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Changes in screening behaviors and attitudes toward screening from pre-test genetic counseling to post-disclosure in Lynch syndrome families

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Abstract

Purpose—This study examined colonoscopy adherence and attitudes towards colorectal cancer (CRC) screening in individuals who underwent Lynch syndrome genetic counseling and testing.

Methods—We evaluated changes in colonoscopy adherence and CRC screening attitudes in 78 cancer-unaffected relatives of Lynch syndrome mutation carriers before pre-test genetic counseling (baseline) and at 6 and 12 months post-disclosure of test results (52 mutation-negative, 26 mutation-positive).

Results—While both groups were similar at baseline, at 12 months post-disclosure, a greater number of mutation-positive individuals had had a colonoscopy compared with mutation-negative individuals. From baseline to 12 months post-disclosure, the mutation-positive group demonstrated an increase in mean scores on measures of colonoscopy commitment, self-efficacy, and perceived benefits of CRC screening, and a decrease in mean scores for perceived barriers to CRC screening. Mean scores on colonoscopy commitment decreased from baseline to 6 months in the mutation-negative group.

Conclusion—Adherence to risk-appropriate guidelines for CRC surveillance improved after genetic counseling and testing for Lynch syndrome. Mutation-positive individuals reported increasingly positive attitudes toward CRC screening after receiving genetic test results, potentially reinforcing longer term colonoscopy adherence.

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Conflict of Interest

The authors declare no conflicts of interest.

Keywords

Lynch syndrome; colorectal cancer screening; genetic counseling and testing; colonoscopy commitment; benefits of and barriers to screening

Introduction

Lynch syndrome, also known as hereditary non-polyposis colorectal cancer (HNPCC), is an autosomal dominant hereditary syndrome characterized by a predisposition to several adult-onset cancers, most commonly colorectal cancer (CRC). Lynch syndrome is attributed to mutations in DNA mismatch repair (MMR) genes (including MLH1, MSH2, MSH6, and PMS2).^{1–5} Compared with the general population, Lynch syndrome mutation carriers have higher lifetime risks for multiple cancers; CRC risk is estimated to be as high as 60% for men and 30% for women, and women also are estimated to have up to a 60% risk of developing endometrial cancer.^{6,7} Individuals with Lynch syndrome also are at increased lifetime risk for ovarian, stomach, small bowel, hepatobiliary tract, pancreatic, urinary tract, brain, and skin cancers.^{6–8}

Features of Lynch syndrome-related CRCs that distinguish them from sporadic CRCs include: 1) earlier average age of onset (45 years for Lynch syndrome-related CRCs versus 63 years in the general population); 2) accelerated carcinogenesis (tiny adenomas can develop carcinomas within 2–3 years versus 8–10 in the general population); and 3) increased survival from CRC.⁸ Additionally, Lynch syndrome-associated CRC survivors have an increased risk of developing second primary cancers. Lynch syndrome CRC survivors who underwent less than subtotal colectomy as treatment for their primary cancer have a 25–30% higher risk of developing a second primary CRC within 10 years of their original diagnosis.⁸

High-risk management recommendations for Lynch syndrome mutation carriers include colonoscopy and screening for endometrial and other cancers associated with the syndrome.^{6,8} Current CRC surveillance recommendations include annual or biennial colonoscopy, initiated by age 25 or 10 years prior to the youngest age at diagnosis in the family (whichever is younger).^{6, 8–12} Individuals who have not had genetic testing, but are at increased risk for Lynch syndrome based on their family cancer history, are advised to follow the same guidelines.⁶ Studies have shown that regular colonoscopies have decreased CRC incidence for mutation-positive individuals when compared with controls, and have improved overall and CRC-related survival for individuals with Lynch syndrome.^{13–15}

Adherence to CRC surveillance is extremely important for those with Lynch syndrome, and studies have examined colonoscopy use or attitudes toward colonoscopy among this group.^{16–24} Findings generally indicate high rates of short and long-term colonoscopy adherence in Lynch syndrome mutation carriers,^{14,15,18,20,22–25} with some exceptions.^{17,21,26} These findings suggest that genetic counseling and testing for hereditary cancer risk may offer a teachable moment to encourage improvements in screening behaviors.²⁷

In prior studies, correlates of colonoscopy adherence among Lynch syndrome mutation carriers have included: 1) having been referred for genetic counseling and testing, 2) being older, 3) having a personal history of cancer, 4) communication of test results to a personal physician, 5) perceived control over developing CRC, and 6) having a first-degree relative under the age of 50 with CRC.^{18,23,26} However, relatively few studies have examined individual-level constructs associated with screening adherence from the health behavior change literature. In this study, we examined attitudes toward CRC screening in persons

without a prior history of CRC who underwent genetic counseling and testing for Lynch syndrome, and also evaluated colonoscopy use up to one year after receiving genetic test results. Guided by Social Cognitive Theory³⁰ and the Health Belief Model³¹, we examined changes in self-efficacy (i.e., confidence in one's ability to undergo screening), response efficacy (i.e., confidence in screening effectiveness) and perceived benefits of and barriers to colonoscopy among Lynch syndrome mutation carriers before and after genetic counseling and testing. While perceived benefits and barriers have been found to be predictors of CRC screening utilization in both average and high risk individuals, less is known about the relationship of perceived behavioral control (e.g. efficacy) in regard to CRC screening adherence among persons at high risk for the disease.³² We also assessed level of commitment to screening, as prior research has found it to be correlated with CRC screening adherence in siblings of individuals diagnosed with CRC at younger ages.³³ Commitment to screening is a potentially relevant construct in our study population because Lynch syndrome mutation carriers are advised to undergo colonoscopy much more frequently compared to the general population.

We hypothesized that individuals who tested positive for a Lynch syndrome mutation would be more likely to follow high risk CRC surveillance recommendations compared with those who tested negative (H1). We also hypothesized that mutation-positive individuals would report an increased commitment to screening (H2), higher screening self-efficacy (H3), higher response efficacy (H4), higher perceived screening benefits (H5) and lower perceived barriers following receipt of genetic test results compared with mutation-negative persons (H6).

Materials and Methods

Participants

This study was approved by the Institutional Review Board at The University of Texas MD Anderson Cancer Center, and was part of a longitudinal study that evaluated psychosocial outcomes associated with Lynch syndrome genetic counseling and testing.³⁴⁻³⁷ In the parent study, eligible CRC patients were offered Lynch syndrome genetic counseling and testing at no cost and completed psychosocial questionnaires. Patients who tested positive for a Lynch syndrome mutation were invited to refer adult CRC-unaffected biological relatives, estimated to be at 50% a priori risk for the syndrome, to the present study. Relatives who were referred by these patients were mailed information about the study and an invitation to participate. CRC-unaffected relatives were offered genetic counseling, including the option of genetic testing, at no cost as well as an invitation to complete psychosocial questionnaires, similar to the CRC patients. Study invitations were sent to 231 family members; 110 (47.6%) unaffected relatives, all of whom were age 25 years or older, responded to the letter and completed a baseline psychosocial questionnaire. Ninety-seven (97) individuals underwent pre-test genetic counseling, 91 chose to undergo genetic testing, and 89 underwent post-test-up genetic counseling and received their test results. Seven (7) unaffected relatives with negative test results and 4 with positive test results declined to complete additional questionnaires beyond the baseline assessment. Seventy-eight (78) individuals completed follow-up questionnaires at 6 and 12 months post-disclosure of test results; of those, 52 were MMR mutation-negative and 26 were mutation-positive.

Study Procedures

Study questionnaires were administered by telephone prior to genetic counseling and testing (baseline) and at 6- and 12-months post-disclosure of test results. Pre- and post-test counseling included both verbal and written screening recommendations for Lynch syndrome.

Measures

The study questionnaire has been described previously and includes the following measures:^{34–37}

Participant Characteristics—We measured several demographic variables including age (continuous), gender (1=female, 0=male), race/ethnicity (1=white, 0=non-white), education (continuous), marital status (1=married, 0=unmarried), household income (continuous), and number of biological children (continuous). We also assessed uptake of genetic testing (1=yes, 0=no) and mutation status post-disclosure (1=positive, 0=negative).

Colonoscopy adherence—Participants self-reported colonoscopy use within the 2 years prior to baseline, and at 6 and 12 months after the disclosure of Lynch syndrome mutation results. At each time point, participants were classified as adherent or not adherent with colonoscopy screening recommendations.

Colonoscopy commitment—A single-item was used to measure commitment that asked participants “How committed are you to having a regular colonoscopy?” Responses ranged from “no thought of having a colonoscopy” to “committed to getting regular colonoscopies.” Responses were dichotomized as “committed” vs. all others.

CRC screening self-efficacy—Participants were asked “how confident are you that you can follow through with regular colonoscopies?” on a scale from 0–100%.

CRC screening response efficacy—Response efficacy was assessed using 4 items adapted from the response efficacy subscale of the Adherents Determinants Questionnaire (ADQ).³⁸ Items such as “being screened for colon cancer will help me to be healthy” were measured on a scale from strongly disagree (1) to strongly agree (5). Mean scale scores were computed.

Benefits of and barriers to CRC screening—Two subscales from the ADQ were used to assess perceived benefits of and barriers to CRC screening.³⁸ Four items were used to measure the screening benefits (e.g. “the benefits of going through colon cancer screening outweigh any difficulty I have going through it”) and four items were used to measure barriers (e.g., “lots of things get in the way of having colon cancer screening”). Items were measured on a scale from strongly disagree (1) to strongly agree (5). Mean scale scores were separately computed for benefits and barriers.

Statistical Analyses

The primary outcomes of interest were: 1) colonoscopy adherence, 2) colonoscopy commitment, 3) screening self-efficacy, 4) screening response-efficacy, and 5) perceived benefits and barriers to CRC screening. Analytical methods for longitudinal data were used to evaluate outcomes over time (H1–H6). Comparisons in primary outcomes between baseline and 6 and 12 month follow-up across the positive and negative mutation groups were done using linear mixed models. A conditional model was fit to the data. In addition to the main effects of mutation status and time, the time by mutation interactions were included as fixed effects in the model to test for differences in average rate of change over time between the two mutation groups. The analysis was done with Proc Mixed (SAS) which allows for unbalanced designs, missing data and different covariance structures. Adjustment for small sample correction was done with the Kenward and Roger method.³⁹

Results

Baseline Characteristics

Participants who completed a baseline questionnaire prior to genetic counseling (n=110) were mostly white, had at least a high school education, and had children (Table 1). Approximately one-third of participants had had a screening colonoscopy in the two years prior to baseline data collection, indicating they were adherent to screening recommendations for persons at risk for Lynch syndrome, and the majority opted to undergo Lynch syndrome genetic testing.

Colonoscopy Adherence

Colonoscopy adherence did not differ between the mutation-positive and mutation-negative groups at baseline. However, the rate of change of colonoscopy adherence over time (from baseline to 6 months post-disclosure and 6 to 12 months post-disclosure) differed between the two groups as indicated by a significant interaction effect between mutation status and time ($F=14.6$; $p<.01$) (Figure 1). Post hoc comparisons revealed that at 6 and 12 months after disclosure of results, a greater number of participants with a positive test result had a colonoscopy compared to persons with a negative test result.

Commitment to Screening

The baseline mean scores on the commitment to screening measure did not differ between mutation carriers and noncarriers; however, the rate of mean score change over time differed between the two groups, as indicated by a significant mutation status by time interaction effect ($F=5.9$; $p<.01$). Post hoc analysis revealed a positive increase in mean scores regarding commitment to have a regular colonoscopy in the mutation-positive group from baseline to 6 and 12 month post-disclosure compared to a decrease in mean commitment scores for the mutation-negative group from baseline to 6-months (Table 2).

Efficacy, Benefits, and Barriers to CRC screening

There were no differences in mean scores for self-efficacy, response efficacy, or in perceived benefits or perceived barriers to screening between the two mutation groups at baseline. The rate of change over time in these mean scores differed between the two groups for self-efficacy ($F=5.7$; $p<.05$), benefits ($F=4.5$; $p<.05$) and barriers ($F=13.7$; $p<.001$) to CRC screening, as indicated by significant mutation status by time interaction effects. Post hoc analysis (Table 2) revealed an increase in mean scores for self-efficacy and perceived benefits of CRC screening in the mutation-positive group from baseline to 6 and 12 month post disclosure but no difference in the mutation negative group. There was also a decrease in mean scores for perceived barriers to CRC screening in the mutation positive group from baseline to 6 months post-disclosure (but not from 6 to 12 months post-disclosure) and no difference in the mutation negative group. There were no differences between mutation-positive and mutation-negative groups in mean scores for response efficacy regarding CRC screening from baseline to 6 and 12 months post disclosure ($F=2.1$; $p<.05$).

Discussion

In this study, we examined the association between Lynch syndrome mutation status and adherence and attitudes towards CRC surveillance recommendations. Our findings are consistent with previous studies which showed that CRC-unaffected persons who tested positive for a MMR mutation were more likely to undergo colonoscopy in the year following receipt of their test results compared with those who had a negative MMR mutation result.^{14,15,18,22–25} Our findings also indicated lower utilization of colonoscopy among persons who tested negative for a MMR mutation in the year following disclosure of

genetic test results, which also is consistent with prior research.^{17,19} These findings indicated that most of our study participants followed appropriate CRC surveillance recommendations for their mutation status within the first year after receiving their genetic test results. We also found that mutation status was associated with changes in perceptions of and attitudes towards CRC screening, particularly among mutation-positive individuals. Although all participants reported generally positive attitudes towards screening at baseline, our results showed increases in means scores for commitment to colonoscopy, self-efficacy, and perceived benefits of colonoscopy among those who were mutation-positive compared with those who were mutation-negative in the year following disclosure of test results. At 12-months post-disclosure, 88% of mutation-positive individuals reported being committed to having regular colonoscopies compared with 58% at baseline. These findings are encouraging, as they suggest that our mutation-positive participants understand the benefits of CRC surveillance, feel confident in their ability to undergo regular colonoscopies, and express a commitment to doing so. These findings also are important because positive attitudes regarding colonoscopy have been predictive of screening adherence in the general population⁴⁰ and among persons at increased risk for CRC based on their cancer family history.³³ It also is encouraging to note that mutation-negative participants generally reported no changes in attitudes toward CRC screening in the year following receipt of their genetic test results, with the exception of a decrease in mean scores for commitment to screening from baseline to 6-months post-disclosure of results. The decrease in level of commitment toward having regular colonoscopies among mutation-negative participants may reflect their awareness that they do not need to undergo colonoscopies as frequently as MMR mutation carriers. Nonetheless, these findings suggest that it is important to emphasize the need to follow appropriate screening guidelines when counseling mutation-negative individuals in Lynch syndrome families. Genetic counseling and risk assessment for hereditary cancers typically addresses the need to follow risk-appropriate recommendations for cancer screening and early detection. Our findings suggest that the genetic counseling process may have had a positive impact on both the attitudes and screening behaviors of our study population. Our findings also underscore the important role that genetic counseling may play in reinforcing positive attitudes and beliefs about screening in families with hereditary cancers. The genetic counseling and testing process can serve as a teachable moment and can potentially facilitate the adoption of, and long-term adherence to, risk-appropriate screening guidelines.

While our findings regarding adherence to and attitudes toward colonoscopy for management of Lynch syndrome CRC risk are promising, it is important to consider them in the context of management of other cancer risks associated with this syndrome. For example, mutation-positive women have up to a 60% lifetime risk of endometrial cancer. Those women who may not be ready to consider total abdominal hysterectomy with salpingo oophorectomy as primary risk management for endometrial cancer are advised to undergo annual endometrial biopsy in addition to annual or biennial colonoscopy. Women who test positive for an MMR mutation may be less adherent to endometrial cancer screening compared with CRC screening.^{22,23,25} It may be possible to improve endometrial cancer screening adherence if women were presented with an option to combine CRC and endometrial screening in one visit.⁴¹ Concurrently performing endometrial biopsies and colonoscopies for women with Lynch syndrome is clinically feasible, and patients reported that they would have a higher likelihood of adherence to Lynch syndrome cancer risk management recommendations if presented with this option.⁴¹ Given the high commitment and perceived benefits to screening among mutation carriers in this study, our results suggest that a combined screening option may also have a positive impact on improving overall adherence to Lynch syndrome cancer risk management recommendations.

Limitations of the study include the fact that the sample included individuals who chose to undergo free genetic counseling and testing as part of a research study. This may limit the generalizability of the results to individuals who undergo genetic counseling and testing as part of clinical care. Some mutation-positive individuals in the study may have been invited to participate in a concurrent chemoprevention trial that included colonoscopies, which may have influenced their utilization of and attitudes toward colonoscopy. The sample size, particularly for patients who tested positive for Lynch syndrome, limited our ability to thoroughly examine predictors of colonoscopy adherence or to conduct mediation analyses. Finally, this study followed individuals for only 12-months following the disclosure of test results. For an individual who has a known Lynch syndrome mutation, commitment to screening is a life-long process and predictors of adherence may continue to change as time increases from the disclosure of genetic testing results. Studies that examine longer term adherence to cancer risk management behaviors in Lynch syndrome can offer insight regarding possible changes in these predictors over time.

Despite these limitations, our findings suggest that genetic counseling and testing may have a positive impact on both adherence to colonoscopy among Lynch syndrome mutation carriers and also on their attitudes towards CRC screening. This dual impact on both attitudes and behaviors may reinforce long-term adherence to following recommended high-risk screening guidelines, and may facilitate the earlier detection of CRC in individuals with Lynch syndrome.

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Figure 1.

Change in colonoscopy adherence from baseline to 6 and 12 months post-disclosure of Lynch syndrome genetic test results (n=78)

* $p < .05$, ** $p < .01$ (change over time)

Table 1

Baseline sample characteristics (n=110)

Characteristic	% (n)
Mean age in years (SD)	42 (13)
Gender-female	66% (73)
Race-white	80% (88)
Education > HS	70% (77)
Income \$50k	40% (44)
Married	66% (73)
Had at least one child	77% (85)
Received genetic testing results	81% (89)
Colonoscopy use	
Within the past 2 years (adherent)	35% (38)
> 2 years ago (not adherent)	10% (11)
Never (not adherent)	55% (61)

Table 2

Comparison of mean scores on psychosocial measures by test result at baseline, 6 months post-result disclosure, and 12 months post-results disclosure (n=78)

	Positive (n=26)			Negative (n=52)		
	Baseline M (SD)	6 months M (SD)	12 months M (SD)	Baseline M (SD)	6 months M (SD)	12 months M (SD)
Commitment to Screening	58%	81% *	88% *	69%	51% *	62%
Self-Efficacy	85% (28)	96% (8) *	96% (11) *	89% (22)	90% (19)	87% (25)
Response Efficacy	4.1 (0.4)	4.3 (0.5)	4.3 (0.5)	4.1 (0.7)	4.1 (0.6)	4.1 (0.6)
Perceived Benefits	4.4 (0.6)	4.6 (0.5) *	4.8 (0.4) *	4.4 (0.6)	4.5 (0.5)	4.5 (0.6)
Perceived Barriers	2.7 (0.6)	2.3 (0.7) *	2.7 (0.6)	2.3 (0.7)	2.3 (0.7)	2.2 (0.7)

* p<.05 (change over time within groups)