

Correlates of Intentions to Obtain Genetic Counseling and Colorectal Cancer Gene Testing Among At-Risk Relatives from Three Ethnic Groups¹

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Abstract

Objectives. An understanding of factors associated with interest in genetic counseling and intentions to obtain colorectal cancer susceptibility testing is an important foundation for developing education, counseling, and genetic services and policies.

Materials and Methods. A survey was mailed to first-degree relatives of patients diagnosed with colorectal cancer. The respondents ($n = 426$, 77% response rate) are siblings and adult children of Caucasian, Japanese, and Hawaiian ethnicity. Data collection was guided by a conceptual framework and included questions on demographics, family cancer history, predisposing factors (cancer worry, perceived risk, well-being), and enabling factors (decision preferences, social support, and health care factors). Logistic regression analysis on two binary dependent variables (interest in counseling and intentions to get genetic testing) was performed using Generalized Estimating Equations to account for family clusters.

Results. Forty-five % of respondents were interested in genetic counseling, and 26% “definitely” intended to get genetic testing for colon cancer when available. For counseling interest, the most important predictors were education, Hawaiian ethnicity, cancer worry, and family support. Cancer worry, perceived risk, and age (older) were directly, and Japanese ethnicity was inversely, associated with testing intentions.

Conclusions. High rates of interest in cancer genetic testing are similar to those found in other studies. Ethnic differences reveal a paradox between objective population risk (higher for Japanese) and greater concerns (among Hawaiians). The substantial lack of awareness of family history warrants further research. Culturally sensitive education and counseling are needed for managing the likely

high demand for personalized information about hereditary cancer risk.

Introduction

Colorectal cancer affects roughly 5% of Americans at some time in their lives, and large bowel cancer represents 15% of all cancers (1). When detected in an early, localized stage, five-year survival rates for colorectal cancer are 92% (1); thus, early detection and intervention have the potential to reduce morbidity and mortality from colorectal cancer significantly. The causes of large bowel cancer are not fully understood. It is more common among men than women and increases with age (2). Diet, exercise, and family history are also risk factors for this disease (3).

The recent discovery of genes associated with hereditary non-polyposis colon cancer has stimulated the development of clinical genetic testing for the most common forms of familial colorectal cancer. Such testing may provide new stimulus to increase surveillance and risk reduction among high-risk persons and eliminate the need for intensive surveillance among members of high-risk families who test negative. However, genetic testing may also lead to increased psychological distress, stigma, discrimination, and loss of privacy (4, 5).

Studies of interest in such testing for breast-ovarian and colon cancer genetic susceptibility indicate that 60–85% of respondents are interested in obtaining predictive genetic testing. High levels of interest were found both among high-risk groups (6–9) and in the general public (10–12).

Several factors have been correlated with interest in genetic testing. Interest in participating has been positively associated with perceived risk, cancer worry (7–9, 11–13), empiric risk levels (7–9), and some sociodemographic factors (7–9, 12). There have been few reports of predictors of participation in cancer genetic counseling. Also, only a few studies to date have investigated factors associated with interest in colon cancer susceptibility testing (5, 9, 12, 14); none have reported correlates of participation in genetic counseling for hereditary colon cancer. Moreover, very few studies have examined cultural or ethnic differences, and most research has involved primarily white, well-educated subjects (5).

In this study, we sought to identify sociodemographic, psychosocial, and social influence factors related to intentions to participate in genetic testing and genetic counseling for colon cancer risk among persons from three ethnic groups who are at increased familial risk.

Conceptual Framework

The conceptual framework for this analysis is based on theories of stress and coping (15), social support and social influence (16, 17), and the Theory of Reasoned Action (18). Constructs

Received 10/7/97; revised 12/18/98; accepted 12/21/98.

¹ Report from the Cancer Genetics Studies Consortium. The work reported here was supported by Grant HG01241 from the National Human Genome Research Institute and Grant CA33619 from the National Cancer Institute.

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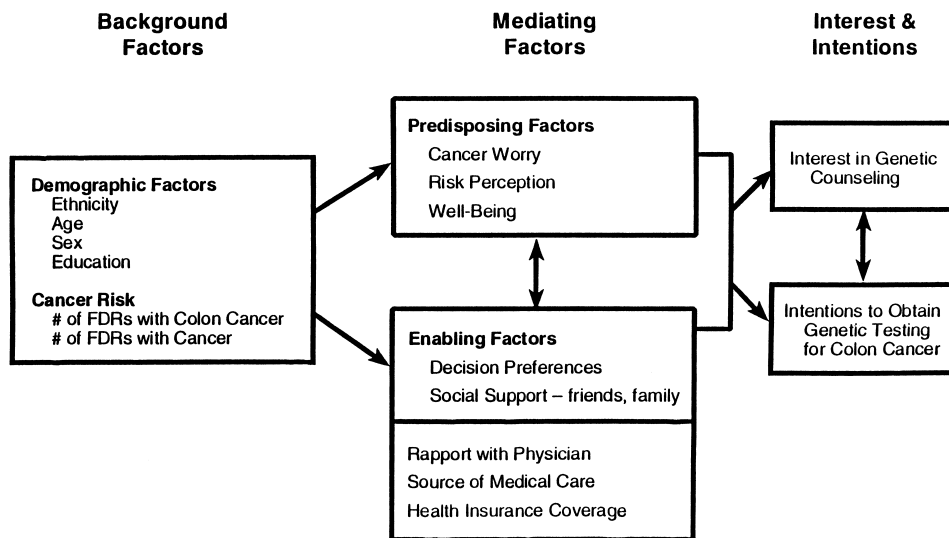


Fig. 1. Conceptual framework.

from these theories were chosen because the prospect of hereditary colon cancer may be perceived as threatening or stressful (15), social support is likely to be important for coping with this threat (16, 17), and we hypothesize that, consistent with the Theory of Reasoned Action, behavioral intentions to undergo genetic testing are a function of (1) individuals' attitudes and appraisals of the action and (2) the attitudes and appraisals of other influential people (18).

We organized the relevant constructs into a schematic framework (Fig. 1) adapted from the classic model of Andersen for factors affecting health services utilization, with emphasis on predisposing and enabling factors (19). Two dependent variables are examined: (a) interest in genetic counseling; and (b) intentions to obtain genetic testing for colon cancer. As shown in Fig. 1, we examined background factors including demographics and reported familial cancers, all of which have been found in the literature to be associated with genetic testing-related attitudes and intentions (5). We conceptualized predisposing factors as primary appraisals of the health threat of hereditary colon cancer (15) and concurrent psychological distress. Enabling factors, which may promote or impede practice of the behavior, include: decision preferences and requirements, social support, and health care factors (rapport with physician; and having health insurance, a regular doctor, and a recent routine check-up). Both predisposing factors and enabling factors are proposed as mediators of the effects of demographics and objective cancer risk on genetic counseling interest and testing intentions—in other words, mediators of the mechanism by which these effects are exerted (20).

Although the background factors are hypothesized to affect the mediators (or mediating factors), it is also possible that they are directly associated with the dependent variables. Our hierarchical approach to the multiple regression analyses (explained below) takes both possibilities into account. Although the design of the research reported here is limited to testing whether various constructs explain variation in counseling interest and testing intentions and does not justify causal inferences, we propose this schematic as a heuristic. The associations tested in the present report are the foundation for longitudinal analyses based on this framework in the future.

Materials and Methods

Family Survey of Attitudes toward Genetic Testing for Colon Cancer. Data reported here are from the Family Survey of the Attitudes toward Genetic Testing for Colon Cancer, a self-administered mail survey of FDRs³ of patients diagnosed with colorectal cancer and FDRs of age, sex, and ethnicity-matched, population-based controls that was conducted in 1995 and 1996. These analyses included all siblings and adult children of cases who had a verified FDR with colon cancer and for whom completed reports of FDR cancers (parents and siblings) were available.

The probands and their FDRs were persons originally identified for, and who agreed to participate in, a population-based, case-control study of the genetic epidemiology of colorectal cancer (21). Case probands consisted of men and women diagnosed with invasive adenocarcinoma of the large bowel between 1987 and 1996 through the Hawai'i Tumor Registry. The Hawai'i Tumor Registry, a Surveillance, Epidemiology, and End Results registry since 1973, collects information on all new cancer cases occurring in the state of Hawaii and has a case ascertainment rate of >99%. Eligibility criteria for probands in the parent study included: age 20–59 years; Caucasian, Japanese, or Hawaiian ethnicity; Oahu residency; and histological confirmation of diagnosis. After cases agreed to participate in the study, they were asked to identify parents, siblings, and adult children (over age 18) living in Hawaii. These family members were asked to complete a mailed survey but were not told in the invitation whether they were included due to a family history of colon cancer. This was done to limit response bias and because it was not possible to know in advance whether control family members had such a family history. For the present study, the "Attitudes Toward Genetic Testing" survey was sent to colorectal cancer-free relatives who completed the genetic epidemiology survey from the original study, which had an 85% response rate.

The analyses reported here include all siblings and adult children of case probands. Parents were surveyed but were

³ The abbreviation used is: FDR, first-degree relative.

excluded here because they were not asked about cancers among their children. The total sample size was 426 people from 160 families, and the response rate to the “Attitudes” survey was 77%.

Measures. Data collected from respondents include background information, family history of cancer, prevention and early detection practices, interest in genetic counseling and intentions to obtain genetic testing for colon cancer, and information on the predisposing and enabling factors identified in our conceptual framework. Many of the measures and items for this survey were adapted from standardized tools or previous work reported in the literature. New items were developed after examining available instruments, establishing face and content validity, and conducting pre-tests and pilot tests before the main data collection period. We then used this information to refine the final instrument. We generated summary scores for multi-item scales by summing the item scores and dividing by the number of items answered; Cronbach’s α was used as a measure of scale internal consistency reliability (22).

Background Factors. Background factors that were assessed included ethnicity, sex, age, education, religion, marital status, employment status, occupation, birthplace, and the number of years lived in Hawaii. Cancer risk variables were calculated based on responses to a series of questions about whether a parent and/or sibling had been diagnosed with cancers of the breast, ovary, colon, lung, prostate, or any other cancers.

Mediating Factors. Mediating factors included predisposing factors and enabling factors. For predisposing factors, risk perception was measured by asking how respondents perceived their chances of getting colon cancer or polyps (two items, $\alpha = 0.92$). Cancer-related worry was measured with a four-item scale to assess colon cancer worry ($\alpha = 0.77$), adapted from the scale for ovarian cancer worry developed by Lerman *et al.* (13). General well-being was assessed by the six items on psychosocial well-being from the Medical Outcomes Study Short-Form ($\alpha = 0.79$). The Medical Outcomes Study Short-Form is a self-administered questionnaire that has been extensively tested in ill and healthy populations and found to be internally consistent, reliable, and valid (23). We also asked subjects to rate the importance of 10 possible reasons for wanting genetic testing (“pros”, $\alpha = 0.90$) and 11 possible reasons for not wanting testing (“cons”, $\alpha = 0.90$).

Enabling Factors. Measures of enabling factors used new items developed by the research team using the methods described above, because no suitable items could be found in the literature. Decision preferences items included three questions (yes/no) on whether the respondent would want to make a decision about genetic testing on his/her own, on his own after talking with a counselor, and/or would want to be advised on whether to get testing by a counselor/health provider. Decision requirements items asked if the following should be required before genetic testing (yes/no): recommendation/referral from a physician, information about benefits and risks, and information about how testing would affect personal goals and values.

Social support was measured by asking how often respondents would talk to family member about serious problems, such as a major illness (4-point scale, never too often), and how many family members they had with whom they could talk about serious health problems. These questions were also asked with respect to friends.

Health care attitudes and utilization included an index of rapport with one’s physician (two items, $\alpha = 0.86$), whether the person had health insurance and a regular doctor, and length of time since last routine medical check-up.

Counseling Interest and Testing Intentions. The cover letter that accompanied the survey included a brief description of what predictive genetic testing for colon cancer involves:

“Recent medical discoveries now show that genetic defects may cause serious diseases, including cancer. Genetic defects are passed from generation to generation in some families. Genetic tests analyze blood or tissue samples to predict one’s chances of getting cancer in the future.”

The survey asked whether, on a 4-point scale (from “definitely not” to “definitely yes”) the respondent planned to have a genetic test for colon cancer susceptibility when it becomes available. In another part of the survey, they were asked whether they were interested in participating in counseling or education on genetic testing and colon cancer risk (yes/no).

Statistical Methods. Composite measures of the psychosocial constructs using multiple items were created after preliminary analyses of inter-item associations and internal consistency. Associations between background and mediating factor variables and each of the two binary dependent variables (interest in counseling, intentions for testing) were examined using *t* tests and contingency table analysis (χ^2 tests). Those variables that were found to be significant or marginally significant ($P < 0.10$) were included in subsequent logistic regression analyses.

Multiple logistic regression was used to assess the independent contributions of background variables and mediating factors (predisposing and enabling factors) to binary measures of: (a) interest in counseling and; (b) intentions to obtain genetic testing for colon cancer. Independent variables that were nominal with more than two classes, such as ethnic group, were treated by creating a set of dummy variables for the classes, with one class (the comparison group) being the intercept (24); a multivariate Wald test was used to test for differences in the mean of the dependent variable across the different classes, using the statistical package SPSS-PC (25). Multivariate analyses proceeded in hierarchical fashion, testing blocks of covariates and independent variables shown in Fig. 1: first, covariates (background factors); next, mediating variables (predisposing and enabling factors); and last, the full model (both background factors and mediating variables).

We recognized that the observations of the end point from family members might be correlated due to shared environments and peer effects. Also, the variance of deviations about a regression line might not be constant. Both of these situations could lead to invalid estimates of standard errors when standard statistical procedures are used for estimation. We used a robust method of estimation known as generalized estimating equations or GEE (26, 27), which gives consistent estimates of regression coefficients and standard errors. When observations are independent within families, the SE are asymptotically equivalent to heteroscedastic-consistent estimators of White (28). We used the SAS program Proc GENMOD which, starting with Release 6.12, can compute estimates for generalized models using generalized estimating equations (29). Adjusted for covariates, the family intraclass correlation for intention to obtain testing is 0.09 and the intraclass correlation for interest in counseling is 0.06.

Results

Sample Characteristics. This report includes 274 siblings and 152 adult children of persons with histologically confirmed colorectal cancer diagnosed before age 59 (Table 1). More than three-quarters were of Japanese ethnicity, 11.7% were Hawaiian/part-Hawaiian, and 9.4% were Caucasian. The sample was approximately equally divided between males and

females, with a mean age of 50. Approximately one-third were college graduates, and most reported their religious affiliation as Protestant, Buddhist, or Catholic. About two-thirds were married, and the same number was used full- or part-time. Most respondents were residents of the state of Hawaii for more than 25 years.

Although all respondents were known by us to have a sibling or parent with colon cancer, 25.4% indicated no FDRs with colon cancer. Upon further examination of this surprising finding, we found that Caucasians, females, less educated persons, Catholics, and older subjects tended to be unaware more often (data not shown). Nine % had two or more FDRs with colon cancer. Forty % reported two or more total cases of cancer (breast, ovarian, prostate, colon, and other) among their FDRs.

Counseling Interest, Testing Intentions, and Predisposing and Enabling Factors. Table 2 describes the responses to questions about counseling interest, testing intentions, and predisposing and enabling factors. Nearly one-half of the respondents stated that they were interested in counseling about genetic testing and colon cancer. About one-fourth indicated that they definitely intend to have genetic testing for colon cancer when it is available; almost half said they “probably” intend to obtain testing, and another quarter said they probably would not be tested. The most important reasons cited for wanting to be tested were “so I would be able to take better care of myself,” “to learn if my children were at risk,” and “so I would know if I need to get colon cancer screening tests more often.” Ratings of the importance of reasons for not wanting to be tested were substantially lower overall, with those ranking highest being “it would cost me too much to have the test,” “I’m not sure if the test is accurate,” “I prefer to live with the hope that I don’t have an altered gene” (data not shown in tables).

Mean cancer worry scores averaged between “rarely or not at all” and “sometimes” worrying or being affected by thoughts of getting colon cancer, and mean risk perception scores were just slightly higher than “the same risk as other people my age.” General well-being scores were fairly high, averaging nearly 5 on a scale of 1 to 6.

With respect to decision preferences, the highest proportion of respondents would want to make a decision about cancer genetic testing on their own after talking with a counselor, and two-thirds would want the counselor (or provider) to advise them about whether to be tested. Only 49.1% would want to make a decision on their own. As to pre-test requirements, nearly everyone indicated that information about benefits and risks of testing should be required, whereas a smaller majority felt information about the effect of testing on personal goals and values or a recommendation or referral from a physician should be required. “Yes” answers to these two groups of items (decision preferences and decision requirements) were not mutually exclusive; therefore, some respondents answered “yes” to more than one related question.

Social support from families (“talk often”) was reported among just over one-quarter of respondents and was lower from friends. Average rapport with physicians was very high, and nearly all respondents had health insurance and a regular doctor. 58.8% reported that their last routine medical check-up was within the past year.

Factors Associated with Counseling Interest and Testing Intentions. In bivariate analyses, we found associations between interest in genetic counseling and being younger, more highly educated, and reporting more FDRs with colon cancer but not with ethnicity, gender, or reported total cancers among

Table 1 Demographic characteristics and familial cancers ($n = 426$)^a

Characteristic	<i>n</i>	%
Demographic characteristics		
Relationship to proband		
Sibling	274	64.3
Adult child	152	35.7
Ethnicity		
Japanese	336	78.9
Hawaiian/part-Hawaiian	50	11.7
Caucasian	40	9.4
Sex		
Male	210	49.3
Female	216	50.7
Age (mean \pm SD)		
All respondents	50.0 \pm 16.4 years; range, 19 to 84	
Siblings	59.8 \pm 11.3 years; range, 29 to 84	
Adult children	32.6 \pm 6.8 years; range, 19 to 51	
Education		
High school graduate or less	151	35.7
Some college	146	34.5
College graduate or more	126	29.8
Religion		
Protestant	105	25.0
Catholic	52	12.4
Buddhist	133	31.7
Other	57	13.6
None	73	17.4
Marital status		
Married	269	63.5
Widowed, divorced, separated	68	16.0
Never married	87	20.5
Employment status		
Full-time	233	55.1
Part-time	42	9.9
Retired/not employed	148	35.0
Birthplace		
USA (including Hawaii)	416	98.1
Outside the USA	10	1.9
Years lived in Hawaii		
25 years or less	42	14.0
More than 25 years	259	86.0
Familial cancers (reported)		
Reported colon cancers among FDRs		
None	108	25.4
One	280	65.7
Two	36	8.4
Three	2	0.5
Reported total cancers among FDRs		
None	57	13.4
One	199	46.7
Two	109	25.6
Three	39	9.1
Four	20	4.7
Five	2	0.5

^a Reflects missing data on some questions.

FDRs (Table 3). Other significant associations were found with higher cancer worry and risk perception, wanting to decide after talking with a counselor, requiring information about benefits and risks of testing, and family social support. None of the health care-related factors were significantly associated with interest in counseling.

Bivariate analyses revealed associations between intentions to obtain genetic testing and being older and reporting more total cancers among FDRs but not with ethnicity, gender, education level, or reported FDRs with colon cancer (Table 3).

Table 2 Interest in genetic counseling, intentions to obtain genetic testing, and predisposing and enabling factors among persons at familial risk for colon cancer ($n = 426$)^a

Interest in counseling and intentions for testing				
		<i>n</i>	% ^a	
Interest in counseling on genetic testing and colon cancer risk (Yes)		186	45.5	
Intentions to obtain genetic testing for colon cancer (Definitely Yes)		109	26.0	
Predisposing factors				
	Range	Mean	SD	
Cancer worry	1 = rarely/never to 4 = almost always	1.43	0.45	
Risk perception	1 = much lower to 5 = much higher	3.18	0.91	
Well-being	1 = lowest to 6 = highest	4.97	0.66	
Enabling factors				
		<i>n</i>	% ^a	
Decision Preferences and Requirements				
Would want to make decision on my own, without help from counselor or health provider		209	49.1	
Would want to make decision on my own, after talking with counselor or health provider		375	88.0	
Want counselor or health provider to advise me about whether to be tested		290	68.1	
Before genetic testing, should require. . .				
Recommendation or referral from physician		300	70.4	
Information about benefits and risks of testing		396	93.0	
Information about how testing will affect your personal goals and values		344	80.8	
Social support				
Social support: Family (High/Talk often)		116	27.2	
Social support: Friends (High/Talk often)		46	10.8	
Family members to talk to (3 or more)		277	65.0	
Friends to talk to (3 or more)		218	51.2	
	Range	Mean	SD	
Rapport with doctor	1 = lowest to 4 = highest	3.49	0.54	
		<i>n</i>	% ^a	
Health insurance (Yes)		402	95.7	
Regular doctor (Yes)		376	90.0	
Last routine medical check-up				
Less than 1 year ago		247	58.9	
One year ago or more		172	41.1	

^a Reflects missing data on some items.

Other significant associations were found with higher cancer worry and risk perception, wanting to decide on one's own, and family and friend social support. Testing intentions were also higher among subjects who had a recent medical check-up less than 1 year ago (29.6% versus 19.4%, $P = 0.02$).

Multivariate Analyses. For both dependent variables (interest in counseling and intentions to get genetic testing for colon cancer), the full models accounted for significantly more variance than either the covariates (background factors) or independent variables (predisposing and enabling factors) alone. Logistic regression analysis for the binary variable "interest in genetic counseling" indicated that ethnicity and education level made independent contributions to the model (Table 4). Other variables with significant contributions were cancer worry, perceived risk, and social support from family.

For the binary variable "intentions to get genetic testing for colon cancer," logistic regression analysis showed that age

and ethnicity made independent contributions to the final model, as did several predisposing factors, *i.e.*, cancer worry and perceived risk, and enabling factors, *i.e.*, wanting to decide on one's own and social support from family (Table 5).

Discussion

This study sought to identify demographic, psychosocial, and social influence factors related to intentions to participate in genetic testing and genetic counseling for heritable colon cancer risk among increased-risk relatives from three ethnic groups. Although demographic and familial cancer correlates differed for counseling interest and testing intentions, three psychosocial factors remained significant for both end points: cancer worry, perceived risk, and family social support. The health care factors that we measured, and most of the social influence variables, did not make independent contributions to the models. Cancer worry and perceived risk have been found to be associated with testing intentions and uptake in virtually all other studies where they have been examined (7–9, 11–13) and appear to be correlated with both testing intentions and counseling interest (as was found in the context of risk counseling trials) (14).

We found the conceptual framework used for this analysis to be a valuable organizing scheme. It helped us to clearly separate the relative contributions of background characteristics, intrapersonal factors related to coping and stress (*e.g.*, cancer worry and risk perception, the predisposing factors), and enabling factors, such as social and health systems influences, to counseling and testing intentions. Despite the fact that it is not a single, tightly woven theoretical model, it serves as a useful heuristic here as for other studies of health-related behaviors (30).

Although we found that the reported number of cancers in the family was not significantly associated with intentions to get genetic testing, subjectively reported risk perception was significant. This has also been found in other studies on cancer susceptibility testing (15–17). However, more than one-quarter of the respondents in this study indicated that they did not have a parent or sibling with colon cancer, despite confirmed diagnosis through the Hawaii Tumor Registry. When the relative's cancer was diagnosed at an earlier stage, or at an older age, a sibling or child was significantly less likely to be aware of it. Those who were aware of an FDR's colon cancer also reported more family and friend social support, more cancer worry, and higher perceived risk. This underreporting of family history of cancer may be due to confusion or lack of awareness of a relative's cancer, lack of communication within families, or reluctance to report family history on a mailed survey.

One enabling factor was found to be significant (or showed a trend toward significance) for both counseling interest and testing intentions: family social support, measured in our study as talking often with immediate family members about serious problems, such as a major illness. Although there has been much discussion of the familial aspects of genetic counseling and genetic testing, most other studies have not empirically examined family interaction or support variables. The measure used in this investigation was limited to a single item, and family variables should be examined in greater depth in future studies.

A unique aspect of this study was its focus on the three largest ethnic groups in the state of Hawaii: Japanese, Hawaiian/part-Hawaiian, and Caucasian. Together, these groups constitute nearly two-thirds of the state's residents (31). It is important to note that these are American ethnic groups, not

Table 3 Factors associated with interest in genetic counseling and intentions to obtain genetic testing for colon cancer: Bivariate analyses

	Interest in counseling			Testing intentions		
	Definitely Yes	Other	P	Definitely Yes	Other	P
Demographic characteristics						
Ethnicity (%)			NS ^a			NS
Japanese	44.0	56.0			23.8	76.2
Hawaiian/part-Hawaiian	59.6	40.4		35.4	64.6	
Caucasian	41.0	59.0		35.2	67.5	
Sex (%)			NS			NS
Male	46.1	53.9		26.3	73.7	
Female	44.9	55.1		25.6	74.4	
Age (mean)	48.2	51.1	0.07	53.9	48.3	0.002
Education (%)			0.001			NS
High school graduate or less	33.1	66.9		27.4	72.6	
Some college	50.0	50.0		25.3	74.7	
College graduate or more	55.8	44.2		24.6	75.4	
Familial cancers (reported)						
Reported colon cancers among FDRs (mean)	0.91	0.77	0.02	0.92	0.81	NS
Reported total cancers among FDRs (mean)	1.50	1.39	NS	1.66	1.40	0.03
Predisposing factors						
Cancer worry (mean)	1.53	1.33	0.001	1.60	1.37	0.001
Risk perception (mean)	3.39	3.00	0.001	3.50	3.07	0.001
Well-being (mean)	4.97	4.98	NS	4.94	4.98	NS
Enabling factors						
Decision preferences and requirements (%)						
Would want to make decision on my own, without help from counselor/health provider			NS			0.03
Yes	44.2	55.8		30.8	69.2	
No	46.7	53.3		21.2	78.8	
Would want to make decision on my own, after talking with counselor/health provider			0.02			NS
Yes	47.5	52.5		26.2	73.8	
No	29.8	70.2		23.9	76.1	
Want counselor/health provider to advise me about whether to be tested			NS			NS
Yes	47.0	53.0		23.9	76.1	
No	42.2	57.8		30.5	69.5	
Before genetic testing should require . . . (%)						
Recommendation or referral from physician			NS			NS
Yes	44.1	55.9		23.8	76.2	
No	48.8	51.2		31.1	68.9	
Information about benefits and risks of testing			0.02			NS
Yes	47.0	53.0		26.1	73.9	
No	25.0	75.0		23.1	76.9	
Information about how testing will affect your personal goals and values			NS			NS
Yes	47.0	53.0		25.7	74.3	
No	39.2	60.8		26.9	73.1	
Social support (%)						
Social support: Family			0.01			0.00
Talk often	56.9	43.1		36.5	63.5	
Other	41.3	58.7		22.0	78.0	
Social support: Friends			NS			0.06
Talk often	55.8	44.2		37.8	62.2	
Other	44.3	55.7		24.5	75.5	
Health care-related factors						
Rapport with doctor (mean)	3.47	3.50	NS	3.54	3.48	NS
Health insurance			NS			NS
Yes	45.3	54.7		25.3	74.7	
No	50.0	50.0		33.3	66.7	
Regular doctor			NS			NS
Yes	46.0	54.0		26.8	73.2	
No	43.9	56.1		11.9	88.1	
Last routine medical check-up			NS			0.02
Less than 1 year ago	46.0	54.0		29.6	70.4	
One year ago or more	45.2	54.8		19.4	80.6	

^a NS, not significant.

Table 4 Factors predicting interest in genetic counseling: Logistic regression results

Logistic regression results, using Generalized Estimating Equations to adjust for within-cluster correlation, $n = 380$. Odds ratios compare those who definitely want genetic counseling *versus* others; significant variables in boldface.

	Odds ratio	95% confidence interval	<i>P</i>
Demographic characteristics			
Age (in decades)	0.94	0.77, 1.15	NS ^a
Ethnicity (Caucasian = reference group)			
Japanese	1.03	0.45, 2.37	NS
Hawaiian	2.68	0.91, 7.89	0.07
Education (\leq high school = reference)			
Some college	1.76	0.95, 3.27	0.07
College graduate or higher	1.92	1.02, 3.60	0.04
Familial cancers (reported)^b			
Reported colon cancers in FDRs	1.12	0.63, 2.02	NS
Reported total cancers in FDRs	1.05	0.78, 1.41	NS
Predisposing factors^c			
Cancer worry	2.94	1.61, 5.37	0.001
Risk perception	1.46	1.10, 1.95	0.01
Well-being	1.20	0.87, 1.64	NS
Enabling factors			
Decision preferences and requirements ^d			
Want to decide on my own after hearing pros/cons	1.49	0.73, 3.04	NS
Should require information about benefits/risks	1.96	0.67, 5.71	NS
Social support ^d			
Social support: Family	1.78	1.14, 2.78	0.01
Social support: Friends	1.05	0.52, 2.14	NS
Health care-related factors			
Rapport with doctor ^c	0.89	0.57, 1.37	NS
Regular doctor ^d	1.00	0.44, 2.25	NS
Health insurance ^d	0.73	0.26, 2.03	NS

^a NS, not significant.

^b The probability of being interested in genetic counseling increases by the amount of the odds ratio for a unit increase in the number of reported cases or colon cancer or total cancers (*e.g.*, odds ratio of 1.12 = + 12% for reported colon cancers).

^c A unit increase in the scale score increases interest in counseling by a factor of the odds ratio.

^d Binary measures; the probability of being interested in counseling = odds ratio \times what it is for people who say "low support" or "no" (no regular doctor or no health insurance).

foreign-born subjects. All three groups are long-time U.S. residents; nearly all of our respondents were born in the United States, and 86% had lived in Hawaii for more than 25 years. We found that, compared to Caucasians, Hawaiians were somewhat more interested in genetic counseling, and Japanese were markedly less interested in obtaining genetic testing for colon cancer susceptibility. These differences were observed even after controlling for other sociodemographic differences between the groups.

Of particular importance in interpreting these findings is the disproportionately high rates of colorectal cancer among persons of Japanese ethnic origin living in Hawaii (32), and the recent finding that the population risk of colorectal cancer attributable to a first-degree family history of the disease is nearly twice as high for Japanese (11.1%) as for Caucasians (6.5%) (21). At the same time, Native Hawaiians have disproportionately high mortality rates for most other cancers (33). It is possible that the public attention to Hawaiians' increased cancer risks account for the greater interest in counseling in Hawaiian respondents. Public, professional, patient, and family education may be necessary to increase the use of early detec-

Table 5 Factors predicting intentions to obtain genetic testing for colon cancer: Logistic regression results

Logistic regression results, using Generalized Estimating Equations to adjust for within-cluster correlation, $n = 390$. Odds ratios compare those who definitely intend to obtain genetic testing *versus* others; significant variables in boldface.

	Odds ratio	95% confidence interval	<i>P</i>
Demographic characteristics			
Age (in decades)	1.28	1.01–1.60	0.04
Ethnicity (Caucasian = reference group)			
Japanese	0.36	0.17–0.79	0.01
Hawaiian	1.06	0.39–2.90	NS ^a
Education (\leq high school = reference)			
Some college	1.57	0.75–3.27	NS
College graduate or higher	1.53	0.68–3.45	NS
Familial cancers (reported)^b			
Reported colon cancers in FDRs	0.99	0.54–1.82	NS
Reported total cancers in FDRs	1.01	0.70–1.45	NS
Predisposing factors^c			
Cancer worry	1.99	1.16–3.42	0.01
Risk perception	1.84	1.29–2.62	0.001
Well-being	1.16	0.74–1.83	NS
Enabling factors			
Decision preferences and requirements ^d			
Want to make my own decision	1.65	0.97–2.81	0.07
Social support ^d			
Social support: Family	1.75	0.98–3.12	0.06
Social support: Friends	1.31	0.54–3.15	NS
Health care-related factors			
Rapport with doctor ^c	1.15	0.66–1.99	NS
Regular doctor ^d	1.84	0.65–5.25	NS
Health insurance ^d	0.48	0.13–1.77	NS
Last routine check-up within 1 year ^d	1.12	0.64–1.95	NS

^a NS, not significant.

^b The probability of definite intentions for genetic testing increases by the amount of the odds ratio for a unit increase in the number of reported cases or colon cancer or total cancers (*e.g.*, odds ratio of 1.01 = + 1% for reported total cancers).

^c A unit increase in the scale score increases intentions for testing by a factor of the odds ratio.

^d Binary measures; the probability of intentions to obtain testing = odds ratio \times what it is for people who say "low support" or "no" (no regular doctor, no health insurance, last check-up >1 year ago).

tion tests among Japanese FDRs of colorectal cancer patients. We need to understand more about how cultural factors affect decision making about genetic testing, genetic counseling, and early detection practices.

During the time this survey was conducted, colorectal cancer susceptibility testing was not widely available in this community, although it could be obtained through research protocols, some of which were marketed to physicians by commercial biotechnology companies. Molecular genetic services are likely to be time, labor, and technology intensive (34). Because they can only be cost effective under highly favorable assumptions about risk and the efficacy of preventive strategies (35), it will be important to develop alternatives to individual and family counseling for persons at only moderately increased risk. This might include patient education and education that can be delivered by primary health care providers.

This study has several limitations: (a) the data are based on self-reports in response to mailed surveys, and both non-response bias and social desirability are potential concerns. However, the use of a population-based tumor registry to identify probands and the high response rates (85% to the parent study, 77% to the attitudes survey) partially offsets concerns about non-response bias. The sample demographics were roughly proportional to the ethnic distribution of ear-

lier-onset colorectal cancer in the state of Hawaii (although not to Hawaii's adult population as a whole); (b) the primary outcome variables in the study were interest in counseling and intentions to seek genetic testing for colon cancer susceptibility. We realize that interest and intentions may not predict actual participation, but they do provide an initial indication of potential response to the availability of clinical genetic services. Still, a considerable body of research supports the predictive validity of intentions for a variety of behaviors (18); and (c) this analysis provides an incomplete examination of the proposed conceptual framework, given the limitations of a self-administered questionnaire and the cross-sectional study design.

Despite these limitations, this is one of the first reports of correlates of interest in genetic counseling and intentions to obtain genetic testing for susceptibility to hereditary colorectal cancer. Our findings regarding Japanese and Hawaiian attitudes and intentions are of wider interest, because Asian Americans and Pacific Islanders are the fastest growing ethnic minorities in America (36). The findings of this research can be used to guide the development of effective and responsible counseling strategies for increased-risk families, as well as professional and public education about genetic testing for colorectal cancer and other cancers. The results are of particular interest in relation to ethnic groups at varying degrees of objective population risk.

Acknowledgments

We acknowledge the contributions of Haiou Yang, Rosemary Casey, Lue Ping Zhao, Maj Earle, Ron Myers, Jana Hall, Susan Donlon, Alvin Nakamura, and Gwen Ramelb. We also thank the Hawai'i Tumor Registry, Kaiser-Permanente Medical Center, Kuakini Medical Center, Straub Clinic and Hospital, Queen's Medical Center, and St. Francis Medical Center for their support of this study. The information in this article does not reflect the opinion of any of the participating medical centers.

References

- Cohen, A. M., Shank, B., and Friedman, M. A. Colorectal cancer. *In*: V. T. DeVita, S. Hellman, and A. S. Rosenberg (eds.), *Cancer: Principles and Practice of Oncology*, Ed. 3, pp. 895-964. Philadelphia: J. B. Lippincott Co., 1989.
- National Cancer Institute, Division of Cancer Prevention, and Control, Surveillance Program. *Cancer Statistics Review 1973-1988*. Bethesda, MD: U. S. Department of Health and Human Services, 1991.
- Selby, J., Friedman, G., Quesenberry, C., and Weiss, N. A case-control study of screening sigmoidoscopy and mortality from colorectal cancer. *N. Engl. J. Med.*, 326: 653-657, 1992.
- Lerman, C., Rimer, B., and Engstrom, P. F. Cancer risk notification: psychosocial and ethical implications. *J. Clin. Oncol.*, 9: 1275-1282, 1991.
- Croyle, R., and Lerman, C. Psychological impact of genetic screening. *In*: R. Croyle (ed.), *Psychosocial Effects of Screening for Disease Prevention and Detection*, pp. 11-38. New York: Oxford University Press, 1995.
- Lerman, C., Schwartz, M., Lin, T. H., Hughes, C., Narod, S., and Lynch, H. T. The influence of psychological distress on use of genetic testing for colon cancer risk. *J. Consult. Clin. Psychol.*, 65: 414-420, 1997.
- Jacobsen, P., Valdimarsdottir, H., Brown, K., and Offit, K. Decision-making about genetic testing among women at familial risk for breast cancer. *Psychosomat. Med.*, 59: 459-466, 1997.
- Struewing, J. P., Lerman, C., Kase, R. G., Giambarrresi, T. R., and Tucker, M. A. Anticipated uptake and impact of genetic testing in hereditary breast and ovarian cancer families. *Cancer Epidemiol. Biomark. Prev.*, 4: 169-173, 1995.
- Lerman, D., Marshall, J., Audrain, J., and Gomez-Camirero, A. Genetic testing for colon cancer susceptibility: anticipated reactions of patients and challenges to providers. *Int. J. Cancer*, 69: 58-61, 1996.
- Andrykowski, M. A., Lightner, R., Studts, J. L., and Munn, R. K. Hereditary cancer risk notification and testing: how interested is the general population? *J. Clin. Oncol.*, 15: 2139-2148, 1997.
- Croyle, R. T., and Lerman, C. Interest in genetic testing for colon cancer susceptibility: cognitive and emotional correlates. *Prev. Med.*, 22: 284-292, 1993.
- Smith, K. R., and Croyle, R. T. Attitudes toward genetic testing for colon cancer risk. *Am. J. Public Health*, 85: 1435-1438, 1995.
- Lerman, C., Daly, M., Masny, A., and Balshem, A. Attitudes about genetic testing for breast-ovarian cancer susceptibility. *J. Clin. Oncol.*, 12: 843-850, 1994.
- Vernon, S., Gritz, E., Peterson, S. K., Amos, C. I., Perz, C. A., Baile, W. F., and Lynch, P. M. Correlates of psychologic distress in colorectal cancer patients undergoing genetic testing for hereditary colon cancer. *Health Psychol.*, 16: 73-86, 1997.
- Lazarus, R. S. *Emotion and Adaptation*. New York: Oxford University Press, 1991.
- Heaney, C. A., and Israel, B. A. Social networks and social support. *In*: K. Glanz, F. M. Lewis, and B. K. Rimer (eds.), *Health Behavior and Health Education: Theory, Research and Practice*, Ed. 2, pp. 179-205. San Francisco: Jossey-Bass, Inc., 1997.
- Joos, S., and Hickam, D. How health professionals influence health behavior: patient-provider interaction and health care outcomes. *In*: K. Glanz, F. M. Lewis, and B. K. Rimer (eds.), *Health Behavior and Health Education: Theory, Research and Practice*, pp. 216-241. San Francisco: Jossey-Bass, Inc., 1990.
- Ajzen, I., and Fishbein, M. *Understanding Attitudes and Predicting Social Behavior*. Englewood Cliffs, NJ: Prentice-Hall, Inc., 1980.
- Andersen, R. A Behavioral Model of Families' Use of Health Services. Center for Health Administration Studies, Research Series No. 25. Chicago: University of Chicago Press, 1968.
- Baron, R. M., and Kenny, D. A. The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *J. Pers. Soc. Psychol.*, 51: 1173-1182, 1986.
- LeMarchand, L., Zhao, L. P., Quiaio, F., Wilkens, L. R., and Kolonel, L. N. Family history and risk of colorectal cancer in the multiethnic population of Hawai'i. *Am. J. Epidemiol.*, 144: 1122-1128, 1996.
- Nunnally, J., and Bernstein, I. *Psychometric Theory*, Ed. 3. New York: McGraw-Hill, 1994.
- Tarlov, A. R., Ware, J. E., Greenfield, S., Nelson, E. C., Perrin, E., and Zubkoff, M. The medical outcomes study: an application of methods for monitoring the results of medical care. *J. Am. Med. Assoc.*, 262: 925-930, 1989.
- Hosmer, D., and Lemeshow, S. *Applied Logistic Regression*, p. 307. New York: Wiley, 1989.
- SPSS, Inc. *SPSS for Windows*, v6.1 (12/5/95) and v7.5 (5/16/97). Chicago, IL: SPSS, Inc., 1995 and 1997.
- Liang, K.-Y., and Zeger, S. L. Longitudinal data analysis using generalized linear models. *Biometrika*, 73: 13-22, 1986.
- Diggle, P. J., Liang, K.-Y., and Zeger, S. L. *Analysis of Longitudinal Data*. Oxford: Oxford University Press, 1994.
- White, H. A heteroscedasticity-consistent covariance matrix estimator and a direct test for heteroscedasticity. *Econometrica*, 48: 817-838, 1980.
- SAS Institute, Inc. *SAS/STAT Software. Changes and Enhancements for Release 6.12*, pp. 23-41. Cary, NC: SAS Institute, Inc., 1996.
- Glanz, K., Kristal, A. R., Tilley, B. C., and Hirst, K. Psychosocial correlates of healthful diets among male auto workers. *Cancer Epidemiol. Biomark. Prev.*, 7: 119-126, 1998.
- Department of Commerce, Bureau of the Census. *Census 1990: General Population Characteristics: Hawai'i, 1990 CP-1-13*. Washington, DC: U. S. Department of Commerce, 1991.
- Stemmerman, G. N., Nomura, A. M. Y., and Kolonel, L. N. Cancer among Japanese-Americans in Hawaii. *Gann Monogr. Cancer Res.*, 33: 99-108, 1987.
- US Department of Health, and Human Services, PHS, NCI, DCPC. *Report of the Special Action Committee, 1992: Special Program Initiatives Related to Minorities, the Underserved, and Persons Aged 65 and Over*. Bethesda, MD: Department of Health and Human Services, 1992.
- Surh, L. C., Wright, P. G., Cappelli, M., Kasaboski, A., Hastings, V. A., and Hunter, A. G. Delivery of molecular genetic services within a health care system: time analysis of the clinical workload. The Molecular Genetic Study Group. *Am. J. Hum. Genet.*, 56: 760-768, 1995.
- Brown, M. L., and Kessler, L. G. The use of gene tests to detect hereditary predisposition to cancer: economic considerations. *J. Natl. Cancer Inst.*, 87: 1131-1136, 1995.
- Yu, E. S., and Liu, W. T. U. S. national health data on Asian Americans and Pacific Islanders: a research agenda for the 1990's. *Am. J. Public Health*, 82: 1645-1652, 1992.