Intention to Learn Results of Genetic Testing for Hereditary Colon Cancer[1]

Sally W. Vernon,[2] Ellen R. Gritz, Susan K. Peterson, Catherine A. Perz, Salma Marani, Christopher I. Amos, and Walter F. Baile

University of Texas-Houston School of Public Health [S. W. V.] and University of Texas M.D. Anderson Cancer Center [E. R. G., S. K. P., S. M., C. I. A., W. F. B.], Houston, Texas 77030, and University of Houston-Victoria, Victoria, Texas [C. A. P.]

Abstract

Introduction. This report investigates the correlates of intention to find out genetic test results in colorectal cancer patients undergoing genetic counseling and testing for hereditary nonpolyposis colon cancer. Specifically, we investigated whether intention to learn genetic test results was associated with sociodemographic factors, medical history, psychosocial factors, attitudes, beliefs, and decisional considerations related to genetic testing.

Materials and Methods. Among 342 colorectal cancer patients who went through an informed consent process and gave blood for genetic testing and who were eligible for a psychosocial questionnaire study, 269 cases completed a baseline interview. Patients were contacted in person during a routine clinic visit or by letter and follow-up telephone call and were interviewed either in person or by telephone.

Results. In univariate analysis, intention to learn test results was positively associated with income, quality of life, a belief that being tested will help family members prevent cancer, being worried about carrying an altered gene, and a belief that one has the ability to cope with test results. It was negatively associated with a belief that genetic counseling is too much trouble relative to the benefits. Intention also was positively associated with scales measuring the pros of learning test results and the pros of informing relatives about test results; it was negatively associated with the cons of learning test results. In multivariable analysis, the belief that testing would help family members prevent cancer, being worried about carrying an altered gene, and the pros of learning test results remained statistically associated with intention when other variables were included in the model.

Conclusions. Our findings showed that the positive aspects of genetic testing were more strongly associated with intention than were the negative aspects. They also showed that persons who stated an intention to learn their genetic test results were more likely than persons who did not to affirm both the benefits and the importance of such testing. These results are consistent with the literature on psychosocial aspects of genetic testing for breast cancer.

Introduction

In 1999, an estimated 129,400 persons will be diagnosed with cancer of the colon or rectum, and ~56,600 persons will die from the disease (1). At least 10–20% of colon cancers occur among persons with a family history of colorectal cancer (2–4). One genetic form of colorectal cancer susceptibility is HNPCC.[3] Family members with this syndrome do not show a dramatic excess of adenomatous polyps, but they generally develop colorectal cancer at an earlier age than persons in the general population, often before age 50. The genetic cause for most cases of HNPCC has been shown to arise from a defect in any of several DNA repair enzymes (5–8). The majority of HNPCC results from defects in either of two genes (9), *hMSH2* and *hMLH1*, and genetic testing for mutations has recently become possible. In families whose colorectal cancer-affected members carry these mutations, such testing permits the identification of asymptomatic persons at >80% lifetime risk of developing colorectal cancer who could benefit from increased colorectal cancer screening and surveillance (10). Recently, medical surveillance guidelines for unaffected carriers have been developed by a subcommittee of the Cancer Genetic Studies Consortium of the Ethical, Legal, and Social Implications Branch of the National Human Genome Research Institute (11, 12).

Until recently, there has been little experience in testing and counseling asymptomatic individuals about their specific risk of inheriting cancer-predisposing mutations (13, 14), and there are few guidelines for communicating genetic information about cancer susceptibility (15). There is, however, a general consensus that genetic testing should be embedded in a process of education and counseling. Pretest counseling and having blood drawn for analysis of mutation status are only the initial steps in the process. Before disclosure of mutation status, persons are again counseled about the risks and benefits of learning their test results, and some may decline at that point. Individuals also may differ in their willingness to inform relatives about their mutation status, even if they choose to learn their own test results. At present, we know relatively little about the receptivity to cancer predisposition testing and counseling, about the psychosocial and behavioral characteristics of persons who undergo testing, or about sequelae of receiving information about one's mutation status (16). To date, most psychosocial studies have focused on susceptibility testing for breast cancer (17–28). Relatively few have been of the psychosocial aspects of predisposition testing for colorectal cancer (29–34).

The study reported here used baseline data from a prospective, observational study whose primary objective is to

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[2] To whom requests for reprints should be addressed, at The University of Texas-Houston School of Public Health, 1200 Hermann Pressler Drive, Houston, TX 77030. Phone: (713) 500-9162; Fax: (713) 500-9149.

[3] The abbreviations used are: HNPCC, hereditary nonpolyposis colon cancer; CES-D, Center for Epidemiologic Studies Depression; QLI, Quality of Life index.

characterize the psychosocial and behavioral impact of genetic testing for HNPCC through a systematic investigation of colorectal cancer cases and families at risk for HNPCC. Details about the study design are reported elsewhere (32, 33, 35). For this report, we analyzed data from a baseline psychosocial survey of colorectal cancer patients who were undergoing genetic counseling and testing. We assessed the association between intention to learn genetic test results and sociodemographic factors, medical history, psychosocial factors, attitudes, beliefs, and decisional considerations related to genetic testing.

Materials and Methods

Study Population and Study Procedures. The study population for this report was composed of 269 persons diagnosed with colorectal cancer at The University of Texas M. D. Anderson Cancer Center, who gave informed consent for genetic testing and for a psychosocial questionnaire study and who were interviewed between June 1995 and June 1997. Among eligible patients who went through an informed consent process, 89% (455/510) had blood drawn for genetic testing. Eligibility criteria for the psychosocial questionnaire study included: ability to give written informed consent; ability to speak, read, and write English; residence in the United States; and diagnosis of adenocarcinoma of the colon or rectum. Exclusion criteria included: presence of a current major psychiatric disorder as defined by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition, and age <18 years. Fifty-six patients were excluded because they did not speak, read, or write English, and 57 patients died before they could be invited to participate in the questionnaire study. Of 342 patients eligible for the psychosocial questionnaire study, 269 (79%) agreed to participate and completed a baseline interview. Nonparticipants included 48 refusals, 16 withdrawals, 7 who had not yet been approached, and 2 who consented but had not yet been interviewed. The primary reasons for refusing to participate were being too ill ($n = 15$), decided not to participate ($n = 16$), and concern about possible insurance or employment discrimination ($n = 7$). Other reasons given by only a few patients were inconvenience, the length of the questionnaire, being too busy, perceiving no benefit, dislike of talking on the telephone, feeling overwhelmed, and not wanting to talk about cancer. Of the 16 withdrawals, five died, five were too ill, five decided not to participate, and one became concerned about the possibility of insurance or employment discrimination.

The baseline psychosocial data were collected after the informed consent and blood draw for genetic testing; however, patients had not yet received test results. Eligible patients were contacted for the psychosocial questionnaire study by project staff in person during a routine clinic visit or by letter and follow-up telephone call. A baseline interview, lasting ~45 min, was conducted either in person or by telephone. Before administering the baseline questionnaire, interviewers gave a brief introductory statement about genetic testing for HNPCC. After completion of the baseline interview but before receipt of genetic test results, patients participated in a genetic counseling session that covered the following topics: HNPCC syndrome and inheritance of colorectal cancer susceptibility; HNPCC gene identification studies and mutation status testing; risks, benefits, and limitations of HNPCC genetic testing; potential implications of genetic test results for other family members; and prevention and surveillance options and their limitations. Participants and nonparticipants in the psychosocial questionnaire study did not differ at baseline on sex, race/ethnicity, stage of disease at diagnosis, or family history of colorectal cancer, but participants were younger than nonparticipants.

Additional details about the study population and study procedures, including eligibility criteria, recruitment, and the informed consent process, are given elsewhere (32, 35).

Measures. The dependent variable was intention to learn genetic test results and was measured by a single item, *i.e.*, "I intend to find out my genetic test results," using a 5-point Likert-type scale from strongly agree to strongly disagree. For independent variables, sociodemographic and medical history factors analyzed were age (<50, ≥50 years), sex (male, female), race/ethnicity (white, nonwhite), religion (Catholic, Protestant, Jewish, Mormon, other, or none), education (≤ high school, > high school), income (≤$30,000, >$30,000), marital status (married, not married), number of children (none, ≥1), stage of disease at diagnosis (local, regional, or distant), and family history of colorectal cancer (no relatives, ≥1 relative). Spirituality (very strong, not very strong) also was measured.

Two measures of psychological distress were used, the CES-D Scale (36, 37) and the State-Trait Anxiety Inventory (38). Coping style was measured with the Miller Behavioral Style Scale (39, 40), social support with the short form of the Sarason Social Support Questionnaire (41), and quality of life with the Ferrans and Powers QLI (42, 43). In our study population, Cronbach's coefficient α was 0.87 or higher for the CES-D Scale, the State-Trait Anxiety Inventory, the QLI, and the two social support subscales of the Sarason Social Support Questionnaire. Internal consistency reliability was low for the monitoring (0.59) and the blunting (0.58) subscales of the Miller Behavioral Style Scale.

Items measuring attitudes and beliefs about genetic testing for HNPCC were adapted from the Adherence Determinants Questionnaire (44, 45) or were developed by the Cancer Genetic Studies Consortium Measurement Task Force and were evaluated during a pilot test (see "Appendix" for the items). Most attitude and belief items were rated on a 5-point Likert-type scale from strongly agree to strongly disagree and were dichotomized for analysis into "agree or strongly agree" *versus* "disagree, strongly disagree, or uncertain" (these two categories are hereafter referred to as "agree" and "disagree"). Attempts to form a scale with the attitude and belief items were unsuccessful, and so the single item measures were used in the analysis. Three other items, measured on 4-point scales, also were dichotomized for analysis.

Measures of the pros and cons, constructs from the transtheoretical model (46), were developed specifically for this study to assess decisional considerations related to learning one's genetic test results and to informing relatives of test results (see "Appendix" for the items). Items were constructed based on discussions with patients and health care practitioners and through two focus groups conducted with patients and their family members and were refined during a pilot test. Pros and cons were rated on a 5-point scale ranging from "not at all important" to "very important." Pros and cons do not simply measure agreement with attitude or belief statements. Rather, the constructs attempt to measure the extent to which a person values or prioritizes the positive and negative aspects of a particular behavior, for example, sharing test results with relatives. For example, a person with a strong family history of colon cancer might agree that genetic testing could help family members prevent colon cancer and yet not rate that statement as very important if he or she was estranged from family members. Likewise, someone might agree that emotional distress may result from undergoing testing but care little about that possibility, *i.e.*, rate it as not very important.

Internal consistency reliability was adequate for the two pros and two cons subscales. For the pros of learning genetic test results, coefficient α was 0.67, and for the cons it was 0.80. For the pros of informing relatives, coefficient α was 0.63, and

Table 1 Intention to learn genetic test results by demographic and medical history variables

Demographics and medical history	*n*	Intention[a] %	χ^2	*P*
Age				
<50	105	89.5		
≥50	164	90.9	0.72	0.833
Sex				
Female	119	90.8		
Male	150	90.0	0.84	1.000
Race				
White	237	90.3		
Non-white	32	90.6	0.95	1.000
Religion				
Catholic	67	92.5		
Protestant	175	89.7		
Jewish	4	100.0		
Mormon	2	100.0		
Other	14	85.7		
None	7	85.7	1.61	0.901
Spirituality				
Very strong	159	89.9		
Not very strong	108	91.7	0.63	0.675
Education				
≤High school	88	89.8		
>High school	181	90.6	0.83	0.828
Income				
≤$30,000	90	86.7		
>$30,000	175	92.0	0.17	0.193
Marital status				
Married	209	90.9		
Not married	59	88.1	0.53	0.618
Number of children				
None	43	93.0		
≥1	221	89.6	0.49	0.779
Disease stage				
Local	36	91.7		
Regional	77	90.9		
Distant	124	90.3	0.07	0.968
Family history of CRC				
No relatives	183	91.3		
≥1 relatives	86	88.4	0.46	0.508

[a] Intention was measured on a five-point Likert-type scale and was collapsed into a dichotomous variable by combining the categories "strongly agree" and "agree" *versus* "strongly disagree," "disagree," and "uncertain."

for the cons it was 0.75. The correlation coefficient between the two pros subscales was 0.39 and for the two cons subscales it was 0.24, providing evidence of discriminant validity. Raw scores for the pros and cons scales were converted into standard T scores (mean, 50; SD, 10). We also created two summary measures of decisional balance, one for learning genetic test results and one for informing relatives of test results, by subtracting the cons T scores from the pros T scores for each of the two sets of pros and cons scales.

Statistical Analysis. One-way ANOVA with two-sample *t* tests were used to compare mean scores for the continuous psychosocial variables, for the pros and cons scales, and for the measures of decisional balance by the dichotomous measure of intention. χ^2 tests were used to evaluate the univariate association between intention and each of the sociodemographic, medical history, and dichotomized attitude items. In addition to age and sex, independent variables were included in the multivariable analysis if they were statistically associated with the dependent variable at $P < 0.25$ in univariate analysis. Hierarchical logistic regression was used to evaluate the independent effects of the predictor variables, and results were summarized using odds ratios and 95% confidence intervals. For continuous independent variables, *e.g.*, the QLI scale, the odds ratios indicate an increased or decreased likelihood of intention to learn test results with a one unit increase in the independent variable. Because we used T scores for the pros and cons scales and decisional balance measures, it is more meaningful to interpret the odds ratios to indicate a 10-unit increase in these variables. The reference category for the attitude and belief items was "agree", *i.e.*, "agree or strongly agree." Independent variables that met the $P < 0.25$ inclusion criterion were entered as three different blocks. Block 1 included sociodemographic and medical history variables; block 2 included the psychosocial variables (*e.g.*, CES-D Scale, QLI); and block 3 included the attitude and belief items and the pros and cons scales or the decisional balance measures. The pros and cons scales could not be entered into the same logistic model as the decisional balance measures because of problems with colinearity. Therefore, we estimated two multivariable models, one that included pros and cons scales that met the $P < 0.25$ criterion and one that included the decisional balance measures that met the cutoff for inclusion.

Respondents with missing values on items in the psychosocial scales were assigned a scale score based on the number of items they answered. Respondents with missing values on single item variables, *e.g.*, age, income, were excluded from the analysis. Response rates were >98% for all questionnaire items included in the analysis. All analyses were done using SPSS for Windows, version 7.5.

Table 2 Intention to learn genetic test results by psychosocial variables, mean (SD)

Psychosocial variables	Intention[a]		*t*[b]	*P*
	Agree (*n* = 243)	Disagree (*n* = 26)		
CES-D	10.2 (9.8)	10.7 (9.6)	0.20	0.841
State-anxiety	32.0 (11.2)	32.9 (12.2)	0.42	0.677
Trait-anxiety	32.5 (9.6)	32.9 (10.0)	0.19	0.849
Social support-number	4.3 (2.2)	4.1 (2.3)	−0.36	0.718
Social support-satisfaction	5.7 (0.6)	5.7 (0.6)	−0.38	0.701
Quality of life	23.4 (4.2)	22.1 (4.3)	−1.47	0.143
MBBS—Monitoring	12.1 (2.2)	12.3 (2.0)	0.33	0.738
MBBS—Blunting	6.8 (2.4)	7.1 (2.4)	0.72	0.473

[a] Intention was measured on a five-point Likert-type scale and was collapsed into a dichotomous variable by combining the categories "strongly agree" and "agree" *versus* "strongly disagree," "disagree," and "uncertain."
[b] Degrees of freedom were 267.

Results

Of the 269 study participants, 243 (90**%)** intended to learn their genetic test results. Among the sociodemographic and medical history variables, only income was statistically associated with intention at $P < 0.25$ in univariate analysis (Table 1). Of the psychosocial scales, only the QLI was associated with intention (Table 2).

As shown in Table 3, several of the attitude and belief items were statistically associated with intention. Persons who intended to learn their genetic test results were more likely to believe that being tested will help family members prevent cancer, to be worried about carrying an altered gene, to believe that one has the ability to cope with test results, and to believe that counseling is not too much trouble relative to the benefits.

Both the pros and cons scales for learning test results were associated with intention in univariate analysis (Table 4). Persons who stated an intention to learn their test results scored higher on the pros and lower on the cons scales compared with persons who did not state such an intention. The pros, but not the cons, scale for informing relatives also was statistically associated with intention

Table 3 Intention to learn genetic test results by attitude and belief items

Attitude and belief items	Intention[a] %		χ^2	*P*
	Agree (*n*)	Disagree (*n*)		
Testing will help family members prevent cancer	94.8 (39)	64.1 (230)	35.9	<0.001
Finding out results won't help me or my family	90.9 (22)	90.3 (247)	0.0	1.000
Worried about carrying gene	94.9 (158)	83.8 (111)	9.3	0.003
Able to cope	9.17 (253)	68.8 (16)	9.1	0.012
Feel singled out	87.5 (24)	90.6 (245)	0.2	0.714
Counseling too much trouble	77.8 (9)	90.8 (260)	1.7	0.212
Cancer is God's will	87.5 (72)	91.3 (196)	0.9	0.357
Cancer is due to bad luck	83.3 (18)	90.8 (250)	1.1	0.397
Stress "causes" cancer	90.2 (132)	91.2 (136)	0.1	0.835
Doctor respects me	89.7 (224)	92.3 (13)	0.1	1.000
Trust doctor's judgment	89.5 (219)	94.4 (18)	0.4	0.434
Worry about family members	All the time[b]	Not all the time		
	95.0 (20)	90.0 (249)	0.5	0.704
Family is at risk for CRC	Very likely[c]	Not very likely		
	90.8 (65)	90.2 (204)	0.0	1.00
Closeness to family	Close[d]	Not close		
	90.9 (263)	75.0 (4)	1.2	0.327

[a] Intention was measured on a five-point Likert-type scale and was collapsed into a dichotomous variable by combining the categories "strongly agree" and "agree" *versus* "strongly disagree," "disagree," and "uncertain."
[b] Dichotomized as "all of the time" *versus* "some of the time," "never," or "don't know."
[c] Dichotomized as "very likely" *versus* "somewhat likely," "not likely," or "don't know."
[d] Dichotomized as "close to all of them" *versus* "close to some of them," "close to none of them," or "not applicable."

Table 4 Intention to learn genetic test results by pros and cons of genetic testing and of informing relatives, mean (SD)

Decisional considerations variables	Intention[a]		t^b	*P*
	Agree ($n = 243$)	Disagree ($n = 26$)		
Learning test results				
Pros	51.1 (8.5)	39.4 (15.7)	−3.77	0.001
Cons	49.6 (10.0)	53.3 (9.3)	1.78	0.076
Decisional balance	1.5 (12.6)	−14.0 (19.6)	−3.94	0.001
Informing relatives				
Pros	50.8 (9.0)	42.4 (15.0)	−2.81	0.009
Cons	49.8 (10.2)	52.0 (7.6)	1.10	0.273
Decisional balance	1.0 (14.8)	−9.7 (20.2)	−2.63	0.014

[a] Intention was measured on a five-point Likert-type scale and was collapsed into a dichotomous variable by combining the categories "strongly agree" and "agree" *versus* "strongly disagree," "disagree," and "uncertain."
[b] Degrees of freedom were 267.

(Table 4). Compared with those who did not intend to learn their test results, persons who intended to learn their test results scored higher on the pros scale for informing relatives. Both measures of decisional balance were associated with intention (Table 4). Decisional balance scores on both measures were positive for persons who intended to learn their test results and were negative for persons who did not.

In multivariable analysis, the belief that testing would help family members prevent cancer, being worried about carrying an altered gene, and the pros of learning test results remained statistically associated with intention when other variables were included in the model (Table 5). Patients who agreed that testing will help family members prevent cancer were 6.7 times more likely than patients who disagreed with this statement to intend to learn their genetic test results.

A separate multivariable model that replaced the pros and cons scales with the two measures of decisional balance showed that the measure of decisional balance for learning test results remained significant when other variables were included in the model (odds ratio, 1.06; 95% confidence interval, 1.02–1.09), but decisional balance for informing relatives did not (odds ratio, 1.00; 95% confidence interval, 0.97–1.04).

The point estimates and confidence intervals for the other variables entered in this model (*e.g.*, age and sex) were similar to those shown on Table 5.

Discussion

Although a number of studies have focused on interest in being tested when it becomes available (17–24, 26, 29–31, 34), ours is the first to evaluate variables associated with intention to receive test results in persons who have had blood drawn for genetic testing and who have not yet received test results. In this study, 90% of patients stated in the baseline interview that they intended to learn their genetic test results, and 10% said that they did not intend to learn their test results or were uncertain about their intention. Although patients were given a brief explanation of genetic testing prior to the initial informed consent process and the blood draw, a detailed counseling session did not occur until after completion of the baseline interview and blood draw. It is possible that some patients felt they did not have enough information to form an intention about disclosure of their test results at the time of the baseline interview.

Of interest was that despite the homogeneity of response patterns across sociodemographic, medical history, and psychosocial variables, there were marked differences in intention by attitudes and beliefs and by decisional considerations related to genetic testing. Our findings showed that the positive aspects of genetic testing were more strongly associated with intention to learn one's genetic test results than were the negative aspects. They also showed that persons who stated an intention to learn their genetic test results were more likely than persons who did not to affirm both the benefits and the importance of such testing.

As described above, we measured the positive and negative aspects of genetic testing in two ways, with traditional attitude and belief items that asked respondents to rate how strongly they agreed with a particular statement and with meas-

Table 5 Multivariable results of intention to learn genetic test results ($n = 264$)

Independent variables	Odds ratio[a]	95% confidence interval	Beta	SE
Age (≥50 *vs.* <50)	0.74	0.25, 2.26	−0.295	0.564
Sex (females *vs.* male)	0.94	0.35, 2.54	−0.058	0.505
Income (≥$30,000 *vs.* <$30,000)	1.42	0.48, 4.18	0.348	0.552
Testing will help family members prevent cancer[b]	6.71	2.27, 19.84	1.903	0.553
Worried about carrying gene[b]	3.59	1.14, 11.32	1.278	0.586
Able to cope[b]	3.37	0.64, 17.85	1.216	0.850
Pros—results[c]	1.07	1.02, 1.13	0.069	0.025
Pros—relatives[c]	1.00	0.96, 1.05	0.023	0.004
Quality of life[d]	1.04	0.92, 1.18	0.042	0.062
Cons—results[c]	0.97	0.92, 1.03	−0.028	0.027
Counseling too much trouble[b]	0.71	0.09, 5.67	−0.346	1.061

[a] Odds ratios are adjusted for the effects of all other variables in the model.
[b] The reference category was "agree," *i.e.,* "strongly agree" or "agree."
[c] A 10-unit increase in these measures is associated with an odds ratio of 2.0 (*i.e.,* 1.07^{10}). Hence, patients for whom this measure increases by 10 units are two times more likely to intend to learn their test results.
[d] The odds ratio indicates an increased or decreased likelihood of intention to learn test results with a one unit increase in the predictor variable.

ures of decisional considerations that asked respondents to rate how important each statement was to them. The multivariable analysis supported an interpretation that we were measuring two different, but interrelated, underlying constructs.

The strongest correlate was a single item measure of the belief that testing will help family members prevent cancer, a perceived benefit of genetic testing. This result may explain why the measures of the pros of informing relatives and of decisional considerations related to informing relatives, although statistically significant in univariate analysis, were not significant in multivariable analysis. The transtheoretical model (46) posits individual prioritization of positive and negative aspects of a behavior to be more relevant to performance of a behavior than simple awareness of positive and negative aspects of the behavior. Our data did not support this assumption with regard to behavioral intention to learn genetic test results.

Because patients in our study had already provided a blood sample for genetic testing, this population, at baseline, consisted of persons who were at a single stage of readiness with regard to being tested, *i.e.,* action. Discussions with focus group participants indicated that patients would not undergo genetic testing unless they also intended to receive test results and to communicate these results to family members. Findings from the focus groups were not completely consistent with our observation that 10% of the study participants who had blood drawn for genetic testing stated that they did not intend to learn their test results. Conceptually, however, the positive association found between intention and the pros of learning genetic test results (and positive decisional balance on this construct) is consistent with the literature on the transtheoretical model that for persons in the preparation and contemplation stages, the pros are more important than the cons in determining behavioral intention. Empirically, our findings are consistent with those reported by others (24, 25). Lerman *et al.* (25) found that men and women who chose to learn their *BRCA1* test results scored higher than decliners on a scale measuring the benefits or pros, rated on an "importance" dimension, of *BRCA1* testing. Jacobsen *et al.* (24) found that mean pros scores were significantly greater and that the mean cons scores were significantly lower among women who, under hypothetical conditions, planned to be tested for "the breast cancer gene" as soon as possible (preparation) compared with women who planned to be tested in the future (contemplation) or with women who did not plan to be tested (precontemplation). Women who planned to be tested as soon as possible had a positive decisional balance, whereas the other two groups of women had a negative decisional balance. Unlike most other researchers, Jacobsen *et al.* (24) used "agreement" rather than "importance" to measure the pros and cons.

In a separate report (27) based on the same study population as described above (25), Lerman *et al.* (27) found that cancer-specific distress, measured by the intrusion subscale of the revised Impact of Event Scale (47) predicted receiving *BRCA1* test results; persons who scored high on distress were more likely than those who scored low to request and receive *BRCA1* test results. This finding is consistent with our result that a higher percentage of persons who were worried about carrying an altered gene for colon cancer intended to find out their test result compared with persons who were not worried about carrying an altered gene. Although we did not find any overall differences in psychological status for patients who did and who did not intend to learn their genetic test results, in other analyses (33) we found that patients in our study population who were part of a high distress subgroup were more likely to state that they would worry about being a mutation carrier and that they felt less able to cope with problems related to their genetic test results. Collectively, these findings indicate that personal concerns about being a gene carrier need to be addressed in genetic counseling sessions before disclosure of test results, particularly because patients who score high on distress appear to be more likely to request their test results.

An issue in studies of intention is whether it is a good proxy measure for behavior. Theoretically, intention is conceptualized as an immediate and necessary precursor to behavior (48). It is more likely to be a useful proxy for behavior when the time interval between measured intention and future behavior is short (48). The process of genetic counseling and testing, including informing relatives, presents such a set of circumstances. The similarity in the predictors of intention in our study with those reported by Lerman *et al.* (25) for a behavioral outcome, *i.e.,* actual receipt of test results, indicates that intention may be a reliable proxy for behavior in this instance. In fact, there is evidence that intention to undergo genetic testing for *BRCA1* is fairly stable over a short time interval and, perhaps of greater consequence, is not changed as a result of an education and counseling intervention on the risks and benefits of genetic testing (26). Lerman *et al.* (26) found that intention measured preintervention, and one month postintervention was similar in three groups of women: those who received education, those who received education plus individualized counseling, and those who were on a waiting list (26). In multiva-

riable analysis, the only predictors of intention postintervention were baseline intention and family history of cancer.

Our findings should be considered within the context of the methodological limitations of our study. As with most observational studies, nonparticipation raises a question about the potential for selection bias. A potential threat to external validity is that The University of Texas M. D. Anderson Cancer Center is a referral center, and so our patient population contained a higher percentage of younger patients and of patients with late-stage disease than colorectal cancer patients seen at other hospitals in the community. However, we found that scores on our psychosocial measures were not affected adversely by stage of disease (49). Another potential source of selection bias was differential participation in the psychosocial questionnaire study. Although the limited data available on demographic and medical characteristics for participants and nonparticipants in the questionnaire study showed statistically significant differences only for age, it is possible that nonparticipants differed on unmeasured psychosocial characteristics such as psychological status or in their interest in taking a genetic test. At present, there are scant data on the characteristics of participants and nonparticipants in genetic testing for any disease. One study found that high-risk individuals who opted for cancer genetic testing were more psychologically vulnerable than those who did not (19), whereas a study of genetic testing for Huntington's disease (50) concluded that persons choosing testing were preselected for favorable psychological reactions. A recent mail survey (51) of persons who had a relative with colon cancer found that nonrespondents to the survey who later completed a telephone follow-up interview were less likely than mail survey respondents to state that they would take a gene test for colon cancer. Another limitation is that, like most other studies of intention, our study design was cross-sectional, and so the possibility of reverse causation, *e.g.*, intention influenced attitudes and beliefs rather than *vice versa*, cannot be ruled out.

Our estimate of persons who intended to learn their test results was consistent with reports of expressed interest in cancer genetic testing both among persons at increased cancer risk (19–21, 24, 31) and among persons not identified as being at increased risk (17, 22, 23, 29), but it was much higher than the ~60% who requested test results among persons who had previously provided a blood sample for experimental genetic studies and who also completed a baseline psychosocial questionnaire (25). It may be the case that because persons in that study (25) gave blood for genetic testing before *BRCA1* mutations were identified, they did so without the expectation that they would eventually be able to learn their test results. The difference also may be due to increased interest in genetic testing among cancer patients compared with unaffected at-risk persons. Our finding that cancer patients' motivation rests largely on their desire to help family members prevent the disease also would explain these disparate results. It will be of interest to see what percentage of patients actually choose to learn their mutation status. It also will be of interest to examine which psychosocial measures are related prospectively to behavior, *i.e.*, the decision to learn one's test results.

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Appendix

Attitude and Belief Items

Response Options:
Strongly disagree; Disagree; Neither agree nor disagree; Agree; Strongly agree.

I believe that being tested for hereditary colon cancer will help my family prevent cancer.
I am worried that I may carry the altered gene for hereditary colon cancer.
I am able to cope with any problems regarding my genetic test results.
Cancer is God's will.
The way stress is handled has a lot to do with a person's chances of getting cancer.
If I found out that I carried an altered gene, I would feel singled out.
Going through genetic counseling is too much trouble for what I would gain from it.
It's hard to believe that finding out my genetic testing results will help me or my family.
Cancer is due to bad luck.

How often do you worry that your family members may be at risk for colon cancer? Would you say:
All of the time **Some of the time** **Never** **Don't know**

How likely do you think it is that someone in your family will get colon cancer? Would you say:
Extremely likely **Somewhat likely** **Not likely** **Don't know**

Which of the following statements best describes how close you feel to other members of your immediate family (includes parents, siblings, and children)?
Close to all of them **Close to some of them** **Close to none of them** **Not applicable**

Pros and Cons Items

Response Values:
Not at all important; Slightly important; Somewhat important; Important; Very important.

I would want to find out my genetic testing results because:
I would be relieved to know I did not have an altered gene for hereditary colon cancer.
I want to learn whether my children are at risk.
I just want to know.
My own experience with cancer makes me more concerned about my family's risk for the disease.

I would NOT want to find out my genetic testing results because:
I am afraid I would get too upset.
I'm not sure if the test is accurate.
I am concerned about my family's reactions.
I just don't want to know.

Appendix, continued.

I would want to share my genetic tests results with my relatives:

Because my relative could do something to reduce his/her risk of cancer.

Because I have a responsibility to let my relative know that he/she may be at greater risk of colon cancer.

So my relative can make family planning decisions.

I would NOT want to share my genetic tests results with my relatives because:

My relative would be worried about getting colon cancer.

I would have to talk to a family member whom I prefer not to talk to.

Talking to my relative about his/her risk of hereditary colon cancer could hurt our relationship.

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