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Colorectal Cancer Survivors' Interest in Genetic Testing for Hereditary Cancer: Implications for Universal Tumor Screening

Deborah Cragun,[1] Teri L. Malo,[2] Tuya Pal,[2,3] David Shibata,[2,3] and Susan T. Vadaparampil[1–3]

Aims: Benefits of universal tumor screening for Lynch syndrome (LS), the most common form of hereditary colorectal cancer (CRC), will be realized only if patients are interested in genetic counseling and testing. This study explores interest in genetic testing for hereditary CRC among CRC patients who have never received genetic counseling or testing. *Methods:* Using results from a cross-sectional survey of CRC patients ($n = 91$) at varying categories of risk for hereditary CRC, bivariate and multivariable analyses were conducted to compare positive and negative attitudinal beliefs regarding genetic testing, risk perceptions, demographics, and tumor stage of those who were interested in genetic testing ($n = 61$) and those who were not interested or were not sure ($n = 30$). *Results:* Although significant at the bivariate level, gender, perceived relative risk of hereditary cancer, employment status, and belief that genetic testing would help in preparing for the future were not significantly related to interest in genetic testing when controlling for all other variables in a logistic regression model. The two factors that remained significant include a single-item question measuring the belief that genetic testing is warranted based on personal/family history and a positive attitudinal scale regarding the utility of genetic testing in medical decision making and cancer prevention. *Conclusion:* Results have potential implications for policies regarding universal tumor screening for LS.

Introduction

Among individuals diagnosed with colorectal cancer (CRC), 2%–4% have Lynch syndrome (LS) (Lynch *et al.*, 2009). LS is a hereditary predisposition to CRC and certain malignancies such as endometrial, gastric, and ovarian cancers (Lynch *et al.*, 2009). Historically, testing has been offered to patients at increased risk for LS based on personal and/or family medical histories (Park *et al.*, 1999; Umar *et al.*, 2004). However, in 2009, the Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group recommended all newly diagnosed CRC patients be offered screening for LS (Recommendations from the EGAPP Working Group, 2009).

Following EGAPP recommendations, some centers have established universal tumor screening policies (Peres, 2010). Possible screening protocols include immunohistochemical testing (with or without *BRAF* mutation testing) and/or microsatellite instability testing (Mvundura *et al.*, 2010). With each of these screening approaches, patients with an abnormal result require subsequent germline DNA testing to confirm LS and genetic counseling to discuss results and recommendations.

Diagnosing LS in CRC patients may lead to a more informed discussion regarding surgical treatment options (Natarajan *et al.*, 2010) and alter non-CRC related cancer screening recommendations (Balmaña *et al.*, 2010). In addition, diagnosing LS in a CRC patient can lead to the prevention of cancers in family members found to have LS (Järvinen *et al.*, 2000).

Benefits of LS screening will be realized only if patients are interested in pursuing genetic counseling and testing. In the only peer-reviewed journal article to report follow-up data from universal CRC tumor screening, only 27% of individuals who screened positive pursued genetic counseling and testing (South *et al.*, 2009). Factors influencing the decision to follow up with genetic counseling were not studied. Understanding CRC survivors' interest, motivations, and concerns regarding genetic testing for hereditary CRC may help increase testing acceptance.

Relatively few studies have explored factors associated with interest in or uptake of genetic testing for hereditary CRC among CRC patients (Vernon *et al.*, 1999; Kinney *et al.*, 2000, 2001; Esplen *et al.*, 2001, 2007; Keller *et al.*, 2002, 2004; Loader *et al.*, 2002; Hadley *et al.*, 2003; Ramsey *et al.*, 2003; Balmaña *et al.*, 2004; Ramsoekh *et al.*, 2007; Keogh *et al.*, 2009; Metcalfe *et al.*, 2009). In addition to provider recommendation (Esplen *et al.*, 2007), interest in and uptake of genetic testing among CRC patients has been consistently

[1]Department of Community and Family Health, College of Public Health, University of South Florida, Tampa, Florida.
[2]Moffitt Cancer Center, Tampa, Florida.
[3]Department of Oncologic Science, University of South Florida, College of Medicine, Tampa, Florida.

associated with or attributed to psychosocial factors (e.g., helping other family members; determining cancer risks for offspring; improving one's ability to make more informed decisions about cancer treatment/screening; increasing one's ability to plan for the future, and more frequent worry about CRC being hereditary) (Vernon *et al.*, 1999; Kinney *et al.*, 2000, 2001; Esplen *et al.*, 2001, 2007; Hadley *et al.*, 2003; Ramsey *et al.*, 2003; Balmaña *et al.*, 2004; Metcalfe *et al.*, 2009). Participants in most of these studies were already pursuing genetic counseling/testing and/or were known to be at high risk for hereditary CRC. In the few studies where this was not the case (Kinney *et al.*, 2000, 2001; Ramsey *et al.*, 2003), quantitative analyses were not performed to determine which attitudinal factors specific to genetic testing outcomes were most strongly correlated with interest in testing.

Understanding genetic testing interest among CRC patients at all levels of risk for hereditary CRC and identifying attitudinal differences between patients based on their interest in testing is necessary to develop a successful universal tumor screening program. The specific purposes of this study are to explore differences between CRC survivors who did and did not express interest in having genetic testing for hereditary CRC if it were made available to them and to determine which factors most strongly correlate with interest in genetic testing.

Materials and Methods

Participant recruitment and data collection

Secondary data analysis was conducted on de-identified, cross-sectional survey data that were collected between April 2005 and January 2006 at a comprehensive cancer center in Florida. Individuals who were eligible for the study included 326 cancer registry patients who were diagnosed with CRC between the years 1999 and 2004. Details regarding recruitment are described by Vadaparampil *et al.* (2010).

Measures

Sociodemographic and medical characteristics. The questionnaire asked participants to provide sociodemographic information including age, race, ethnicity, marital status, education, occupation, employment status, and income. Medical characteristics including disease stage, treatment, and CRC recurrence status were asked on the patient survey and verified with medical records.

Intention to pursue genetic testing. Intention to pursue genetic testing was assessed with a single question, "*A genetic test for hereditary colon cancer is a blood test to determine which members of families have hereditary changes or alterations in certain genes that may increase their risk of colon cancer. If such a test were available to you, would you want to take the test?*" Response options included: "*yes, definitely*"; "*yes, probably*"; "*not sure*"; "*no, probably not*"; and "*no, definitely not*." Responses were then dichotomized by collapsing the yes categories into a single group and the other three categories into a second group.

Risk perceptions. Perceptions of risk for hereditary CRC were measured using three separate questions. The first question, *"Compared to a person with a similar personal and family history of cancer, what do you think the chances are that you are a carrier of an altered colon cancer gene?"* Response options included: "*much higher*"; "*higher*"; "*the same*"; "*lower*"; and "*much lower*." The responses were later collapsed to form three perceived relative risk categories (higher, the same, lower). The second question asked, *"On a scale from 0% to 100%, what do you think your chances are of having an altered colon cancer gene, where 0 is no chance of having it and 100 means you definitely have it?"* Responses were kept as a continuous variable which captured the participants' perceived absolute risk. The third question was used to represent whether participants felt their risks were high enough to justify having genetic testing for hereditary CRC. The question was, *"Do you consider yourself to be an appropriate candidate for this genetic testing, given your personal and/or family history of cancer?"* Response options included: "*yes, definitely*"; "*yes, probably*"; "*not sure*"; "*no, probably not*"; and "*no, definitely not*." Responses were then dichotomized by collapsing the yes categories into a single group and the other three categories into a second group.

Attitudes regarding genetic testing for hereditary CRC. Attitudes about genetic testing for hereditary CRC were assessed using a modified version of the "Motivations and Concerns for GeNEtic Testing questionnaire" (Balmaña *et al.*, 2004). The modified scale consists of 27 items. As shown in Table 1, the items cover five general categories: (1) gaining knowledge for medical care and prevention, (2) fear of discrimination, (3) familial influences on the decision to undergo genetic testing, (4) planning for the future, and (5) inability to cope with the test results. All items were rated on a 5 point Likert-type scale (1 = *strongly disagree*, 2 = *disagree*, 3 = *neither agree nor disagree*, 4 = *agree*, 5 = *strongly agree*). After removing one item from two of the subscales, all five subscales exhibited adequate to good internal consistency reliability with Cronbach's alphas ranging from 0.71 to 0.94 (Table 1).

Average subscale scores were created for individuals who answered six or more of the eight items from the "medical care and prevention" subscale, four or more of the six items from the "fear of discrimination" subscale, two or more of the three items from the "negative familial influence" subscale, two or more of the three items in the "planning for the future" subscale, and three or more of the five items comprising the "inability to cope" subscale. Each subscale score ranges from 1 to 5.

Empirical risk for hereditary cancer. Empirical risks were calculated based on self-reported family medical history data and verified by matching patient reported data with cancer registry records. Participants were considered to be at moderate to high risk for hereditary cancer if they met the following NCCN criteria (Levin *et al.*, 2003): (1) early age onset of CRC (< age 50), (2) clustering of same or related cancer in a first degree relative, (3) multiple CRCs in a patient, or (4) >10 adenomas in the same individual. Low risk patients were categorized by the absence of all aforementioned risk criteria.

Data analysis

Data were analyzed using SPSS 19.0. Descriptive analyses were performed for all participants. Bivariate comparisons were made between those who indicated that they would have genetic testing and those who would not or were not sure if they would have genetic testing using independent samples t-tests for continuous variables and chi-square tests

Table 1. List of Items Included in Each of the Five Subscales from the Modified Motivations and Concerns About Genetic Testing for Hereditary Cancer Syndromes

Medical Care and Prevention ($\alpha = 0.935$)
I want to learn my test result, so I can get appropriate medical care.
If I have an altered gene, I want to know.
Learning my results will help me to prevent cancer in the future.
I want to know what my chances are of getting cancer again.
Learning my test results will allow me to plan better for the future.
Learning my results will help my doctor and me to make a plan for monitoring for signs of cancer.
Learning my results will help my doctor and me make decisions about treatment.
I want to learn my results, so I will know my children's chances of getting cancer.
Fear of Discrimination ($\alpha = 0.829$)
I am worried about losing my health insurance if I have an altered cancer susceptibility gene.
I may be discriminated against if I learn my results.
If I have an altered cancer susceptibility gene I will not be able to obtain or maintain life insurance.
Having an altered cancer susceptibility gene will make it difficult for my family members to get or keep health insurance.
I am worried about the consequences if my employer finds out my results.
I won't be able to control who gets to learn my results.
Negative Familial Influence ($\alpha = 0.728$)
Some of my children don't want to know whether we have an altered cancer susceptibility gene.
My partner will be angry if I go ahead with testing.
My partner does not want to know whether I have an altered cancer susceptibility gene.
It is important for my partner that I am tested. (reverse coded)[a]
Future Planning ($\alpha = 0.768$)
Learning my results will help me make decisions about marriage and family.
Knowing that I DO have an altered cancer susceptibility gene will help me to live my life to the fullest.
Knowing that I DO NOT HAVE an altered cancer susceptibility gene will help me to live my life to the fullest.
Learning my results will help me make decisions about having children.[a]
Inability to Cope ($\alpha = 0.705$)
I do not know how I would cope with knowing that I have an altered cancer susceptibility gene.
It seems wrong to have this type of testing. Time will tell if I have an altered gene.
Learning my results will be upsetting to me.
It would be overwhelming to know that I have an extremely high chance of developing cancer.
Knowing my results will change how I feel about myself.

[a]Question was not included in the final subscale due to reliability concerns.
Cronbach's alphas for the final subscales are listed in parentheses next to each subscale.

for categorical variables. Variables from bivariate analyses that were statistically significant at a two-sided critical alpha of ≤ 0.05 were entered as a single block into a logistic regression model to determine whether they remained statistically significant ($p \leq 0.05$) after controlling for other variables in the model. Only cases with complete data were used in the logistic regression model.

Results

Sample

Of the 326 eligible participants, 128 could not be reached during the data collection period, leaving 198 potential participants for the study. After being contacted by the study coordinator, 16 failed to meet eligibility and 75 declined study participation. Among those who were contacted and met eligibility criteria, the response rate was 59% ($n = 107$).

From this sample of 107, those who answered "*yes*" or had a missing response to the following questions were excluded from the current study: (1) *Have you had a counseling session with a health care provider (*i.e., *a genetic counselor or nurse specialist) to determine if you would be a candidate for genetic testing for colon cancer?* ($n = 9$); and (2) *Have you ever had a genetic test (*i.e., *a nurse or other health care professional drew your blood) to see if you carried a gene that may put you at risk for hereditary cancer?* ($n = 4$). Lastly, participants were excluded if they did not answer the question regarding their interest in genetic testing ($n = 5$). Once exclusions were made, 91 participants remained.

The final sample ($n = 91$) was predominately male (59.3%), White (94.4%), married (69.2%), had attended at least some college (65.5%), retired (52.2%), and had health insurance (97.8%). The average age of participants at the time of the study was 65.0 years ($SD = 11.9$, range = 35–93). Additionally, 81.2% were diagnosed with CRC at or after age 50, 60.9% had a Stage 1 or 2 tumor, and 59.3% were at low risk for having hereditary CRC based on family and medical history records.

Differences based on interest in genetic testing

Results from comparisons between those who would have genetic testing ($n = 61$) and those who would not or were not sure if they would have genetic testing ($n = 30$) are shown in Tables 2 and 3. Those who would have genetic testing scored significantly higher on the "Prepare for the Future" and "Medical Care and Prevention" attitudinal subscales. Groups also differed in terms of gender, employment status, perceived risk relative to others, and belief that their risk makes them an appropriate candidate for genetic testing.

Table 4 shows results from the logistic regression model. After controlling for other variables in the model, the belief

Table 2. Comparisons of Colorectal Cancer Patients Who Would Not and Those Who Would Have Genetic Testing with Regard to Age, Perceived Absolute Risk of Hereditary Colorectal Cancer, and Genetic Testing Attitude Subscales

Variable	n[a]	*Not have test/not sure* n = *30* *mean (SD)*	*Would have test* n = *61* *mean (SD)*	t	*df*	p
Age	90	68.66 (14.15)	63.21 (10.32)	1.85[b]	43	0.071
Perceived absolute risk[c]	73	48.67 (31.9)	55.8% (30.3)	−0.93	71	0.350
Inability to cope with results[d]	84	2.64 (0.76)	2.29 (0.75)	1.79	82	0.077
Negative familial influence[d]	80	2.12 (0.72)	1.92 (0.77)	1.07	78	0.288
Fear of discrimination[d]	83	2.59 (0.71)	2.43 (0.86)	0.82	81	0.417
Prepare for the future[d]	84	2.71 (1.02)	3.38 (0.97)	−2.91	82	0.005[e]
Medical care and prevention[d]	84	2.94 (0.94)	4.00 (0.75)	−5.53	82	<0.0001[e]

[a]Total number of participants varies due to missing responses for some items.
[b]Satterthwaite test statistic used due to unequal variances.
[c]Values for perceived absolute risks are percentages with a possible range of 0%–100%.
[d]Values indicate averages of attitudinal items rated on a scale from 1 to 5.
[e]Independent samples t-test is statistically significant at a two-sided critical alpha level of 0.05.

that risk justifies genetic testing and a higher score on the "Medical Care and Prevention" subscale both significantly increase the odds of intention to pursue genetic testing. All other variables were not statistically significant. The logistic regression model was able to correctly classify 84.5% of the individuals into one of two groups, those who were definitely or probably interested in genetic testing and those who were not interested or were unsure.

Discussion

Results from this exploratory study provide several insights that may be useful when implementing universal tumor screening for LS. Universal tumor screening presents an opportunity to identify most of the estimated 28% to 50% of individuals with LS who would not otherwise be identified with the common practices of limiting tumor screening to

Table 3. Comparison of Those Who Would and Those Who Would Not Have Genetic Testing with Regard to Demographic and Categorical Hereditary Cancer Risk Variables

Variable	*Not have test/not sure* n (%)[a]	*Would have test* n (%)[a]	χ^2	*df*	p
Gender (*n* = 91)					
Female	17 (56.7)	20 (32.8)	4.75	1	0.029[b]
Male	13 (43.3)	41 (67.2)			
Employment status (*n* = 90)[c]					
Employed	5 (16.6)	26 (43.3)	6.23	1	0.012[b]
Unemployed/retired	25 (83.3)	34 (56.7)			
Education level (*n* = 90)[c]					
High school or less	13 (43.3)	18 (30.0)	1.57	1	0.210
At least some college	17 (56.7)	42 (70.0)			
Tumor Stage (*n* = 86)[c]					
Stage 0 or 1	10 (35.7)	13 (22.4)	4.34	2	0.114
Stage 2	11 (39.3)	17 (29.3)			
Stage 3 or 4	7 (25.0)	28 (48.3)			
Perceived relative risk (*n* = 82)[c]					
Lower than others	10 (35.7)	7 (13.0)	6.88	2	0.032[b]
Equal to others	13 (46.4)	27 (50.0)			
Higher than others	5 (17.9)	20 (37.0)			
Risk justifies genetic test (*n* = 91)					
Yes	5 (16.6)	47 (77.0)	29.94	1	<0.001[b]
No/uncertain	25 (83.3)	14 (23.0)			
Empiric risk for hereditary CRC (*n* = 91)					
Medium to high	16 (53.3)	21 (34.4)	2.98	1	0.084
Low	14 (46.7)	40 (65.6)			

[a]Column percentages for each variable are adjusted for missing data and may not total 100 due to rounding error.
[b]Chi-square test is statistically significant at a two-sided critical alpha level of 0.05.
[c]Total number is <91 due to missing responses.
CRC, colorectal cancer.

Table 4. Logistic Regression Results Showing the Estimates and Adjusted Odds of Intention to Pursue Genetic Testing if it were Available ($n = 79$)

Variable	*Estimate (SE)*	*Odds ratio*[a]	*95% CI*	p
Gender				
Male	Reference	Reference		
Female	−0.30 (0.68)	0.74	0.20–2.81	0.661
Employment status				
Unemployed/retired	Reference	Reference		
Employed	0.19 (0.82)	1.21	0.243–5.98	0.818
Perceived relative risk				
Higher than others	Reference	Reference		
Same as others	−0.23 (0.87)	0.80	0.15–4.40	0.796
Lower than others	0.89 (1.04)	2.41	0.31–18.56	0.398
Risk justifies genetic testing				
No	Reference	Reference		
Yes	2.55 (0.82)	12.75	2.58–62.93	0.002[b]
Medical care and prevention (attitudinal subscale)[c]	1.86 (0.78)	6.39	1.37–29.70	0.018[b]
Prepare for the future (attitudinal subscale)	−0.65 (0.63)	0.52	0.15–1.79	0.302

[a]Odds ratios are adjusted for all other variables in the model.
[b]Odds ratio is statistically significant at a critical alpha level of 0.05.
[c]Scale ranges from 1 to 5; for every 1 point increase on the scale there is a 6.39-fold increase in the odds of wanting genetic testing when controlling for all other variables in the model.

patients who fulfill family history or age criteria (Hampel *et al.*, 2008; Mvundura *et al.*, 2010).

Evidence to recommend universal tumor screening for LS is strong (Palomaki *et al.*, 2009; Recommendations from the EGAPP Working Group, 2009; Sjursen *et al.*, 2010; Tranø *et al.*, 2010); however, there is little evidence regarding real-life effectiveness of screening programs (Hall, 2010). Tumor screening will be effective only if CRC patients are interested in genetic testing. The current study found that the percentage of CRC survivors interested in genetic testing for hereditary CRC (67%) was comparable to the percentage found by Kinney *et al.* (2000) in a survey of 98 CRC patients (72%). These two studies provide the only published estimates that could be identified regarding interest in genetic testing among CRC patients who are not already known to be at high risk for hereditary cancer or pursuing genetic counseling. Nevertheless, the level of interest in genetic testing reported in these two studies may not be representative of CRC patients in general due to sampling issues and potential participation bias. Nonparticipants would in all likelihood be less inclined to pursue genetic testing for many of the same reasons they chose not to participate in the respective surveys (e.g., medical complications from cancer treatment). As such, it is possible that a substantial proportion of CRC patients (at least 28%–33%) are not interested in or are uncertain whether they would undergo genetic testing for hereditary CRC if it were made available to them.

Based on results from the current study, lack of interest in genetic testing may be partially explained by a lack of belief that personal and/or family history makes individuals appropriate candidates for testing. This finding is clinically relevant because universal tumor screening programs that require informed consent may have relatively low rates of uptake unless patients are convinced that they are appropriate candidates for screening. Automatic screening of all tumors may be more successful because a positive screen, even in the absence of a strong family history of cancer, may lead to increased interest in confirmatory germline testing if it convinces patients that they are appropriate candidates for such testing. However, the only published data currently available from a center performing automatic screening on tumors from all CRC patients suggests that this approach may not necessarily lead to increased test uptake as only 27% of those who screened positive proceeded with genetic counseling (South *et al.*, 2009).

The current study also suggests that the benefits of genetic testing for hereditary CRC are more important than the barriers in the decision making process among this population of CRC patients who had not received genetic counseling/testing. These attitudinal factors were similar to those commonly reported among other populations, including: clinic samples of CRC patients who were pursuing genetic counseling/testing (Vernon *et al.*, 1999; Esplen *et al.*, 2001; Balmaña *et al.*, 2004); individuals at moderate to high risk for hereditary CRC who underwent genetic counseling as part of a research study (Hadley *et al.*, 2003; Esplen *et al.*, 2007); CRC patients who participated in focus groups (Kinney *et al.*, 2001; Ramsey *et al.*, 2003); and 98 CRC patients, the majority of whom were at low risk for hereditary CRC (Kinney *et al.*, 2000).

After controlling for other variables in the model, the current study failed to find statistically significant relationships between interest in genetic testing and various demographic factors including age, gender, disease stage, level of education attained, and employment status. Among the few studies of CRC patients where significant relationships between demographic variables and genetic testing interest/uptake were found, the magnitude of associations appeared to be relatively small in most cases (Vernon *et al.*, 1999; Kinney *et al.*, 2000; Loader *et al.*, 2002; Keller *et al.*, 2004). Given that demographic variables generally cannot be altered, attitudinal factors that strongly correlate with interest in genetic testing may serve as better leverage points or targets for increasing interest in genetic testing in order to maximize the effectiveness of universal tumor screening for LS.

Although interest in genetic testing may be a necessary precursor for action, uptake of testing is generally lower

than interest (Keller *et al.*, 2004). One potential reason for the discrepancy between interest and uptake may be financial barriers. Costs associated with tumor screening range from ~$250 to $500, depending on the laboratory and screening strategy. Whereas, costs associated with confirmatory germline testing for LS are higher, generally around $900 to $3,000 depending on the number of genes tested. The percentage of participants in this study who would be willing to pay $2,000 for genetic testing (13.6%; data not shown) was substantially lower than the 67% who were interested in having genetic testing. Assessing the maximum amount that individuals would be able/willing to pay and determining the likelihood that insurance would cover costs associated with both tumor screening and gene sequencing may be helpful before implementing universal tumor screening as this will likely affect screening interest, uptake, and overall effectiveness. Unfortunately, published information regarding insurance coverage for LS screening and germline testing is limited.

The current study provides data to refine assumptions used in modeling the cost-effectiveness of universal tumor screening. A previous paper modeling universal tumor screening assumed that 2/3 of CRC patients will pursue voluntary screening; and of those who screen positive, all will undergo confirmatory gene sequencing (Mvundura *et al.*, 2010). In a more recently published cost-effectiveness study, the baseline assumption was that screening would be performed on all CRC tumors and 90% of probands with CRC would accept confirmatory gene sequencing following a positive screen (Ladabaum *et al.*, 2011). Our findings suggest these percentages may be overestimates.

Although results from this study illuminate important considerations when implementing universal tumor screening for LS, findings should be considered in light of certain limitations. First, interest in genetic testing may substantially change when patients are given results from a positive tumor screen. Second, the relatively small sample size may result in limited power to detect small effect sizes and likely contributes to the large confidence intervals associated with the calculated odds ratios. Third, not all factors that might correlate with testing interest were measured. Specifically, worry about carrying a cancer susceptibility gene should be included in future studies. Fourth, the cross-sectional nature of the current study does not allow for causation to be determined. Fifth, nonrandom recruitment methods, a relatively homogeneous sample with regard to certain demographic characteristics, and potential for nonresponse bias may limit the ability to generalize study findings. Lastly, attitudes toward genetic testing may have shifted since this data were collected. However, no published studies describing changes in genetic testing attitudes over the last six years could be identified. Given these limitations, additional studies are needed that explore factors associated with patients' intentions to pursue genetic testing in response to a positive tumor screen and determine how well intentions correspond with uptake of genetic counseling/testing.

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No competing financial interests exist. All authors listed above report having no actual or perceived financial or personal relationships that might bias their work or create a conflict of interest. The study sponsor played no role in any aspect of this study design, data collection, data analysis, data interpretation, or decisions regarding article submission.

References

Balmaña J, Castells A, Cervantes A (2010) Familial colorectal cancer risk: ESMO Clinical Practice Guidelines. Ann Oncol 21 Suppl 5:v78–v81.

Balmaña J, Stoffel EM, Emmons KM, *et al.* (2004) Comparison of motivations and concerns for genetic testing in hereditary colorectal and breast cancer syndromes. J Med Genet 41:e44.

Esplen MJ, Madlensky L, Aronson M, *et al.* (2007) Colorectal cancer survivors undergoing genetic testing for hereditary non-polyposis colorectal cancer: motivational factors and psychosocial functioning. Clin Genet 72:394–401.

Esplen MJ, Madlensky L, Butler K, *et al.* (2001) Motivations and psychosocial impact of genetic testing for HNPCC. Am J Med Genet 103:9–15.

Hadley DW, Jenkins J, Dimond E, *et al.* (2003) Genetic counseling and testing in families with hereditary nonpolyposis colorectal cancer. Arch Intern Med 163:573–582.

Hall MJ (2010) Counterpoint: implementing population genetic screening for Lynch Syndrome among newly diagnosed colorectal cancer patients—will the ends justify the means? J Natl Compr Canc Netw 8:606–611.

Hampel H, Frankel WL, Martin E, *et al.* (2008) Feasibility of screening for Lynch syndrome among patients with colorectal cancer. J Clin Oncol 26:5783–5788.

Järvinen HJ, Aarnio M, Mustonen H, *et al.* (2000) Controlled 15-year trial on screening for colorectal cancer in families with hereditary nonpolyposis colorectal cancer. Gastroenterology 118:829–834.

Keller M, Jost R, Haunstetter CM, *et al.* (2002) Comprehensive genetic counseling for families at risk for HNPCC: impact on distress and perceptions. Genet Test 6:291–302.

Keller M, Jost R, Kadmon M, *et al.* (2004) Acceptance of and attitude toward genetic testing for hereditary nonpolyposis colorectal cancer: a comparison of participants and nonparticipants in genetic counseling. Dis Colon Rectum 47:153–162.

Kinney AY, Choi YA, DeVellis B, *et al.* (2000) Attitudes toward genetic testing in patients with colorectal cancer. Cancer Pract 8:178–186.

Kinney AY, DeVellis BM, Skrzynia C, *et al.* (2001) Genetic testing for colorectal carcinoma susceptibility: focus group responses of individuals with colorectal carcinoma and first-degree relatives. Cancer 91:57–65.

Keogh LA, van Vliet CM, Studdert DM, *et al.* (2009) Is uptake of genetic testing for colorectal cancer influenced by knowledge of insurance implications? Med J Aust 191:255–258.

Ladabaum U, Wang G, Terdiman J, *et al.* (2011) Strategies to identify the lynch syndrome among patients with colorectal cancer: a cost-effectiveness analysis. Ann Intern Med 155: 69–79.

Loader S, Shields C, Levenkron JC, *et al.* (2002) Patient vs. physician as the target of educational outreach about screening for an inherited susceptibility to colorectal cancer. Genet Test 6:281–290.

Levin B, Barthel JS, David D, *et al.* (2003) Colorectal cancer screening: The NCNN colorectal screening clinical practice guideline, version 1.2003. Available at http://nccn.org/physician_gls/index.html, accessed March 29 2004.

Lynch HT, Lynch PM, Lanspa SJ, *et al.* (2009) Review of the Lynch syndrome: history, molecular genetics, screening,

differential diagnosis, and medicolegal ramifications. Clin Genet 76:1–18.
Metcalfe A, Werrett J, Burgess L, *et al.* (2009) Cancer genetic predisposition: information needs of patients irrespective of risk level. Fam Cancer 8:403–412.
Mvundura M, Grosse SD, Hampel H, *et al.* (2010) The cost-effectiveness of genetic testing strategies for Lynch syndrome among newly diagnosed patients with colorectal cancer. Genet Med 12:93–104.
Natarajan N, Watson P, Silva-Lopez E, *et al.* (2010) Comparison of extended colectomy and limited resection in patients with lynch syndrome. Dis Colon Rectum 53:77–82.
Palomaki GE, McClain MR, Melillo S, *et al.* (2009) EGAPP supplementary evidence review: DNA testing strategies aimed at reducing morbidity and mortality from Lynch syndrome. Genet Med 11:42–65.
Park JG, Vasen HF, Park KJ, *et al.* (1999) Suspected hereditary nonpolyposis colorectal cancer: International Collaborative Group on Hereditary Non-Polyposis Colorectal Cancer (ICG-HNPCC) criteria and results of genetic diagnosis. Dis Colon Rectum 42:710–716.
Peres J (2010) To screen or not to screen for Lynch syndrome. J Natl Cancer Inst 102:1382–1384.
Ramsey SD, Wilson S, Spencer A, *et al.* (2003) Attitudes towards genetic screening for predisposition to colon cancer among cancer patients, their relatives and members of the community. Results of focus group interviews. Community Genet 6:29–36.
Ramsoekh D, van Leerdam ME, Tops CMJ, *et al.* (2007) The use of genetic testing in hereditary colorectal cancer syndromes: genetic testing in HNPCC, (A)FAP and MAP. Clin Genet 72:562–567.
Recommendations from the EGAPP Working Group (2009) Genetic testing strategies in newly diagnosed individuals with colorectal cancer aimed at reducing morbidity and mortality from Lynch syndrome in relatives. Genet Med 11:35–41.
Sjursen W, Haukanes BI, Grindedal EM, *et al.* (2010) Current clinical criteria for Lynch syndrome are not sensitive enough to identify MSH6 mutation carriers. J Med Genet 47:579–585.
South CD, Yearsley M, Martin E, *et al.* (2009) Immunohistochemistry staining for the mismatch repair proteins in the clinical care of patients with colorectal cancer. Genet Med 11:812–817.
Tranø G, Sjursen W, Wasmuth HH, *et al.* (2010) Performance of clinical guidelines compared with molecular tumour screening methods in identifying possible Lynch syndrome among colorectal cancer patients: a Norwegian population-based study. Br J Cancer 102:482–488.
Umar A, Boland CR, Terdiman JP, *et al.* (2004) Revised Bethesda Guidelines for hereditary nonpolyposis colorectal cancer (Lynch syndrome) and microsatellite instability. J Natl Cancer Inst 96:261–268.
Vadaparampil ST, Quinn G, Malo TL, *et al.* (2010) Knowledge about hereditary colorectal cancer among colorectal cancer survivors. Genet Test Mol Biomarkers 14:603–609.
Vernon SW, Gritz ER, Peterson SK, *et al.* (1999) Intention to learn results of genetic testing for hereditary colon cancer. Cancer Epidemiol Biomarkers Prev 8:353–360.

Address correspondence to:
Susan T. Vadaparampil, Ph.D., M.P.H.
Moffitt Cancer Center
12902 Magnolia Drive
MRC-CANCONT
Tampa, FL 33612

E-mail: susan.vadaparampil@moffitt.org