Attitudes toward Colon Cancer Gene Testing: Survey of Relatives of Colon Cancer Patients[1]

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Abstract

Objectives. Various studies have identified psychosocial factors that may influence attitudes toward colon cancer gene testing. Whereas family history of colon cancer has been associated with interest in gene testing, this has not been examined extensively. We hypothesized that the strength of family history of colon cancer is associated with risk perception and willingness to undergo gene testing.

Materials and Methods. We evaluated attitudes toward colon cancer gene testing among persons who had at least one first-degree relative with colon cancer. A total of 2680 at-risk relatives in 863 kindreds were identified and mailed an extensive survey regarding sociodemographic variables, family history, health behaviors and knowledge, and willingness to take a colon cancer gene test. A total of 56.6% of persons completed and returned surveys. We conducted a brief telephone survey of a random sample of 200 persons who did not respond to the mail survey.

Results. The combined study sample of 1373 people was 42% male, had a mean age of 55 $\pm$ 15 years, was 96% white, and had moderate-to-high SES. A total of 77.4% were very likely to take the gene test, and 92.4% were somewhat or very likely to take the gene test. A total of 78% of the sample perceived a higher colon cancer risk, although patterns of risk perception and worry differed significantly between mail survey and telephone survey respondents. More of the telephone survey respondents were also somewhat unlikely or very unlikely to take the gene test compared to the mail survey respondents (13.7% *versus* 6.9%). In the combined sample, concern about developing colon cancer and risk perception increased with number of relatives with colon cancer ($P < 0.0001$). Eight percent expressed no concern about developing colon cancer; 4.8% felt their chance of developing colon cancer was lower than others of the same age, sex, and race; and 3.3% felt that they were very unlikely to develop colon cancer in their lifetime. However, there was strong interest in gene testing regardless of the number of affected relatives, and persons with more affected relatives were generally willing to pay more for the gene test (up to $1000).

Conclusions. The strength of family history of colon cancer is associated with risk perception but not with willingness to undergo gene testing.

Introduction

In the last decade, the main emphasis of cancer genetics research has been gene discovery, identification of causal mutations, and elucidation of molecular mechanisms. The concomitant implications for clinical translation of the discoveries have led to intense public interest in cancer gene testing. In particular, the recent phenomenal increase of discoveries related to the genetic and molecular basis of colon cancer has spawned efforts to apply them clinically, primarily in the form of gene tests that can reveal constitutional or hereditary predisposition to colon cancer (1–5). These efforts are directed to clinical and cancer prevention goals that will improve the management of colon cancer families, the identification of high-risk persons, and the development of effective interventions.

A variety of studies have found that there is great interest in cancer genetic testing across all risk groups, whether for breast, ovarian, or colon cancers (6–15). Studies among first-degree relatives of colon cancer patients have found that the majority probably or definitely want genetic testing. However, when limited to those who definitely want testing, there are differences in the results. Lerman *et al.* (14) reported that 51% of 45 first-degree relatives of colorectal cancer patients would definitely want genetic testing, whereas Glanz *et al.* (15) found this to be the case for 26% of 426 relatives.

Cancer risk perception is increased among those with a positive family history, and these individuals may be more likely to choose genetic testing to learn more about their cancer risk (8–9, 11, 13). Generally, those with a family history of a given disorder are more likely to engage in disease prevention behaviors for that disorder (16–18). Adherence with screening recommendations after genetic testing is likely to be associated with pre-gene testing screening behavior (16–19) and with previous symptoms suggestive of cancer (20). Indeed, studies assessing attitudes toward gene testing have found that intention was associated with health-protective behaviors (6–10, 12, 14).

In an ongoing colon cancer gene testing study, we have observed that colon cancer risk perception among 62 adults was increased but did not correlate well with objective measures of risk, such as family history or personal history of adenomatous polyps (21). Rather, risk perception appeared to be correlated with closer personal exposure to affected relatives, cancer worry, and younger age. In this and the companion paper by Codori *et al.* (22), we report a two-pronged examination of attitudes and hypothesized factors that influence the uptake of

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colon cancer genetic testing among the group most likely to be offered or to consider genetic testing or preventive interventions: first-degree relatives of patients with colon cancer. In this report, using mail and telephone surveys, we studied persons who had one or more relatives with colorectal cancer. In the companion study (Codori *et al.*; Ref. 22), we studied in more depth the factors associated with the uptake of testing in at-risk individuals who are actually offered gene testing for hereditary colon cancer.

The purpose of the present study was to examine the relationship between family history, risk perception, and interest in colon cancer gene testing. It would be appropriate for persons who have a positive family history to have increased risk perception because a number of epidemiological studies have shown that colon cancer risk is increased 2- to 3-fold in persons with a family history of colon cancer (23, 24). Indeed, in 1997, the American Cancer Society and American Gastroenterology Association introduced family history as a risk factor category, warranting screening guidelines that differ from those for the average-risk population (25, 26). We conducted a survey of attitudes toward colon cancer gene testing among persons who were members of families in which colon cancer occurred. We hypothesized that the strength of family history experience of colon cancer is associated with risk perception and willingness to take a colon cancer gene test.

Materials and Methods

Subjects. This protocol was reviewed and approved by the Institutional Review Board of the Johns Hopkins Medical Institutions. The potential subjects for the survey were identified from family histories provided by individuals (probands) from three sources: (*a*) persons who expressed interest in colon cancer genetic research and who had contacted the Johns Hopkins Hereditary Colorectal Cancer Registry over the past decade. The majority of these persons live across the United States, with a small proportion residing in foreign countries; (*b*) colon cancer patients listed in the Johns Hopkins Hospital Tumor Registry from 1990–1996. Most of these patients live in the eastern half of the United States; and (*c*) patients in Johns Hopkins Hospital gastroenterology clinics who were undergoing colonoscopy for a variety of indications, only a few of whom actually had colon cancer or a family history of colon cancer. Most of these patients live in the mid-Atlantic region of the United States. Eligibility for this study was defined as adult persons without a personal history of colorectal cancer who had at least one first-degree relative with colorectal cancer. The majority of pedigrees and diagnoses in affected relatives had been previously documented by the Johns Hopkins Hereditary Colorectal Cancer Registry staff.

Letters describing the study were sent to 1662 individuals from these sources to ask them to participate and/or to identify and permit us to contact family members who had at least one first-degree relative with colon cancer. Fig. 1 illustrates the sources and flow of subject sources. A total of 668 of the 1662 contacted probands responded with names and addresses of family members who they reported as meeting our eligibility criterion. The Hereditary Colorectal Cancer Registry had previously obtained permission from 195 probands to contact their relatives; therefore, the number of potential subjects would be derived from 863 kindreds.

Mail Survey. A total of 2720 surveys were mailed between May and October 1996. Of the mailed surveys, only 40 were returned because of wrong addresses or information, leaving a total of 2680 surveys that were delivered. Of this group, 1200 persons returned completed surveys within a month; 65 declined to complete the form. A reminder postcard was mailed to 1360 persons who did not respond (55 were not sent a reminder due to a clerical error), and 318 people returned surveys in response to the postcard, whereas 34 people declined. Thus, a total of 1063 persons did not respond to either mailing, and a total of 1518 persons completed and returned surveys.

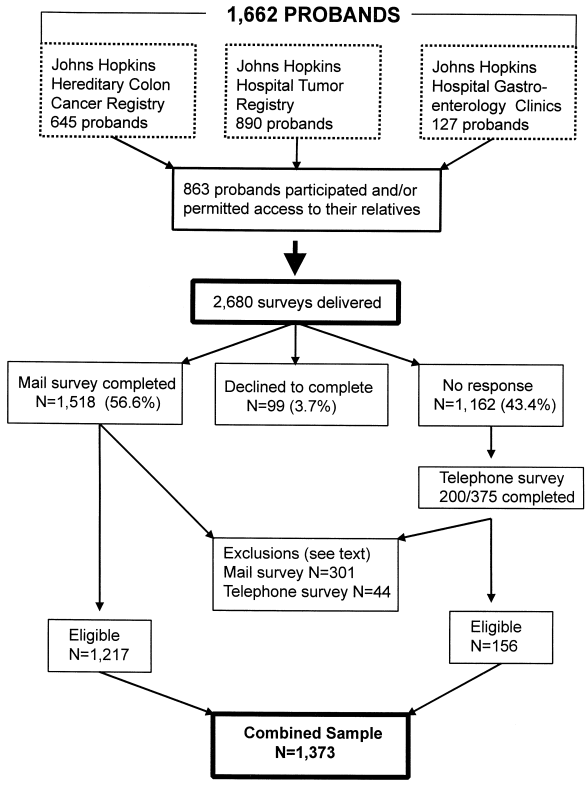

Fig. 1. Flow diagram of sources of subjects for study and the final study sample. For this analysis, we excluded the following respondents: (*a*) those who reported a personal history of colorectal cancer; (*b*) those under the age of 18 years; (*c*) those who did not live in the United States; and (*d*) those who reported no first-degree relatives with colon cancer.

There was no overlap between the subjects of this study and the acceptors who participated in the colon cancer gene testing study reported in Codori *et al.* (22). Subjects recruited for the gene testing uptake study (22) were in pedigrees in the Johns Hopkins Hereditary Colon Cancer Registry specially set aside for that study. These pedigrees were not used for recruiting into the mail survey (this study). Only when potential subjects declined to be in the gene testing study (22) were they invited to complete a mail survey. Therefore, 70 persons who declined to participate in the companion study were offered the opportunity to complete the mail survey. Of the 35 who completed the mail survey, 29 were included in the final survey sample.

The vast majority of persons who received surveys had never before participated in research of this type. The mailing consisted of a cover letter describing the study, a consent form, and a 30-page survey (entitled "Colon Cancer and Genetic Testing: A Confidential Survey of Your Opinions, Beliefs, Concerns, & Experiences") containing 62 questions encompassing 250 items related to sociodemographic medical history variables (age, sex, race, education, income, religion, religios-

Table 1 Demographic and other characteristics of sample

Unless otherwise specified, characteristics between the mail survey responders and the telephone interview sample were not significantly different.

	Mail survey	Telephone survey
n	1217	156
Male (%)	41	47
Mean age ± SD (yr)	54.5 ± 14.7	55.1 ± 14.5
Race (%)		
White	96.9	91.9
Black	0.9	3.4
Hispanic	0.2	2.0
Asian	1.1	2.0
Other	0.8	—
Highest education level (%)		
No high school diploma	1.5	[a]
High school graduate	10.5	
Some college	25.7	
College graduate	32.1	
Graduate degree	28.4	
Household income last year (before taxes) (%)		
Less than $20,000	7.3	9.8
$20,000 to $35,000	13.3	15.4
$35,001 to $50,000	17.4	14.0
$50,001 to $75,000	24.4	23.1
More than $75,000	37.7	37.8
Current health (%)		
Excellent	42.4	51.6
Good	49.9	39.6
Fair	7.0	8.1
Poor	0.7	0.7
Ever had a colonoscopy examination (%)[b]		
Yes	60.2	49.4
No	39.8	50.6
No. of first-degree relatives with colon cancer (%)		
One	79.4	84.0
Two	16.4	14.1
Three or more	4.3	1.9

[a] The telephone interview did not include this item.
[b] $P < 0.006$.

ity, and personal and family history of cancer), health behaviors and knowledge (prior colonoscopy screening, sources of information, colon cancer risk perception, concerns, and attitudes), willingness to take a colon cancer gene test and related factors (affordability, insurance, and children), and experiences with cancer in the family. Family history of colon cancer was assessed by a series of questions to which respondents were asked to mark boxes for yes/no/don't know (including "Has your mother ever had colon cancer?" and "Has your father ever had colon cancer?") and to fill in a number in response to the following questions: (*a*) "How many of your children have had colon cancer?" (*b*) "How many sisters have had colon cancer?" (*c*) "How many brothers have had colon cancer?" and (*d*) "How many other relatives have had colon cancer?" We did not attempt to validate the accuracy of these self-reported family histories.

Because opinion on genetic testing was the primary focus of this survey, a description of the test was included before asking subjects about likelihood of taking the gene test: "The Colon Cancer Gene Test uses a small sample of your blood to tell if you have certain colon cancer genes in your body. If you have any of these genes, you have a higher-than-average chance of getting colon cancer. About 80% of people with these genes will get colon cancer sometime in their life. The Colon Cancer Gene Test does *not* tell if you have cancer now. It tells if you have a high *chance* of getting colon cancer. Right now, the main thing you can do if you have the colon cancer gene is have a doctor check your colon regularly to make sure you don't have cancer or to find it if it is there. Doctors may soon discover other things you can do to prevent colon cancer."

Telephone Survey of Nonresponders. Because of our concern that the persons who completed and returned the mail survey (responders) would be more likely to be interested in genetic testing, we conducted a telephone survey of a random sample of those 1063 persons who did not respond (nonresponders) and asked them to complete a brief 5-min interview to characterize their interest in genetic testing. The questions were a subset of those asked in the mail survey and covered basic demographic information (age, sex, and race), health behavior questions, colon cancer risk perception, and interest in gene testing.

A target sample size of 200 was based on calculations assuming power (β) of 0.8, significance level (α) of 0.05, and a responder:nonresponder ratio of 1:7, using a dichotomous response (yes/no) for the variable "Has ever had a colonoscopy exam." This variable was selected because we hypothesized that this health-seeking behavior would be a discriminator, because colonoscopy is included in widely known recommendations for colon cancer screening in this at-risk population. A preliminary analysis of the mail survey revealed that the mean age of respondents was 54.5 years, and approximately 60% had had a colonoscopy. We hypothesized that 50% of nonresponders would have had a colonoscopy. A random sample of 600 nonresponders was generated by a program written in C++ that used the computer clock time as the random seed. Ninety-nine individuals selected by computer randomization could not be contacted because no correct phone number could be found by using directory assistance or Internet locator sites.

Using the generated sample list of nonresponders for whom telephone numbers were available, telephone interviews were sequentially attempted until a total of 200 interviews were completed. Six attempts were made at various times of day and various days of the week over a period of several weeks. If an individual could not be reached after at least six attempts, the next person on the generated list was contacted. A total of 375 people were contacted to complete 200 interviews (53.3%). Seventy-six persons (20.3%) refused the interview, 90 (24%) individuals could not be reached after six or more attempts, and 9 (2.4%) were unable to complete the interview due to illness or other health reason.

Postsurvey Exclusions. Surveys were mailed to all relatives whose names and addresses were provided by the proband. However, we were unable to verify before mail or telephone surveys that the persons whose names were provided to us were adults or first-degree relatives of patients with colon cancer. For the purpose of this analysis, we excluded the following respondents: those who reported a personal history of colorectal cancer, those under the age of 18 years, those who did not live in the United States, and those who reported no first-degree relatives with colon cancer. Based on these criteria, a total of 301 surveys and 44 interviews were excluded. The final sample used in this analysis consisted of a total of 1373 completed surveys ($n = 1217$) and interviews ($n = 156$). The individuals who completed the surveys were members of a total of 650 kindreds.

Data Analysis. All returned surveys and interview data were coded and entered by double entry verification into a data set using Epi-Info 6 (Centers for Disease Control-WHO). Database

Table 2 Concern about colon cancer risk

A. Compared to most people of your same age, sex, and race, what do you think your chances are of getting colon cancer sometime in your life?[a]	Mail survey (%)	Telephone survey (%)	Total (%)
I have a much higher chance	448 (37.9)	35 (23.3)	481 (36.1)
I have a little higher chance	488 (41.2)	69 (46.0)	557 (41.8)
I have about the same chance	199 (16.8)	29 (19.3)	228 (17.1)
I have a little lower chance	31 (2.6)	11 (7.3)	42 (3.1)
I have a much lower chance	18 (1.5)	6 (4.0)	24 (1.8)
Total	1184	150	1334

B. During the past month, how often have you thought about your chances of getting colon cancer?[b]	Mail survey (%)	Telephone survey (%)	Total (%)
Not at all or rarely	528 (44.5)	108 (70.1)	636 (47.4)
Sometimes	526 (44.3)	34 (22.1)	560 (41.8)
Often	100 (8.4)	10 (6.5)	110 (8.2)
A lot	33 (2.8)	2 (1.3)	35 (2.6)
Total	1187	154	1341

C. How likely do you think it is that you will get colon cancer sometime in your life?[c]	Mail survey (%)	Telephone survey (%)	Total (%)
Very likely	172 (15.0)	11 (7.5)	183 (14.1)
Somewhat likely	703 (61.1)	68 (46.6)	771 (59.5)
Somewhat unlikely	140 (12.2)	30 (20.5)	170 (13.1)
Very unlikely	37 (3.2)	6 (4.1)	43 (3.3)
I have no feeling or opinion on my chances of getting colon cancer	98 (8.5)	31 (21.2)	129 (10.0)
Total	1150	146	1296

[a] Mail *versus* telephone, $\chi^2 = 23.0$; $P < 0.001$.
[b] Mail *versus* telephone, $\chi^2 = 36.8$; $P < 0.001$.
[c] Mail *versus* telephone, $\chi^2 = 37.9$; $P < 0.001$ (excluding no opinion category).

management and data analyses were conducted with Paradox (Borland) and SPSS for Windows (SPSS Inc.). Descriptive statistics were generated on data from mail and telephone survey responders for most comparisons. Because few relevant differences were found between the two groups, the data were pooled to test the main hypotheses of the association of family history with cancer concern, risk perception, and willingness to take a colon cancer gene test. Family history was quantified using the total number of relatives with colon cancer reported by the respondent (1, 2, 3, or 4 or more).

Comparisons were performed by *t* tests, χ^2 statistics, and ANOVA. Multivariate stepwise regression analysis was performed to examine factors that were associated with persons who indicated "very likely," compared to all others, in response to the question on willingness to take the colon cancer gene test for free. Independent variables examined included age, sex, telephone *versus* mail group, concern about colon cancer, colon cancer risk perception, income, health perception, and whether the subject had ever had a colonoscopy examination.

Results

Demographic Analysis of Sample. Fig. 1 illustrates how the final, combined sample was derived, and Table 1 lists characteristics of our sampled groups. The mean age was 54.5 ± 14.7 years (SD), 41% were male, and the sample was overwhelmingly white (96.9%). This sample was highly educated and had moderate-to-high household incomes (over 60% were college graduates and had total household income levels of $50,000 or more). In general, this was a group in good health; 60.2% had had at least one colonoscopy screening examination.

Among the 1162 persons who did not return mail surveys, 962 persons did not participate in this study at all. We had no information on these persons other than inferring from information provided by probands that 51% were male. We found no differences between the mail survey and telephone survey groups with respect to sex, mean age, race, or household income (Table 1). Although not significantly different from the mail survey responders, more of the telephone survey responders perceived themselves to be in excellent health, but significantly fewer had had a screening colonoscopy examination. With respect to family history, the majority of both samples had only one first-degree relative with colon cancer; more of the mail survey group had two or more relatives with colon cancer, but this difference was not statistically significant.

Colon Cancer Risk Perception and Worry. In this study, we asked about colon cancer risk perception and worry in multiple ways. Several patterns emerged with respect to perceptions in the overall sample and differences between the two sampled groups (mail survey and telephone survey groups). The patterns were consistent across measures of risk perception. As shown in Table 2A, 78% of the overall sample perceived their chance of developing colon cancer to be higher than that of other people of the same age, sex, and race. However, a significantly greater proportion of the telephone group (30.6%) thought that they had the same or lower chance of developing colon cancer compared to the mail group (20.9%).

Table 3 Knowledge and likelihood of taking a colon cancer gene test

A. Before you answered the questions on this survey, how much had you read or heard about gene testing for colon cancer?[a]

	Mail survey (%)	Telephone survey (%)	Total (%)
A lot	61 (5.1)	17 (11.0)	78 (5.8)
A fair amount	297 (24.8)	27 (17.4)	324 (23.9)
Only a little	550 (45.9)	69 (44.5)	619 (45.8)
Nothing	290 (24.2)	41 (26.5)	331 (24.5)
Total	1198	154	1352

B. If you could take the colon cancer gene test for free, how likely is it that you would take the test?[b]

	Mail survey (%)	Telephone survey (%)	Total (%)
Very likely	925 (78.7)	98 (67.1)	1023 (77.4)
Somewhat likely	170 (14.5)	28 (19.2)	198 (15.0)
Somewhat unlikely	53 (4.5)	11 (7.5)	64 (4.8)
Very unlikely	28 (2.4)	9 (6.2)	37 (2.8)
Total	1176	146	1322

[a] Mail *versus* telephone, $\chi^2 = 19.4$; $P < 0.001$.
[b] Mail *versus* telephone, $\chi^2 = 13.3$; $P = 0.004$.

Table 2B shows that 10.8% of the overall sample think about their risk of colon cancer often or a lot. However, a large majority of the telephone survey group, 70.1%, thought rarely or not at all about their chances of getting colon cancer in the previous month, compared with 44.5% of the mail survey group. The same pattern of risk perception is seen in Table 2C, in which 83.1% of the mail survey group who had an opinion thought that it was somewhat or very likely that they would develop colon cancer, whereas 68.7% of the telephone survey group thought this way. Indeed, 21.2% of the telephone survey group had no feeling or opinion regarding their chance of getting colon cancer compared to 8.5% of the mail survey group.

Knowledge and Likelihood of Taking a Colon Cancer Gene Test. Few of the subjects in this study had read or heard a lot about gene testing for colon cancer before receiving the survey. The majority of the overall sample, 70.3%, had known only a little or nothing. Twice as many members of the telephone survey group indicated that they had read or heard a lot, compared to the mail group (11% *versus* 5%; Table 3A).

The majority of all persons surveyed, 77.4%, were very likely to take the gene test if it were offered for free (Table 3B), and an aggregate 92.4% were somewhat or very likely to take the gene test. More members of the telephone survey group were somewhat unlikely or very unlikely to take the gene test compared to members of the mail survey group (13.7% *versus* 6.9%).

Relationship of Family History to Attitudes toward Colon Cancer Gene Testing. We analyzed the relationship of family history to cancer risk perception and attitudes toward colon cancer gene testing separately in the mail survey and telephone survey groups and observed similar patterns of responses; therefore, data on the combined sample are shown in Table 4. We measured strength of family history by the number of relatives with colon cancer. In general, concern about developing colon cancer and risk perception (measured in two ways) increased with the number of relatives with colon cancer (Table 4A).

Although family history was associated with attitudes toward gene testing, it was not associated with the likelihood of taking a colon cancer gene test if it were offered for free (Table 5A). Regardless of the number of first-degree relatives with colon cancer, there was strong interest in gene testing. When persons were asked how much they were willing to pay for the colon cancer gene test, there was an association with family history (Table 5B). That is, more persons with multiple relatives with colon cancer were willing to pay more (up to $1000) for the gene test.

Multivariate Analysis. When we examined family history, risk perception, and willingness to undergo gene testing in a multivariate regression analysis that included demographic characteristics and the responder group (mail survey *versus* telephone survey), we found that only two variables, concern about developing colon cancer and female sex, were associated with willingness to have the colon cancer gene test ($P < 0.001$). Previous colonoscopy examination ($P = 0.054$) and perception of risk compared to others were marginally associated with willingness to take a gene test ($P = 0.084$). All other variables, including family history and the responder group, were not significant.

Discussion

The purpose of this study was to evaluate attitudes toward colon cancer gene testing among persons who had at least one first-degree relative with colon cancer because family members of colon cancer patients may be among the first to benefit from the development of predictive genetic testing. We found that the majority of persons in this study had appropriate increased perceptions of risk of colon cancer, but that this risk was not thought about often. This was largely a middle-aged group of individuals who considered themselves to be in good health and who engaged in cancer prevention behavior (the majority had had at least one screening colonoscopy). Whereas this group had not read or heard much about colon cancer gene testing, the vast majority (92.4%) would be likely or very likely to take the test.

We found that there was a linear relationship between cancer concern and risk perception and increasing numbers of first-degree relatives with colon cancer, but surprisingly, interest in gene testing was high regardless of the number of relatives with colon cancer (Table 5A).

From a clinical genetics risk assessment perspective, the disjunction between the strength of colon cancer family history and interest in genetic testing may be an advantage. Whereas such persons may seek or be willing to be referred for genetic risk assessment, they may not necessarily benefit from undergoing genetic testing for a variety of reasons (current gene testing technology, clinical sensitivity may be low, or the family history does not warrant gene testing for known syndromes). However, because persons who have a family history of colon cancer are recommended to undergo colon screening at an earlier age than the general population (25, 26), such persons may benefit from educational and genetic counseling alone. Conversely, persons with family histories that do not suggest genetic syndromes may have potentially exaggerated perceptions of cancer risk and can be appropriately counseled. It is also of concern that there are individuals who perceive the same or lower chance of getting colon cancer than others of the same age, sex, and race but are at much greater risk and do need risk counseling. It will be important to identify the factors, whether psychological, medical, or social, that shape this lowered risk perception.

Table 4 Relationship of family history to attitudes toward colon cancer gene testing

Column percentages are given in parentheses. Analyses are based on the combined sample.

A. How concerned are you about getting colon cancer?[a]

	No. of relatives with colon cancer				
	1	2	3	4 or more	Total
Extremely concerned	48 (10)	43 (11)	41 (15)	33 (17)	165 (12)
Moderately concerned	164 (34)	150 (38)	109 (40)	99 (51)	522 (39)
Mildly concerned	205 (43)	165 (42)	106 (39)	60 (31)	536 (40)
Not at all concerned	60 (13)	33 (8)	17 (7)	3 (2)	113 (9)
Total					1296

B. Compared to most people of your same age, sex, and race, what do you think your chances are of getting colon cancer sometime in your life?[b]

	No. of relatives with colon cancer				
	1	2	3	4 or more	Total
Much higher chance	110 (23)	135 (35)	123 (45)	113 (58)	481 (36)
Somewhat higher	206 (43)	179 (46)	111 (41)	63 (32)	557 (42)
About the same	126 (27)	57 (15)	29 (11)	16 (8)	228 (17)
Somewhat lower	20 (4)	15 (4)	6 (2)	1 (1)	42 (3)
Much lower chance	14 (3)	5 (1)	3 (1)	2 (1)	24 (2)
Total	476	391	272	195	1334

C. How likely do you think it is that you will get colon cancer sometime in your life?[c]

	No. of relatives with colon cancer				
	1	2	3	4 or more	Total
Very likely	37 (8)	44 (12)	54 (21)	48 (25)	183 (14)
Somewhat likely	246 (54)	238 (62)	164 (62)	123 (63)	771 (60)
Somewhat unlikely	91 (20)	49 (13)	18 (7)	12 (6)	170 (13)
Very unlikely	19 (4)	12 (3)	8 (3)	4 (2)	43 (3)
I have no feeling or opinion on my chances of getting colon cancer	62 (14)	39 (10)	20 (8)	8 (4)	129 (10)
Total	455	382	264	195	1296

[a] Linear $\chi^2 = 38.1$; $P < 0.0001$.
[b] Linear $\chi^2 = 93.3$; $P < 0.0001$.
[c] Linear $\chi^2 = 58.1$; $P < 0.0001$.

Among the strengths of this study is the way in which the study sample was selected. The population that was identified for the mailed survey were persons who represented a risk group that would most likely be among the first to be targeted for future genetic testing. The persons to whom surveys were mailed were, in the vast majority of cases, unaware of our study until they received the survey and had not participated in research of this type before. We believe the fact that the majority of persons responded to the mail survey (57%) reflects the novelty of the issue and the specific personal interest of this group.

Another strength of the sample construction is that we were able to evaluate the potential sources of bias among the responders by a surveying a sample of the mail nonresponders. Because of the likelihood of strong interest in gene testing among voluntary responders to a mail survey, we felt it was essential to include this component. Indeed, we found that persons who did not respond to the mail survey did have lower risk perception and rarely thought about their risk for colon cancer, compared to those who did return the mail survey. Whereas fewer members of the telephone survey group stated that they were very likely to take the gene test compared to the mail survey group, the majority of the telephone survey group (67%) still indicated that they were very likely to take the test. This finding has implications for voluntary studies that survey attitudes toward gene testing. Generally, those persons with lower cancer risk perception may be less likely to respond. However, even among persons who do not respond, there appears to be substantial interest in gene testing. Another interesting finding among this group was that a higher proportion of the telephone survey group felt that they knew a lot about gene testing.

A limitation of this study is that it is a fairly homogeneous sample with respect to race, socioeconomic status, and preventive health behaviors. Three other limitations of this study are related to the way in which the sample was constructed: (*a*) almost one-half of the probands from the Johns Hopkins sources did not provide the names of relatives for this study, so that the extent to which the findings can be generalized is unknown; (*b*) different methods (*i.e.*, mail and telephone) were used to collect data, and these were based on different initial response status. Although survey research has shown that these methods generally produce comparable data when respondents are randomly or systematically assigned to one method or the other, this may not be the case when the initial response status itself determines the data collection method; and (*c*) it was possible in this study that multiple respondents from the same family might bias the observed associations due to shared

Table 5 Attitudes toward colon cancer gene testing and cost of test by family history

Column percentages are given in parentheses.

A. If you could take the colon cancer gene test for free, how likely is it that you would take the test?[a]

	No. of relatives with colon cancer				
	1	2	3	4 or more	Total
Very likely	338 (73)	312 (79)	222 (82)	151 (79)	1023 (77)
Somewhat likely	86 (18)	57 (15)	31 (11)	24 (13)	198 (15)
Somewhat unlikely	27 (6)	12 (3)	12 (4)	13 (7)	64 (5)
Very unlikely	14 (3)	13 (3)	7 (3)	3 (1)	37 (3)
Total	465	394	272	191	1322

B. How much would you be willing to pay for the colon cancer gene test if it was not offered for free?[b]

	No. of relatives with colon cancer				
	1	2	3	4 or more	Total
0–$50	275 (61)	177 (47)	125 (47)	84 (46)	661 (51)
$100–$200	146 (32)	171 (45)	106 (40)	75 (41)	498 (39)
$500–$1,000	22 (5)	22 (6)	28 (11)	20 (11)	92 (7)
$2,000 or more	11 (2)	11 (3)	8 (3)	5 (3)	35 (3)
Total	454	381	267	184	1286

[a] P = nonsignificant.
[b] Linear $\chi^2 = 16.2$; $P < 0.0001$.

familial experiences. In our sample, 315 persons represented the sole respondent from their respective kindred. Of the 650 kindreds represented in this sample, 335 contained two or more respondents, with one family having 12 respondents, and the mean number of respondents/kindred was 3.2. However, it was not possible to know how closely related the respondents from the same family were (*e.g.*, whether they were siblings or distant cousins). Because of the large number of kindreds represented in the sample, it is unlikely that the incorporation of kindred membership into the analysis would be meaningful.

The importance of this study is that persons at risk are indeed interested in at least one method to assess their risk of colon cancer, *i.e.*, genetic testing. By virtue of being a relative of a patient with colon cancer, this group of individuals might benefit from following recommended colon cancer screening guidelines for this risk category (25, 26). One of the hopes of colon cancer genetic testing is that it would identify those who are at even higher risk, to whom more intensive surveillance might be offered. Although this study examined the attitudes of at-risk persons toward a hypothetical free gene test for colon cancer, it is important to understand how such persons might respond when actually presented with this opportunity. This issue is addressed in our companion study (22).

In summary, we present the results of a study that tests a hypothesis about the relationship between the strength of family history of colon cancer, risk perception, and interest in colon cancer gene testing in a group of at-risk relatives. We found that colon cancer risk perception is generally high in this sample and that more persons expressed high cancer risk perception and concern with increasing numbers of first-degree relatives with colon cancer. However, the likelihood of taking a gene test for colon cancer is not related to the number of first-degree relatives with colon cancer; in fact, interest is high in the entire sample, regardless of the number of affected relatives.

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