

Attitudes toward Genetic Testing for Colon Cancer Risk

ABSTRACT

This study examined public interest regarding genetic testing for colon cancer susceptibility. Survey data were collected from 383 adults in Utah. Respondents were very (47.3%) or somewhat (36.6%) interested in taking this genetic test. Nearly 95% reported that they would share their results with others. Individuals with higher income and with a perceived risk of getting colon cancer were the most interested in testing. Individuals without health insurance and widowed individuals were the least likely to share their test results. If respondents were told that they carried a gene for colon cancer, most would be concerned with how to reduce their risk of getting the disease. (*Am J Public Health*. 1995;85:1435-1438)

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Introduction

It is now possible for individuals to be tested for genetic susceptibility to certain types of breast, colon, and ovarian cancers.¹⁻³ To date, the availability of such testing has been limited. Relevant research and government organizations recommend that testing for most cancer genes (or their markers) be restricted to research samples that examine the psychosocial, ethical, or legal effects of communicating this type of risk information.^{4,5} Although most genetic testing for cancer susceptibility has been conducted with individuals in high-risk families, population screening for such susceptibility may be possible once the relevant genes have been sequenced and cloned provided that the test can accurately distinguish disease-causing mutations from other polymorphisms. At this time, it is useful to consider public attitudes concerning genetic testing and the demands they may place on genetic testing services.

The purpose of this study was to examine more thoroughly who might be interested in taking a genetic test for colon cancer susceptibility, whether individuals would share the information with anyone if they were found to carry the gene, and what factors might affect their interest in and attitudes toward genetic testing.

Methods

Random-digit dialing methods were used to identify a sample of 383 Utah adults 18 years of age or older. The sample was based on a cooperation rate of 80.6% (i.e., the survey was completed by a household member for four of every five working residential numbers called). A telephone interview was conducted with a randomly selected adult within the household. Interviewers used computer-assisted telephone interviewing software in a centralized interviewing facility supervised by the University of Utah Survey Research Center.

The survey instrument included a series of questions about genetic testing beginning with a general query about

respondents' interest in a blood test that could determine whether they were at an increased risk for colon cancer. Respondents were also asked whether they would discuss their results with anyone (and with whom) if the results were positive. All respondents were asked about their concerns about the test whether or not they expressed interest in taking the test. Information on sociodemographic and family characteristics was also collected. About half the sample was composed of active members of the Church of Jesus Christ of Latter Day Saints (Mormons). Mormons and non-Mormons in this sample did not differ in their attitudes toward genetic testing. The data were weighted so that the sample mirrored the characteristics of the state in terms of sex, age, and region.

Results

Most respondents were either very interested (47.3%) or somewhat interested (36.6%) in taking a genetic test for colon cancer; only 16.1% expressed no interest. Ninety-four percent of respondents reported that they would share positive test results with others. Table 1 lists the types of persons with whom respondents would first discuss their results. The majority would talk either to a physician or their spouse. For those who were married, more than one third would share their test results with a physician first. The results showed that respondents who reported a family history of colon cancer would be more likely to talk first to a physician than those without such a family history. This difference is only suggestive given the small numbers; however, it may reflect, ironically, the fact that those familiar with the disease (those with a family history) see a positive genetic test

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This paper was accepted June 7, 1995.

TABLE 1—Individuals with Whom Survey Respondents Would First Share Positive Test Results, by Family History of Colon Cancer and Health Insurance Status

	Total	Family History of Colon Cancer		Health Insurance	
		Yes (n = 21)	No (n = 344)	Yes (n = 329)	No (n = 42)
Family, %					
Spouse	35.8	39.0	36.0	36.3	31.9
Sibling	2.1	0.0	2.2	2.3	0.0
Parents	15.0	0.0	15.5	14.2	21.3
Children	2.7	4.3	2.4	2.7	2.4
Other family members	3.8	0.0	4.1	4.0	2.3
Health professional, %	34.4	48.7	33.6	35.0	29.4
No one, %	6.2	9.5	7.6	5.4	12.6
Mean age, y (SD)	44.9 (17.7)	50.1 (15.0)	43.2 (17.7)	44.2 (18.1)	41.0 (16.8)

Note. Percentages and mean ages are weighted statistically. Values may not add up to the total because of missing data on family history or insurance questions.

TABLE 2—Concerns that Respondents Would Have if a Genetic Blood Test Showed They Had a High Risk for Colon Cancer

Concern	Primary Concern, No. (Weighted %)	Primary, Secondary, or Tertiary Concern, No. (Weighted %)
Prevention		
Avoid getting it/reduce the risk	71 (21.7)	85 (17.8)
Change diet	44 (13.6)	60 (12.7)
Find out cures/accept medical help	35 (10.6)	57 (12.1)
Do more exercise	...	15 (3.1)
Frequent checkups/watch symptoms	13 (3.9)	24 (5.1)
Change life-style	2 (0.6)	6 (1.2)
Follow doctor's advice	3 (1.0)	5 (1.1)
Worry/anxiety		
Very concerned/high concern/be nervous/get worried	16 (4.8)	16 (3.3)
Whether I would get it	27 (8.1)	30 (6.3)
Death/how much longer to live	22 (6.6)	25 (5.3)
Health condition/severity/prognosis/impact on life	17 (5.3)	28 (5.9)
Family		
Health of family and relatives/passing on to kids	40 (12.1)	62 (13.1)
Tell family how it came about	2 (0.6)	5 (1.0)
Economic		
Insurance	4 (1.1)	6 (1.2)
Expense/costs of medical care	4 (1.1)	5 (1.1)
Causation		
Want to learn more about it	4 (1.1)	5 (1.0)
How I got it	3 (0.9)	5 (1.0)
No concern	13 (4.1)	20 (4.2)
Other	9 (2.8)	16 (3.4)

Note. Sample data were statistically weighted to reflect the state's population in terms of age, sex, and region.

result as a call for personal medical attention rather than as a family problem. Table 1 also shows that those with medical insurance were more likely to share their

positive results with a physician, while those without medical insurance were more apt to talk to no one or to their parents.

Respondents were asked to identify up to three concerns that they might have if they were told that they had a genetic susceptibility to colon cancer. The verbatim responses were analyzed, and six distinct types of concerns were identified (Table 2). Respondents could give more than one answer, so Table 2 lists the percentages of respondents who mentioned a primary concern and the percentages who mentioned any concern. Three dominant concerns were observed: (1) interest in taking available preventive measures to reduce risk of getting colon cancer (51.4%), (2) increased anxiety (24.8%), and (3) worry about colon cancer risks for other family members, particularly the respondents' children (12.7%). Unlike the first two themes, which are common reactions to risk factor notification, the third most common concern dealt specifically with the genetic component of the risk for colon cancer.⁶ Finally, note that few respondents stated that they would be worried about their health insurance coverage or their medical care costs. Respondents expressed no concerns about the possible effects of being a gene carrier with respect to their employment situation, perhaps reflecting the public's currently low level of understanding of socioeconomic issues related to genetic testing.

We examined several factors that might explain why individuals are interested in being tested genetically for colon cancer risk. We estimated a logistic regression in which we compared persons who were very interested in taking the test with those who were somewhat or not interested. Several sociodemographic, economic, familial, and psychological measures were used as independent variables. Table 3 summarizes the effects of each variable in terms of odds ratios. Two characteristics are important statistically: higher levels of income and a greater perceived risk of colon cancer are associated with a strong interest in taking the test.

Table 3 also describes characteristics that affected whether or not the respondent would discuss positive test results with anyone. Widowed individuals were 80% less likely to talk with others about their results than were married individuals. Those who had health insurance were nearly three times more likely to share results with others than those without such insurance. Finally, individuals with a greater perceived risk of colon cancer were significantly more likely to share their positive test results.

TABLE 3—Factors Affecting Respondents' Interest in Taking a Genetic Test for Colon Cancer and Sharing the Test Results

Independent Variable	Dependent Variable	
	Very Interested vs Somewhat/Not Interested in Taking Test	Discuss vs Does Not Discuss Results with Others
	Odds Ratio (95% CI)	Odds Ratio (95% CI)
Demographic		
Age, y	1.01 (0.99, 1.03)	1.00 (0.96, 1.03)
Female	1.27 (0.79, 2.04)	0.85 (0.35, 2.09)
Economic		
Income	1.02 (1.00, 1.04)	1.00 (0.97, 1.03)
Health insurance coverage	1.16 (0.54, 2.47)	3.31 (1.32, 9.58)
Family		
Parents/siblings with cancer	1.62 (0.47, 5.52)	0.51 (0.78, 3.39)
No children present in home	0.80 (0.46, 1.39)	0.98 (0.34, 2.84)
Family satisfaction ^a	0.88 (0.72, 1.08)	0.96 (0.67, 1.38)
Marital status		
Married	Reference	Reference
Divorced/separated	1.30 (0.59, 2.86)	0.47 (0.13, 1.75)
Widowed	1.82 (0.59, 5.63)	0.21 (0.05, 0.89)
Never married	0.79 (0.40, 1.57)	1.06 (0.28, 4.09)
Psychological		
How often nervous last year ^a	1.04 (0.92, 1.17)	1.09 (0.88, 1.35)
Chances of getting cancer in lifetime ^b	1.30 (1.13, 1.50)	1.25 (0.97, 1.61)

^aOn a scale ranging from 1 to 7.

^bOn a scale ranging from 1 to 10.

Discussion

In anticipation of greater public access to genetic testing for cancer susceptibility, this study examined people's interest in such testing and their expected reactions should they be told that they were genetically at greater risk of getting colon cancer. Consistent with the results of Croyle and Lerman,⁵ we found considerable interest in genetic testing for colon cancer. Most people would also be willing to share their test results (most commonly with a spouse or physician) if the results were positive. While a minority of respondents stated that their main concern about positive test results would be uneasiness or anxiousness about their health and future, most individuals perceived their test results as useful information. These findings suggest a latent demand for genetic testing that could create significant changes in disease prevention and life-style behaviors for tested individuals and their family members.⁷ At the same time, we recognize that surveys such as this may overestimate use of actual medical testing.^{8,9}

Individuals who considered themselves to be at high risk of colon cancer

were the most interested in testing. This is consistent with the health belief model,^{10,11} which predicts that preventive health behaviors are most likely to occur for individuals who have a perceived susceptibility to a serious health condition. We also found that as household income rose, people were more interested in being tested. This suggests at least two alternative interpretations. First, individuals with higher incomes may view the benefits of knowing their genetic status as greater because they may be in a better position to act on this information. Poorer individuals may not have the resources to manage their health status over time. Second, individuals with higher incomes, being more educated, on average, have a longer planning horizon than those with lower incomes. Accordingly, information about a health condition that might not occur for many years might be less salient for those with a shorter time horizon.

One of the major policy concerns regarding genetic testing involves privacy and access to test results. Our survey results indicate that widowed individuals and those without health insurance are the least likely to share their test results.

The widowed may be reluctant to share their test results because they are likely to have fewer individuals with whom to share such information.¹² Reports of respondents with health insurance indicated that they would be much more likely to share their results than the uninsured. Thirty-five percent of insured individuals reported that they would first talk to a physician about their results (Table 1), which suggests that many of the insured may view genetic testing as yet another medical procedure covered by their insurance. The insured may not yet be aware of the potential financial implications of revealing their genetic status to their physicians or their insurers.¹³ Those without insurance, on the other hand, are less likely to talk to anyone about their genetic status, possibly because they are concerned about jeopardizing their prospects of ever obtaining medical coverage; further study is needed to verify this interpretation.

This study is limited by the fact that, for most respondents, genetic testing is not salient in their everyday lives, and they may simply view it as another medical test. However, the study demonstrates that as genetic testing becomes more widely understood by the public, there is likely to be considerable individual variation in interest in testing as well as responses to test results, particularly in relation to privacy issues.¹⁴ Our findings suggest that special attention needs to be paid to issues of equitable access to genetic testing across the range of socioeconomic groups. □

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Fourteenth World Congress on Occupational Safety and Health to Be Held April 22 to 26, 1996, in Madrid

The Fourteenth World Congress on Occupational Safety and Health will be held in Madrid from April 22 to 26, 1996. The organizers are the Spanish Ministry of Labour and Social Security, through the National Institute for Occupational Safety and Health (INSHT), the International Labour Office (ILO), Geneva, and the International Social Security Association (ISSA), Geneva.

The congress aims to be an open forum for all persons involved in safety and risk prevention at work, safety and health safety specialists, occupational health physicians, labor inspectors, entrepreneurs and managers in enterprises, trade union representatives, manufacturers and importers, heads of public administration, and social security administrators.

The main focuses of this congress will be (1) the consequences for occupational safety and health of processes

of international and regional integration (e.g., EU, NAFTA) and of the globalization of economic relations; (2) an in-depth analysis of chemical risks; and (3) new proposals for cooperation and participation within enterprises. Other issues will include training and information and control of working conditions. Special emphasis will be placed on small and medium-sized enterprises and sectors facing specific occupational health problems (such as construction and agriculture).

In addition, the International Section on "Electricity" of the ISSA will be organizing the Third International Film and Video Festival on Occupational Safety and Health.

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