Medicare				
Healthcare Affordability	18.0%	19.1%	17.9%	0.344
Reported Issues	82.0%	80.9%	82.1%	
No Issues				

The majority of participants (63%) reported having a discussion with a doctor regarding CRC screening. It was even more common among FDRs of people with CRC than their peers (75% compared to 62%; $p < 0.001$). The frequency of CRC screening modalities are summarized in Table 2. Colonoscopy was by far the most utilized. Fifty-eight percent of participants reported undergoing colonoscopy within the prior 10 years and, of those whom were adherent to screening recommendations, 94% had undergone colonoscopy.

Table 2
Colorectal Cancer Screening

	Study Population N = 11,381	First-Degree Relative w/ Colorectal Cancer N = 1,074	No First-Degree Relative w/ Colorectal Cancer N = 10,307	P-Value
Colonoscopy in the prior 10 years	58.4%	74.7%	56.6%	< 0.001
Fecal Immunochemical Test (FIT) in the prior 1 year	9.4%	7.8%	9.6%	0.058
Sigmoidoscopy in the prior 5 years	1.9%	2.0%	1.9%	0.849
Computed Tomography Colongraphy (CTC) in the prior 5 years	0.7%	1.1%	0.6%	0.071
Any of the above	62.4%	76.2%	61.0%	< 0.001

Of those who underwent colonoscopy, 36% reported a doctor notifying them of precancerous lesions found. This was more common among FDRs of people with CRC than their peers (49% compared to 35%, $p < 0.001$). The majority of participants had the colonoscopy covered by insurance, 67% reported no cost sharing related to the procedure, while 30% reported paying some, and 4% reported paying all of the cost. FIT was the second most common modality of CRC screening with 8% of participants undergoing the test in the prior year. Sigmoidoscopy and CTC were not common; less than 2% and 1% of participants underwent the procedures in the prior 5 years, respectively.

Overall, 62% of participants were adherent to CRC screening recommendations. FDR of people with CRC were more likely to be adherent than their peers (76% compared to 61%, $p < 0.001$). which can be attributed to higher colonoscopy utilization (75% compared to 56%; $p < 0.001$). FIT, sigmoidoscopy, and computerized tomography rates were similar between the groups.

Multivariable models of CRC screening adherence are summarized in Table 3. Having a FDR with CRC was associated with an 86% increase in odds of being adherent to recommendations (aOR 1.86; 95% CI 1.59–2.59). Black Americans were more likely to be adherent than Caucasian Americans (aOR = 1.15; 95% CI 1.01–1.31) while those who identified as a race other than Caucasian or Black were less likely to be adherent (aOR 0.72; 95% CI 0.61–0.85) as were Hispanic people compared to non-Hispanics (aOR 0.74; 95% CI 0.65–0.85). Increased odds of being adherence to CRC recommendations were also observed for those with advancing age, with a personal medical history of cancer, residing in the Northeast region of the United States, those married, and those with a college education. Decreased odds were observed for those living in poverty and those who were uninsured or enrolled in Medicaid.

Table 3
Multivariable Models of Colonoscopy Recommendation Adherence

	Model 1		Model 2		Model 3		P-Value
	All Participants N = 11,381		First-Degree Relative w/ Colorectal Cancer N = 1,074		No First-Degree Relative w/ Colorectal Cancer N = 10,307		
First-Degree Relative with Colorectal Cancer	1.86 (1.59–2.18)	< .001					
Age (per year)	1.05 (1.04–1.06)	< .001	1.07 (1.04–1.11)	< .001	1.05 (1.04–1.06)	< .001	0.181
Female Gender	1.07 (0.98–1.16)	0.150	1.60 (1.16–2.19)	0.004	1.03 (0.94–1.13)	0.502	0.009
Black Race	1.15 (1.01–1.31)	.040	0.80 (0.49–1.32)	0.388	1.18 (1.03–1.35)	0.020	0.147
Other Race	0.72 (0.61–0.85)	< .001	0.90 (0.48–1.66)	0.727	0.71 (0.60–0.84)	< .001	0.474
Hispanic	0.74 (0.65–0.85)	< .001	0.71 (0.40–1.29)	0.261	0.75 (0.65–0.86)	< .001	0.882
Midwest Region	0.72 (0.63–0.83)	< .001	0.84 (0.51–1.39)	0.499	0.71 (0.62–0.82)	< .001	0.531
Southern Region	0.69 (0.60–0.78)	< .001	0.89 (0.55–1.44)	0.628	0.68 (0.59–0.77)	< .001	0.286
Western Region	0.74 (0.65–0.85)	< .001	0.82 (0.51–1.33)	0.428	0.74 (0.64–0.85)	< .001	0.677
Married	1.30 (1.18–1.42)	< .001	1.06 (0.75–1.49)	0.735	1.32 (1.20–1.45)	< .001	0.232
College Degree	1.55 (1.42–1.70)	< .001	1.54 (1.11–2.14)	0.011	1.56 (1.42–1.71)	< .001	0.947
Personal Cancer History	1.75 (1.53–2.01)	< .001	2.20 (1.34–3.61)	0.002	1.71 (1.48–1.98)	< .001	0.344

	Model 1 All Participants N = 11,381		Model 2 First-Degree Relative w/ Colorectal Cancer N = 1,074		Model 3 No First-Degree Relative w/ Colorectal Cancer N = 10,307		P- Value
Below Poverty	0.76 (0.65– 0.88)	< .001	0.58 (0.33– 1.02)	0.06	0.78 (0.66– 0.91)	0.002	0.328
Uninsured	0.26 (0.21– 0.31)	< .001	0.20 (0.10– 0.38)	< .001	0.26 (0.21– 0.32)	< .001	0.431
Medicaid	0.81 (0.69– 0.94)	0.006	0.68 (0.37– 1.24)	0.206	0.82 (0.70– 0.96)	0.014	0.548
Medicare	0.96 (0.84– 1.08)	0.474	0.55 (0.35– 0.88)	0.012	1.00 (0.88– 1.14)	0.997	0.016
Healthcare Affordability Issues	1.01 (0.90– 1.14)	0.823	1.06 (0.71– 1.60)	0.768	1.01 (0.90– 1.14)	0.885	0.808

The results of the multivariable analysis were largely consistent across both analyses, of FDRs and non-FDRs. Among FDRs of people with CRC, females were more likely to be adherent than males (aOR 1.60; 95% CI 1.16–2.19) and enrollment in Medicare was associated with a decrease in odds of being adherent (aOR 0.55; 95% CI 0.35–0.87). Among those without a FDR with CRC gender and Medicare enrollment were not associated with screening adherence. The difference in the model results were statistically significant ($p = 0.009$ and $p = 0.016$, respectively).

Discussion

This study found that the predictors of CRC screening adherence were largely similar between FDR of people with CRC and the general public. Moreover, FDR were more likely to have had a discussion with a doctor regarding CRC screening and be adherent to screening recommendations than the general public. This suggests that many members in the group understand the increased risk. However, it is still likely that many do not.

Efforts to improve CRC screening among FDRs of people with CRC should focus on tailored communications specific to the population and their increased risk for the disease. Tailored communications have been shown to be about twice as likely to result in colonoscopy compared to more general communications [17]. In addition, having the FDR with CRC advocating for screening to their relatives at increased risk is an effective way to reduce barriers related to fear of or apprehension to the procedure [18].

Promoting CRC screening may not benefit some of the population who would undergo the procedure but cannot due to cost issues. CRC screening is now provided largely without cost sharing for those insured [13]; however, one-third of participants in this study still reported paying some or all of the costs out-of-pocket. As this study found, being in poverty, uninsured, or covered by Medicaid were among the strongest associated variables with adherence. This is not limited to CRC screening, financial hardship has been associated with decreased likelihood of undergoing screening for breast and cervical cancer as well [19].

Among FDR of people with CRC, Medicare insurance was associated with reduced odds of colonoscopy compared to private insurance. This was not observed among the general population. The reason for these conflicting results are unclear. Medicare covers CRC screening at no-cost unless a polyp is detected, in that event, it is no longer considered screening and cost-sharing applies. About half of all participants in this study with a FDR with CRC reported polyps. It is possible that people are avoiding the procedure because of the anticipated out-of-pocket costs.

The concept of financial toxicity, the negative outcome that results from perceived 'subjective financial distress' and 'objective financial burden', has become widely accepted among people with cancer [20]. It puts patients with cancer at greater risk for medical non-adherence, the delaying, rationing, or foregoing of needed care in attempt to reduce costs [21]. I suggest that a similar phenomenon may be occurring here where people may be forgoing CRC screening because of the potential costs. Interestingly, the study did not observe an association between self-reported healthcare affordability issues and CRC screening. As the models also included health insurance coverage, Medicaid enrollment, and household income, all related to CRC screening and also likely to healthcare affordability, it is possible that these mediate the previously reported relationship [12].

Groups like the American Cancer Society advocate for eliminating cost-sharing associated with cancer screenings to improve adherence among those with more limited finances [22]. Sweden implemented universal free mammography for females age 40–74 in 2016; previously the charge was approximately \$23 US dollars on average. This resulted in statistically significant increases in adherence among females with the lowest incomes and in areas with higher cost sharing [23].

Another finding of the current study is that while Black Americans were more likely to be adherent to CRC than their white peers. This finding is inconsistent with earlier reports [15]. Interestingly, in the current study, among people with a FDR with CRC there was a trend for reduced adherence among Black Americans compared to Caucasians, but it was not statistically significant. A prior study found that among Black Americans, a familial history of CRC did not increase adherence rates, but did for all other racial groups [24]. In a post-hoc analysis, the current study found that Black Americans with a family history of CRC were more likely to be adherent to screening recommendations (70% compared to 61%; $p = 0.040$; data not shown).

Efforts to increase adherence in the Black and African American community in recent years seem to have been effective, possibly even more effective among those with a FDR with CRC. Additional efforts are

needed among members of other racial groups and the Hispanic community who still have lower rates. In particular, patient navigators, a specifically trained person who helps a person obtain medical care, are beneficial for increasing screening rates but availability is still limited and some patients are hesitant to use the services [25].

The association of lower CRC screening adherence among males who are FDRs of a person with CRC is novel. A prior study using the 2005 California Health Interview Survey had very contrary findings. The researchers reported that females who had a familial history of CRC (first- or second-degree relatives) were 17% less likely to be adherent than their male counterparts [26]. Among those without a family history of CRC, neither the current study nor the former found an association between gender and CRC screening adherence among the general population. Other studies regarding in the general population have reported mixed results [27]. Additional research is needed to clarify the inconsistent results and determine the causes of any gender-based disparities.

The strength of the study is its large and nationally representative sample. However, it is not without its limitations. All measures were patient self-report and may not reflect actual screening behaviors or other measures. As with all observational studies, causality cannot be assumed for the associations found. Additionally, the data was collected in 2015 and may not be representative of current trends. While the NHIS is now collecting data for the CCS annually with each survey, the content is rotating and rather limited. It is unclear if/when the colorectal screening behavior and family history modules will be collected concurrently in future years. Lastly, the study was conducted in the United States, a country without universal healthcare coverage, and findings may not generalize to other countries.

Despite these limitations, this study adds to limited, although growing, body of literature regarding the screening behaviors of FDRs of people with CRC. The data suggests that although FDRs of people with CRC are more adherent to screening recommendations than their peers, about one-quarter still are not. Additional outreach is needed to members of the Hispanic community and those who identify as a race other than Caucasian or Black. If these measures are designed to target those with FDRs with CRC, tailored communications to members of that group will likely be more effective than more general communications regarding CRC screening. There is also a need to increase accessibility of CRC screening as living under the poverty level, being uninsured, or enrolled on Medicaid were among the strongest predictors of adherence.

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