Factors associated with colorectal cancer risk perception: the role of polyps and family history

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Abstract

It is unclear how objective risk factors influence the factors associated with colorectal cancer (CRC) risk perception. The goals of this study were to investigate factors associated with perceived risk of CRC and to explore how these relationships were modified by personal history of polyps or family history of CRC. The study involved a mailed questionnaire completed by 1646 men and women aged 50-75 years, which assessed perceived risk, demographic and health history variables and CRC worry. Participants were patients of primary care providers in a community medical group in central Massachusetts. The study sample seemed to have a generally accurate perception of CRC risk, which was appropriately increased in the presence of known risk factors. In multivariable analyses that controlled for all measured covariates, financial situation modified the association between perceived risk and a personal history of polyps, while age and insurance status modified the association

¹Department of Epidemiology, Harvard School of Public Health, 677 Huntington Avenue, Boston, MA 02115, USA, ²Department of Public Health, School of Public Health and Health Sciences, University of Massachusetts, Amherst, MA 01003, USA, ³Division of Hematology/Oncology, Department of Medicine, University of Massachusetts Medical School, Worcester, MA 01655, USA and ⁴Center for Statistical Analysis and Research, New England Research Institutes, Watertown, MA 02472, USA *Correspondence to: J. R. Stark. E-mail: stark@hsph.harvard.edu between perceived risk and family history of CRC. CRC worry, self-reported health, personal history of other cancer and compliance with screening guidelines remained significant predictors of perceived risk. Potential interactions between objective risk factors and socioeconomic characteristics should be further explored in longitudinal studies.

Introduction

In the United States, colorectal cancer (CRC) accounts for 10% of cancer-related mortality and is the third most common cancer in terms of incidence [1]. However, the American Cancer Society (ACS) estimates that 90% of all CRC cases and associated deaths could be prevented by early detection and existing preventive measures [2]. According to the 2001 Behavioral Risk Factor Surveillance System, only 23.5% of respondents reported having a fecal occult blood test (FOBT) within the last 12 months and 38.7% reported a lower endoscopy test (sigmoidoscopy or colonoscopy) within the last 5 years [3]. When comparing screening prevalence rates in 2001 with those reported in 1997 and 1999, the average absolute annual rate of increase in adherence with guidelines has been $\sim 1-2\%$ [3]. At the current rate of adoption, it will take >10 years for national CRC screening rates to approach the 80% level reached by mammography [3].

A person's risk perception is thought to play a significant role in the adoption of precautionary health behavior and is incorporated into a number of health behavior models. According to the Health Belief Model, individuals are more likely to take action to prevent or control an adverse health condition if they perceive themselves to be susceptible to the condition [4]. Because there is general support for a positive relationship between perceived risk and both CRC screening utilization [5–9] and intention to be screened [10], understanding the factors associated with perceived risk may reveal important determinants of screening behavior and inform efforts that aim to accelerate the adoption of CRC screening.

Few studies have explored factors associated with perceived risk of CRC [11]. One study comparing high- and average-risk siblings of CRC patients [12] found few differences in screening rates other than that siblings of high-risk patients had somewhat higher rates of CRC screening. Another study focused on African-American patients of a community health center [13] and found that higher levels of perceived risk were positively associated with being male, smoking, a perception of poor comparative health and more accurate beliefs about CRC. A population-based study found that higher perceived risk of CRC was associated with having a family history of CRC, poorer selfreported health, bowel symptoms, feelings of anxiety, smoking and lack of exercise, while being male and being older tended to be associated with lower perceived risk [14].

Relatively little is known regarding how perceived risk for CRC may be modified by demographic and other factors. To explore how objective risk factors influence perceived risk of CRC, Vernon et al. used data from the Next Step Trial, a work site-based health promotion trial that involved a cohort of white male automotive employees, a group shown to be at increased risk for CRC [15–18]. The authors compared factors associated with perceived risk in men with and without a history of colon polyps [19]. In a cross-sectional analysis, perceived risk was positively associated with family history of colon polyps or cancer, familial support for screening and CRC worry among men both with and without polyps. In men without polyps, perceived risk was also positively associated with current smoking status. Given that all the study participants were male and at higher risk for CRC, it is unclear whether differences in objective CRC risk factors, such as polyp history or family history, would affect factors associated with risk perception in a more diverse community-based population. The goals of this study were to explore the factors associated with perceived risk for CRC in a primary health care population comprising men and women, and to determine how these associations are modified by a personal history of colorectal polyps or a family history of CRC.

Methods

This investigation used data from a communitybased randomized, controlled intervention study. The study protocol was approved by the Institutional Review Board of the University of Massachusetts Medical School. Using a provider encounters database, we identified a random sample of 3500 male and female patients aged 50-75 years who had visited one of the 39 participating primary care providers (PCPs) within the previous 2 years. Participating PCPs belonged to UMass Memorial Community Practices located in Worcester County, MA, USA. With the goal of obtaining 10% of patients with low incomes in the sample, we stratified by insurance type and over-sampled patients with free care, welfare, Medicaid, veteran's insurance and the neighborhood health plan, an insurance program for Medicaid-eligible patients. Participating PCPs were asked to exclude their own patients meeting the following criteria from the original recruitment pool: (i) life expectancy <3-4years; (ii) serious cognitive impairment; (iii) non-English speaking; (iv) not the PCP's patient; (iv) deceased or (vi) history of CRC, adenomatous polyps or other bowel diseases requiring more frequent screening. PCPs were given explicit instructions not to exclude patients who were up to date with CRC screening or who had refused CRC screening in the past. Patients with hyperplastic polyps were included in the sample. A total of 470 patients (13%) were excluded by the PCPs: 24 for limited life expectancy, 52 for cognitive impairment,

13 for not speaking English, 294 because they were not patients of the PCP, 31 because they were deceased, 18 for adenomatous polyps or history of CRC, 5 for other colon diseases and 33 for other reasons, including living in a nursing home or having relocated. Two of the physicians dropped out of the study during this phase, leaving 2934 patients of 37 physicians eligible to receive the mailed surveys.

Baseline survey distribution occurred in four monthly waves beginning in July 2002. All study participants were mailed a study packet that included an introductory letter mentioning the patient's PCP by name and signed by the study's principal investigator, a one-page study fact sheet that addressed patient confidentiality, a baseline survey, a postage-paid envelope for returning the survey and a refrigerator magnet with the UMass logo. A reminder postcard was sent 10 days after the initial mailing, and a second survey mailing was sent to all non-responders 2 weeks after the postcard mailing.

The 28-page optically scannable baseline survey contained a total of 92 questions and was divided into seven sections: personal information/health history, FOBT history and attitudes/beliefs, sigmoidoscopy history and attitudes/beliefs, colonoscopy history and attitudes/beliefs, double-contrast barium enema (DCBE) history, attitudes and beliefs regarding CRC and CRC screening in general and demographic information (marital status, race/ ethnicity, education level, health insurance and income/financial situation). The sections for FOBT, sigmoidoscopy, colonoscopy and DCBE each began with a brief description of the test. Questions that addressed the study objectives were selected from other validated CRC surveys. The survey was pretested for both content and format in a focus group of men and women. On average, the focus-group participants completed the survey in 25-30 min.

Perceived risk was measured by self-report on a validated two-item scale taken from the National Cancer Institute's Health Information National Trends Survey (HINTS) [20] and used previously in similar studies focused on mammography [21, 22]. The perceived risk items asked (i) 'What is the

chance that you will develop colon cancer in the future? very low; fairly low; moderate; fairly high; very high' and (ii) 'Compared with the average person your age, would you say that you are: more likely to get colon cancer, less likely or about as likely?' The responses for Question 1 were recoded as -1 for 'very low', 0 for 'fairly low', 1 for 'moderate', 2 for 'fairly high' and 3 for 'very high'; for Question 2, responses were recoded as -1 for 'less likely', 0 for 'about as likely' and 1 for 'more likely'. Because we wanted our perceived risk measure to incorporate a participant's perception of absolute risk of disease and his/her perception of individual susceptibility as compared with others, scores from Questions 1 and 2 were then summed to create an ordinal perceived risk score ranging from -2 to +4, with a score of 0 or 1 indicating an 'average' risk and -2 indicating a very low and +4 a very high perceived risk. A similar approach has been used previously [21].

All independent variables examined in relation to perceived risk were measured on the baseline survey. History of colon polyps was assessed by the following question: 'Polyps are lumps of tissue that grow in the colon and can develop into colon cancer over time. Have you ever been told by a doctor or nurse that you have one or more polyps? yes, no, don't know'. To obtain information on a family history of CRC, we asked 'Have any of your close blood relatives, that includes your parents, brothers, sisters or children, ever been told by a doctor or nurse practitioner that they had cancer of the colon or rectum? yes, no, don't know'. Patients were considered up to date with a single CRC screening test if they reported FOBT within the last year, sigmoidoscopy within the last 5 years, colonoscopy within the last 10 years or DCBE within the last 5 years. To be compliant with the ACS-preferred screening guidelines for averagerisk patients aged 50 and older [2], patients had to meet the single test criteria for colonoscopy, DCBE or the combination of both FOBT and sigmoidoscopy.

All analyses were carried out using the PC version of SAS Version 8 statistical software. For bivariate analyses, the associations of perceived

risk with the categorical explanatory variables were analyzed by the analysis of variance. To control for potential confounders and explore the interactions between the covariates and both personal history of polyps and family history of CRC, we conducted a linear least square regression analysis (analysis of covariance). Only participants with complete covariate data were included in the multivariable analysis (n = 1376). Although the outcome was a six-level ordinal variable, these methods are robust to departures from normality [23]. We included all potential covariates in the model, regardless of their statistical significance level in bivariate analyses, to explore the possibility of negative confounding and effect modification by polyps/ family history through the inclusion of multiplicative interaction terms. Based on our study hypothesis, we determined a priori that interactions would only be explored between the covariates and two objective risk factors-personal history of polyps and family history of CRC-to limit spurious associations due to multiple testing. Only statistically significant interaction terms were retained in the model. Statistical significance was determined by a *P*-value < 0.05.

Results

Of the 2934 mailed surveys, 23 patients refused survey participation and 149 patients were found to be ineligible (2 for cognitive impairment, 18 for history of CRC, 6 for not speaking English, 85 because they were not a patient of a participating PCP, 12 for having relocated, 3 for residing in a nursing home, 61 for incorrect addresses and 23 because the patient was deceased). A total of 1878 completed surveys were returned for a response rate of 67%. Individuals reporting a history of Crohn's disease, ulcerative colitis or inflammatory bowel disease (n = 86) and respondents who did not answer one or both of the perceived risk questions (n = 146) were excluded from the analysis. The remaining 1646 patients comprised the analysis sample. Eligible baseline survey responders were similar to the non-responders in terms of gender (55% female in both groups) and age (59.9 versus 61.4 years, respectively). The mean perceived risk score for the sample was 0.11 (range -2 to +4).

Background characteristics of the study sample are presented in Table I. Significant differences in mean perceived risk score were observed for a number of participant characteristics. Poorer self-reported health status (P < 0.0001), greater CRC worry (P < 0.0001) and lower income (P =0.04) were associated with higher perceived risk. Mean perceived risk score also differed significantly by a history of colon polyps (0.47 versus -0.01, P < 0.0001), a family history of CRC (1.01) versus -0.04, P < 0.0001), a personal history of another cancer (0.27 versus 0.08, P = 0.02) and less favorable financial situation (0.26 versus 0.08, P = 0.05). Level of education (P = 0.01) was also significantly associated with perceived risk. Less than half of the respondents overall were compliant with the ACS-preferred guidelines (Table I), and of those without a history of polyps or a family history of CRC only, 25% were compliant (data not shown). Participants who had been screened within the recommended interval had a significantly higher mean perceived risk score (0.37 versus -0.09, P < 0.0001).

Table II presents the adjusted mean perceived risk from a multiple regression model that controlled for all the covariates in Table I and contained interaction terms between the covariates and both a personal history of polyps and a family history of CRC. The 1376 participants with complete covariate data were included in the multivariate model. These patients were significantly more likely to be in the younger age category than patients not included in multivariate analyses (74.7% versus 64.8%, chi-square *P*-value < 0.01). Personal history of polyps was a marginally significant effect modifier of the association between financial situation and perceived risk ($P_{\text{interaction}} = 0.05$). Among patients without a history of polyps, a comfortable versus difficult financial situation appeared to have little impact on perceived risk (1.22 versus 1.23). However, among patients with a history of polyps, having a more favorable financial situation was associated with perceived risk level of 1.41, as

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Characteristic	% ^a	Average perceived risk score	Standard deviation	<i>P</i> -value
Age				
50-64	73	0.13	1.25	
65–75	27	0.05	1.13	0.20
Race				
White	94	0.11	1.21	
Non-white	6	0.11	1.37	0.99
Gender				
Male	43	0.10	1.19	
Female	55	0.12	1.25	0.79
Insurance stratum				
Low income	4	0.32	1.42	
Not low income	96	0.10	1.21	0.17
Education				
<hs grad<="" td=""><td>5</td><td>0.04</td><td>1.31</td><td></td></hs>	5	0.04	1.31	
HS grad	19	0.18	1.21	
Post-HS	28	0.17	1.23	
College grad	22	0.19	1.22	
Post-graduate education	25	-0.06	1.19	0.01
Financial situation				
Very comfortable/making ends meet	85	0.08	1.21	
Difficult to make ends meet/losing ground	13	0.26	1.25	0.05
Income				
<\$25K	14	0.28	1.27	
\$25K to <\$40K	16	0.14	1.24	
\$40K+	64	0.06	1.19	0.04
Marital status				
Married/living with partner	79	0.09	1.22	
Single	20	0.20	1.23	0.13
Personal history of colon polyps				
Yes	24	0.47	1.29	
No/do not know	74	-0.01	1.18	< 0.0001
Family history of CRC				
Blood relatives with CRC	14	1.01	1.37	
No/do not know	85	-0.04	1.13	< 0.0001
Self-reported health status				
Excellent	22	-0.09	1.29	
Very good	42	0.10	1.17	
Good/fair/poor	35	0.27	1.23	< 0.0001
Personal history of other cancer				
Yes	15	0.27	1.19	
No/do not know	83	0.08	1.22	0.02
Worry about CRC				
Very worried	2	1.93	1.61	
Somewhat worried	15	0.91	1.09	
Slightly worried	43	0.22	1.01	
Not worried	39	-0.44	1.14	< 0.0001
MD recommendation within 12 months				
Advised to have CRC screening	51	0.16	1.23	
Not advised to have CRC screening	48	0.06	1.22	0.10

Characteristic	% ^a	Average perceived risk score	Standard deviation	P-value
Frequency of medical checkups				
Every year or two	89	0.09	1.21	0.08
Less than every 2 years/only when problem	8	0.30	1.37	
Screening status: ACS-preferred guidelines				
Up to date with guidelines	43	0.37	1.13	
Not up to date with guidelines	57	-0.09	1.29	< 0.0001

HS grad, high-school graduate.

^aPercentages may not sum to 100 due to missing values.

opposed to a level of 1.85 among those reporting more financial difficulties. No other covariates appeared to interact with a personal history of polyps.

Family history of CRC appeared to modify the association between perceived risk and both age and low-income insurance stratum ($P_{\text{interaction}} <$ 0.01 for both). Among those with no family history, perceived risk level was similarly moderate in the two age groups. In both income strata, those with family history had higher perceived risk than those without a family history but the difference was greater for those in the low-income strata than the others. Age and insurance stratum were the only covariates that were modified by family history of CRC.

After controlling for other covariates, less favorable self-reported health status (P < 0.01), personal history of other cancer (P = 0.01), increasing worry about CRC (P < 0.0001) and being up to date with the ACS-preferred screening guidelines (P = 0.05) remained significantly associated with higher perceived risk. In addition, less frequent medical checkups and being up to date with the ACS-preferred screening guidelines appeared to be marginally associated with higher perceived risk (both P = 0.05).

Discussion

The overall goal of this study was to determine factors associated with perceived risk in a community-based survey of men and women, and to determine if predictors of perceived risk differed according to family history of CRC or personal history of polyps. It is concerning that although almost 90% of patients reported having a medical checkup every year or two, only half recalled receiving a recommendation for CRC screening within the last year and only 43% were up to date with the ACS-preferred guidelines. Furthermore, in individuals without both polyps and a family history, compliance with the preferred guidelines was just 25%.

The mean perceived risk score in the sample was 0.11, which represents an average perceived risk level based on our measure. As expected, a personal history of polyps and a family history of CRC were both associated with increased perceived risk in bivariate analyses. Both of these variables modified associations between perceived risk and sociodemographic characteristics in multivariate analyses. Being in the younger age group appeared to be associated with higher perceived risk, but only in patients with a positive family history of CRC. This inverse relationship between age and perceived risk is consistent with other studies [8, 19]. In fact, no study has reported perceived risk to increase with age [14] even though CRC risk is age related. Because of its cross-sectional design, our study was unable to directly evaluate potential changes in risk with age.

Education and income level were the only covariates that did not remain significant in multivariate analyses, suggesting that the associations between perceived risk and these factors were confounded by other covariates. However, other

Table II. Adjusted mean perceived risk with standard errors and	l P-values from multiple regression (n = 1376)
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1.41 1.85	0.18 0.24	
1.85		
1.85		
	0.24	
1.22		0.05^{b}
1.00		
1.00		
1.22	0.17	
1.23	0.18	0.05^{b}
2.29	0.28	
1.75	0.32	< 0.01 ^c
2.77	0.53	
1.27	0.13	0.01^{c}
0.82	0.12	
0.84	0.14	< 0.01 ^c
0.92	0.19	
		0.01^{c}
1.50	0.16	
		0.28 ^d
1.43	0.17	
		0.97 ^d
	0117	0.77
1.36	0.21	
		0.38 ^d
1.00	0110	0.00
1 38	0.17	
		0.67 ^d
1.10	0.17	0.07
1 40	0.17	
		0.44 ^d
1.10	0.10	0.11
1.28	0.18	
		< 0.01 ^d
1.50	0.17	\0.01
1.52	0.18	
		0.01 ^d
	2.29 1.75 2.77 1.27 0.82	2.29 0.28 1.75 0.32 2.77 0.53 1.27 0.13 0.82 0.12 0.84 0.14 0.92 0.19 0.74 0.11 1.50 0.16 1.36 0.20 1.43 0.17 1.36 0.21 1.43 0.17 1.36 0.21 1.47 0.18 1.49 0.18 1.44 0.18 1.35 0.18 1.44 0.17 1.44 0.17 1.44 0.17 1.44 0.18 1.28 0.18 1.44 0.17 1.52 0.18

Characteristic	Average perceived risk score ^a	Standard deviation	P-value
Worry about CRC			
Very worried	2.74	0.25	
Somewhat worried	1.57	0.18	
Slightly worried	0.99	0.17	
Not worried	0.41	0.17	< 0.0001 ^d
MD recommendation within 12 months			
Advised to have CRC screening	1.46	0.17	
Not advised to have CRC screening	1.40	0.17	0.27 ^d
Frequency of medical checkups			
Every year or two	1.33	0.17	
Less than every 2 years/only when problem	1.52	0.19	0.05^{d}
Screening status: ACS-preferred guidelines			
Up to date with guidelines	1.49	0.17	
Not up to date with guidelines	1.36	0.18	0.05^{d}

HS grad, high-school graduate.

^aMultivariable analysis adjusted for all variables listed in the table, as well as multiplicative interaction terms between history of polyps and financial situation and between family history and both age and insurance stratum. ^bP-value for test of interaction with history of polyps. ^cP-value for test of interaction with family history of CRC. ^dP-value for test of main effect.

measures of socioeconomic status, such as lowincome insurance stratum and financial situation, were modified by family history and history of polyps. Participants in the low-income insurance stratum had higher perceived risk among those with and without a family history of CRC, but the absolute levels and magnitude of the difference were greater in the family history group. Although this finding should be interpreted cautiously because there were only four patients with a family history of CRC who were also in the low-income insurance stratum, it is possible that lower income participants have more feelings of vulnerability because of limited access to care, and that the greatest increase in vulnerability is among those who are aware of their family history. Similarly, the differential effect of lower financial status on perceived risk among individuals with polyps could be related to health care access issues among a group who feel regular medical care is particularly important.

In this cross-sectional study, we cannot assess the temporal relationship between perceived risk and the covariates. The Health Belief Model suggests that higher perceived risk would lead to CRC screening utilization and subsequent detection of polyps [4]. However, existing data provide evidence that an understanding of certain screening outcomes and objective risk factors could also be acting on perceived risk. In a prospective study of automotive employees [19], perceived risk was lower among those with a normal screening test or no screening test during the study period. In addition, the current study and the work of Vernon et al. [19] suggest that family history, an objective risk factor which is unlikely to be a downstream consequence of perceived risk, was associated with higher perceived risk levels. Longitudinal studies are needed to disentangle the temporality of perceived risk and screening/polyp detection.

Without a universally accepted perceived risk measure, it is difficult to make direct comparisons across studies. We chose a validated two-item scale from the National Cancer Institute's HINTS [20] that asks individuals to assess their own likelihood of getting CRC in the future and then to compare their risk to others their age. Our qualitative measure was chosen based on the fact that it is often difficult for individuals to provide absolute risk estimates and, as a result, these types of estimations may not be accurate reflections of how an individual actually perceives his or her risk [24-26].

Further, our measure incorporated the patients' perceptions of their own lifetime risk of disease as well as how the risk compared with the risk of others. If someone thinks that a disease is rare, for instance, even if they are at average risk, they can think that it is very unlikely that they will get it. On the other had, they may understand the true disease prevalence but think that they themselves are particularly susceptible or protected. Both components of perceived risk are especially important in this analysis, given that we are comparing predictors of perceived risk according to objective risk factors.

Patients may have over- or underreported factors such as history of colon polyps or family history of CRC, which has been documented in other studies [27]. In addition, our reliance on self-report allowed us only to assess a history of polyps in general, despite the fact that different types of polyps (i.e. hyperplastic or adenomatous) are associated with different risks for developing CRC. At the beginning of the study, PCPs were asked to exclude patients with a history of adenomatous polyps or colon cancer. Therefore, we would assume that the majority of the polyps reported was non-adenomatous.

A recent study found self-reported CRC screening behavior to be reliable and that the accuracy of self-report did not vary by gender, age, ethnicity or family history of CRC [28]. However, it is common for patients to underestimate the time since their last screening exam [29–31], a phenomenon known as 'telescoping' [32, 33]. As a result, the number of patients determined to be compliant with the ACS-preferred guidelines may be overestimated. The effect of this misclassification would be an underestimate in the differences between perceived risk scores between these groups.

The response rate for the community-based survey was 67%. Responders who chose to complete the 28-page survey may have had higher levels of education and health/general literacy, greater interest in the subject of CRC screening, higher rates of CRC screening compliance and higher levels of perceived risk compared with nonresponders. Consequently, the relation between screening history and perceived risk may be overestimated. The population from which the study sample was drawn is \sim 90% white, highly educated and most often married/living with a partner, which will make it difficult to generalize results to individuals of different racial/ethnic background and socioeconomic status. Finally, this study did not examine other lifestyle factors known to influence risk perception, such as diet, smoking, physical activity and alcohol consumption [13, 19, 34–38].

This is the first study to investigate factors associated with perceived risk of CRC in a communitybased sample of men and women. A number of sociodemographic characteristics are associated with perceived risk, and socioeconomic measures appear to interact with objective CRC risk factors to influence perceived risk level. To inform efforts to accelerate the adoption of CRC screening, our results should be explored in longitudinal studies. In particular, future studies should aim to uncover the specific factors that may lead lower income patients aware of their objective CRC risk factors to have high levels of perceived risk. If health care access is the most important income-related factor associated with perceived risk, it is possible that a group of especially vulnerable patients is highly motivated to undertake CRC screening, given the appropriate logistical assistance.

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Conflict of interest statement

None declared.

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