A novel approach to increase awareness about hereditary colon cancer using a state cancer registry

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Purpose: The aim of this project was to conduct educational outreach about hereditary colon cancer to a targeted high risk population identified through a state cancer registry. **Methods:** Individuals who met one of the first three Bethesda criteria guidelines were identified through the Colorado Central Cancer Registry. The physician of record received a brochure, survey and form to provide written consent to contact patient(s). Cases were mailed an educational brochure, initial and follow-up survey. **Results:** Five hundred seventy-five cases and 412 physicians were identified; 81% provided consent. Ninety percent of physicians felt the registry should provide this information to at-risk patients. Twenty-three percent of the cases returned the survey. Cases were generally glad to get the information. Only four cases reported concern. The majority agreed the cancer registry should send the information, however most preferred their physicians be consented first. At follow-up, 20 cases reported having or intending to have a risk assessment. **Conclusions:** Response from physicians and cases was positive, suggesting that targeted outreach using cancer registries, in combination with physician notification, may be a viable approach to educational outreach about cancer genetics. A proportion of cases sought risk assessment, suggesting that mail-based outreach may be effective in increasing uptake of information and/or genetic services. ***Genet Med* 2010:12(11):721–725.**

Key Words: *Lynch syndrome, colon cancer, cancer-registry*

Colorectal cancer (CRC) is a significant cause of morbidity and mortality in the United States. An estimated 153,000 Americans are diagnosed with CRC and 52,000 people die from this disease each year.[1] Lynch syndrome, also called Hereditary Nonpolyposis Colorectal Cancer (HNPCC), is the most common of the inherited colon cancer susceptibility syndromes accounting for 2–3% of all colon cancer cases and about 2% of uterine cancer.[2,3] Lynch syndrome is characterized by increased risk for cancer of the ovary, upper urologic tract (renal pelvis and ureter), gastric, small bowel, biliary/pancreatic, and brain.[4] The lifetime risk of colon cancer in individuals with Lynch syndrome is between 52% and 80% compared with the general population lifetime risk of 5–6%.[4] Individuals with Lynch syndrome can reduce their cancer risk by following recommended guidelines for cancer screening. Thus, identification of these individuals and families is important for reducing morbidity and mortality from these associated cancers.

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Identification of individuals at-risk for Lynch syndrome is less than optimal resulting in underutilization of cancer risk assessment, genetic testing, and counseling about risk reduction.[5,6] Lynch syndrome can be identified clinically through microsatellite instability (MSI) testing of colon tumors in susceptible individuals. The revised Bethesda guidelines were established to determine individuals at risk for Lynch syndrome, for whom tumor testing by MSI testing is recommended.[7] However, while MSI testing is an effective screening tool for Lynch syndrome, it is not widely used because of concerns of cost effectiveness and ethical concerns about whether consent is needed for tumor testing. A more common means for identifying Lynch families is through family history analysis and cancer risk assessment. However, this process requires systematic collection of adequate and accurate family history data, which is often lacking, especially in primary care settings.[8]

Other factors contributing to poor identification of at-risk individuals include reduced awareness about hereditary colon cancer among providers and limited knowledge about key cancer genetics concepts and Lynch syndrome specifically.[9] Given the current limitation, surrounding systematic collection and assessment of family history data in medical settings and the concerns about global use of MSI as a screening test for Lynch syndrome, many at-risk individuals are not being identified. Because many referrals for cancer risk assessment are patient-driven,[10] it is also likely that lower uptake of services may be attributed to limited patient knowledge about hereditary colon cancer. Other means of increasing awareness about Lynch syndrome are needed to facilitate identification of at-risk individuals.

The purpose of this project was to increase awareness and knowledge about hereditary colon cancer through a targeted outreach program for physicians and at-risk patients identified through the Colorado Central Cancer Registry (CCCR). The outreach provided education about hereditary colon cancer including characteristics of Lynch syndrome families and information about the potential benefits of cancer risk assessment and genetic testing. A secondary aim of this project was to determine the feasibility of using a cancer registry for identifying at-risk individuals and conducting an outreach program.

MATERIALS AND METHODS

Overview of study design

This was a targeted outreach study to provide information about hereditary colon cancer to at-risk colon cancer patients identified through the state cancer registry. Physicians of patients identified were contacted to obtain permission to contact their patients and were asked to complete a brief survey. Colon cancer patients were mailed an educational brochure about hereditary colon cancer along with an initial patient survey at the time of first contact, and mailed a follow-up patient survey approximately 4 months later.

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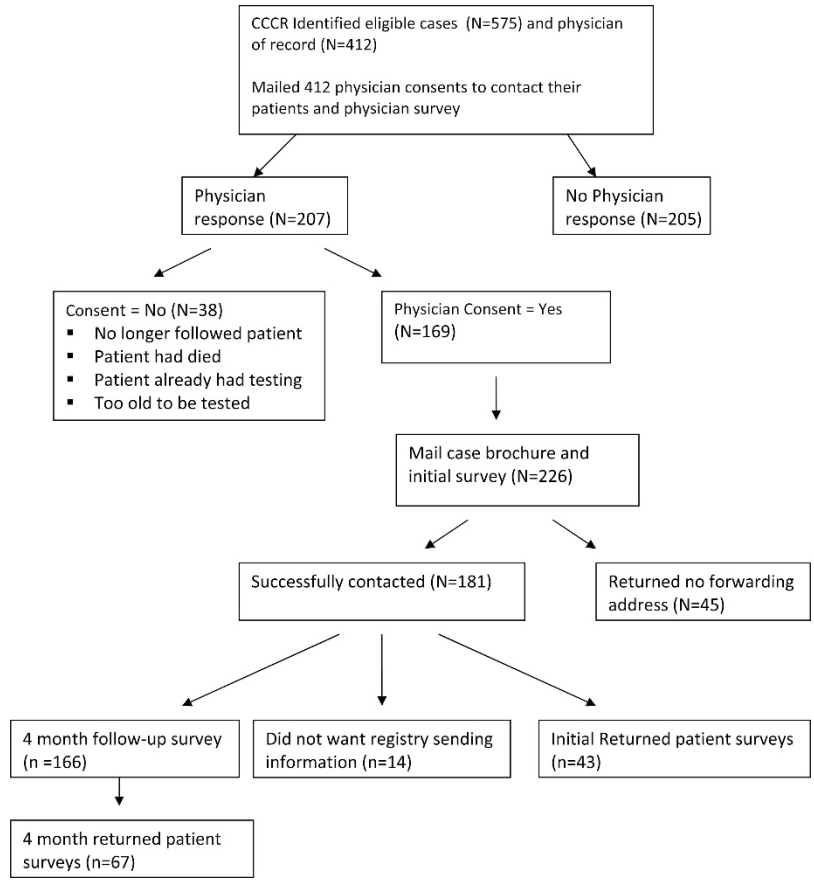

Fig. 1. Study design and data.

Target population

Individuals targeted for the educational outreach were identified using the CCCR. CCCR is a population-based cancer registry that collects information on all cancer cases diagnosed and/or treated in the state of Colorado. For this project, at-risk individuals were defined as those who had a recent diagnosis of colon cancer (2001–2005) and met one of the first three Bethesda guidelines: diagnosis of CRC younger than 50 years, diagnosis of metachronous or synchronous CRC or other HNPCC-related cancers (ovarian, endometrial, stomach, pancreas, ureter and renal pelvis, biliary tract and brain) regardless of age, or diagnosis of CRC younger than 60 years that exhibits MSI-high histology (mucinous/signet ring, medullary types). All cases aged 18 or older who met these criteria were included.

To mail educational materials to eligible patients identified through the registry, it was necessary to obtain physician consent. The physician of record for eligible patients was contacted by mail and asked for permission to contact their patient(s). Only patients for whom physician consent was provided were included in the outreach. A flowchart illustrating the study design and flow of information is shown in Figure 1.

Educational materials and surveys

An educational brochure written in lay terms was created by genetic counselors on the study staff to provide an overview of features specific to hereditary CRC, including who may be at risk, what cancer risk assessment is, and who might benefit from cancer risk assessment. The brochure also provided contact information for all Colorado cancer genetic counselors and a toll-free number to speak with a counselor at the University of Colorado Cancer Center. Development of the final brochure incorporated input received from a focus group of 15 colon cancer survivors that were convened for this study. Focus group members consisted of participants in the Colorectal Cancer Family Registry at the University of Colorado. The CFR is a national registry of individual and families affected by CRC. Local CFR participants were contacted by mail to elicit feedback on the brochure content, language and format, and on the introductory letter to be sent to patients identified for this study. The focus group members either mailed back their written responses or were contacted by phone by study staff to obtain their feedback. A copy of the final brochure developed for this project is available from the authors.

A laminated 5 × 6 card was also created for this study that outlined the Amsterdam Criteria and Bethesda Guidelines for identifying at-risk patients and that provided current screening recommendations for individuals determined to have Lynch syndrome. The laminated card was mailed to physicians whose patients were identified by the registry for this project.

Three surveys were developed for this study: a provider survey, an initial patient survey, and a follow-up patient survey. The provider survey was mailed to physicians identified by the CCCR along with the request to contact their patients and the laminated card described above. The purpose of the provider survey was to obtain physicians' feedback on the educational brochure, to inquire about their current prac-

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tices for providing information about cancer genetics to their patients and to elicit their reaction to having the state cancer registry conduct outreach on this topic. Use of the registry for conducting outreach of this nature is unprecedented and thus determining the feasibility of this approach from both the provider and patient perspective for future efforts was an important aim of this project.

The initial patient survey was sent at the time of first contact with patients along with the educational brochure. The initial survey included general questions about age, gender, year of diagnosis of colon cancer, and patient residence (urban versus rural). Additional questions sought to obtain feedback about the brochure, and about how the patient felt about getting the information (glad, angry, concerned), and whether they thought it would be useful for them. The survey also asked how the patients felt about getting the information about hereditary cancer from the state cancer registry. Patients were asked to indicate on their returned survey if the registry could contact them again by mail in 4 months to complete a follow-up survey.

The follow-up survey was mailed approximately 4 months after the initial survey was sent out to all patients for whom we had a valid address and who did not indicate that they did not want to be contacted again. The purpose of the follow-up survey was to assess whether and/or how the educational outreach may have affected behaviors related to cancer risk assessment. Patients were asked if they recalled getting the brochure, whether they had discussed or had risk assessment or genetic testing in the previous 4 months or whether they intended to have these done in the future. All surveys (provider and patient) were anonymous and did not contain any personal identifying information about the physicians or the patients.

A toll-free telephone number was established to provide patients an opportunity to speak with a genetic counselor to get more information about the cancer risk assessment process or to obtain referrals to counselors in their area. Patients were also offered telephone risk assessment with a genetic counselor if they did not have medical insurance or did not have access to a counselor in their geographical area.

RESULTS

The cancer registry identified 575 at-risk cases that were diagnosed with CRC in the previous 5 years and who met one of the first three Bethesda guidelines. There were 412 physicians of record identified for these cases. In total, 207 of the 412 physicians contacted (50%) responded to the initial mailing and among those who responded, 169 (81%) provided consent to contact their patients. These 169 physicians combined represented 226 patients that could be contacted for this study. There were 38 physicians that responded but did not consent to patient contact. The most common reasons given for nonconsent were that the physician no longer followed the patient ($n = 15$), the patient had died (4), the patient had already been tested (3), or was too old to be tested (3). There were no differences in medical specialty of the 169 physicians who consented and the 38 physicians that did not consent to have their patients contacted. We did not have the information available with which to compare medical specialty between the physicians who responded to the request to contact patients and the larger group of physicians ($n = 205$) that did not respond to the original mailing.

Responses to the physician survey that was included in the original mailing are presented in Table 1. The majority of physicians thought the information provided was clear and potentially useful for their patients. Most said they currently talk with their patients about cancer and genetics. Most physicians felt the cancer registry should provide education to at-risk cases either with (30%) or without (60%) seeking physician consent. Only 3% of physicians did not support the registry doing this type of outreach. When asked whether they were the appropriate physician to contact, 139 said yes and 17 said no. The majority of physicians surveyed felt that the oncologist (99) or primary care physician (112) would be the most appropriate provider to contact regarding outreach about cancer and genetics to their patients. Fewer believed that the surgeon (41) or gastroenterologist (7) should be contacted.

Table 1 Response to provider survey

Survey question	Yes	No	Not sure
Was the information in the brochure clear and easy to understand?	159 (95%)	8 (5%)	
Do you think this information will be useful to your patients?	143 (85%)	2 (4%)	22 (13%)
Do you currently provide information about cancer and genetics to your patients?	130 (77%)	34 (21%)	4 (2%)
Do you think the cancer registry should provide educational materials to individuals who may be at risk for hereditary cancer?		5 (3%)	12 (7%)
Yes, physician consent IS necessary	51 (31%)		
Yes, physician consent IS NOT necessary	99 (59%)		

Overall, 226 at-risk individuals were included in the outreach and were mailed the educational materials and initial patient survey. Forty-five packets were returned without a forwarding address leaving 181 cases who we believe to have been successfully contacted. Initial patient surveys were completed and returned by 43 patients for a response rate of 23% (43/181). The patient respondents were equally split between men (23) and women (20) and ranged in age from 33 to 91 years. The majority of respondents lived in urban versus rural areas (79% vs. 21%). Responses to the initial patient survey are presented in Table 2. Most cases thought that the information presented in the brochure was clear and easy to understand (98%) and that the information was potentially useful for them (71%), although 21% of patients were not sure that it would be useful. When asked how they felt about getting the information in the mail, 77% of respondents were glad, 42% indicated they wanted to know more about hereditary cancer and risk assessment, and 12% expressed no strong feelings either way. Four respondents (10%) said they were concerned or worried about getting the information and no cases reported being angry as a result of receiving the information. More than 90% of respondents agreed that the registry should send out information about hereditary cancer; however, the majority of these patients (71%) preferred to have their physician involved.

Responses to the 4-month patient follow-up survey are shown in Table 3. A total of 166 surveys were mailed to patients that agreed to be contacted again and for whom we believed we

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Table 2 Response to initial patient survey

Survey question	Yes	No	Not sure
Was the information in the brochure clear and easy to understand?	42 (98%)	1 (2%)	
Do you think this information will be useful for you?	30 (71%)	3 (7%)	9 (21%)
How do you feel about getting this information?[a]			
I am glad this information was sent to me	33 (77%)		
I want to know more about genetics and cancer	18 (42%)		
I am angry about getting this information	0		
I am concerned/worried about getting this information	4 (10%)		
Do you think the registry should send this information to individuals at risk for hereditary cancer?		3 (7%)	
Yes, physician consent IS necessary	31 (71%)		
Yes, physician consent IS NOT necessary	10 (22%)		

[a] Patients asked to mark all that apply.

had a viable address. Response rates improved somewhat, from 23% for the initial survey to 40% (67/166) for the follow-up survey due in part to a second mailing that the registry conducted to all 166 patients (responders and nonresponders), a strategy we employed to increase response given the lack of identifying information available on responders. Most patients had remembered getting and reading the educational brochure. When asked whether they had discussed cancer risk assessment with anyone in the past 4 months, 40% of patients indicated that they had spoken with one or more of the following: their doctor (24%), a genetic counselor (3%), family members (16%), or friends (16%). About one third reported that they had had a risk assessment in the previous 4 months or had intentions to have risk assessment in the near future. Nine respondents said they had genetic testing in the past 4 months since receiving the educational materials and eight reported having been tested in the past.

No patients contacted called the toll-free number provided in the brochure. Because no patients called the number, no referrals were given, and no telephone risk assessments were performed.

Table 3 Response to patient follow-up survey (mailed 4 months after initial mailing)

Survey question	Yes	No	Not sure
Do you remember getting the brochure about genetics and cancer?	48 (74%)	7 (11%)	10 (15%)
Did you read the brochure?	40 (64%)	14 (22%)	9 (14%)
In the past 4 months, have you discussed cancer risk assessment with anyone?	27 (40%)	40 (60%)	
In the past 4 months, have you had a cancer risk assessment or do you intend to in the near future?	20 (32%)	31 (48%)	13 (20%)
In the past 4 months, have you had genetic testing or intend to in the near future?	9 (15%)	34 (53%)	13 (20%)
Previously tested	8 (12%)		

DISCUSSION

This project sought to use a novel approach, by way of using a cancer registry, to conduct a targeted outreach program about hereditary colon cancer. To this end, this project successfully contacted over 400 providers and 180 colon cancer patients identified through the CCCR. The response to the material was generally positive both in terms of readability and usefulness. The majority of patients who responded were glad to have received the information and in fact wanted to know more, suggesting that there is a need and desire among individuals affected with colon cancer to have this information.

The mail-based approach appears to have affected behaviors among recipients, in triggering dialogue between recipients and their physicians and/or family members. This is a positive and desirable outcome. It is recognized that the topic of cancer and genetics and risk assessment is complex and beyond what can be presented in detail in a brochure intended for a wide audience. The brochure recommended that individuals discuss the material with their physician or genetic counselor as a first step in considering risk assessment. About one third of respondents indicated they had had or had made plans to have risk assessment since receiving the materials and nine had already undergone risk assessment. This response is similar to that seen by other studies. Keller et al.[11] found a 26% uptake of genetic testing following educational intervention among high-risk patients. Although confirmation of services rendered was not possible, it is intriguing given the relatively short follow-up period of 4 months, that this many individuals showed at a minimum, interest in pursuing risk assessment. It would be of interest to follow these individuals over a longer period of time to track utilization of genetic services.

It was surprising that no recipients called the toll-free counseling line, which was implemented to provide risk assessment to persons either without insurance or persons living in remote areas without access to genetic counseling services. The lack of patient-initiated calls may reflect patients' preference to confer first with providers and/or persons of trust regarding these issues. Uptake for telephone-based counseling in future outreach efforts may be improved if it is offered after establishing a clinical relationship with patients or following a direct physician referral.

An important and provocative finding was that both physicians and providers supported having the cancer registry involved in the dissemination of information about hereditary cancer. Utilizing the cancer registry to conduct targeted outreach for this purpose is unprecedented in Colorado. Past col-

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laborations with the state registry have been effective for recruiting cancer cases for national cancer family registries or for individual research studies.[12–14] However, the CCCR, and to our knowledge, all other state cancer registries (in the United States), have not been used to identify high-risk persons for educational interventions about hereditary cancer risk. An a priori concern before embarking on this project was that individuals identified and contacted by mail would be upset or offended by having been contacted by the state registry. Although cancer is a reportable disease, it is likely that most people diagnosed with cancer are unaware that information about them and their cancer resides in a centralized registry. Responses from the recipients did not confirm this fear. It is notable, however, that the majority of patients in favor of the registry sending out the information wanted their physicians contacted first. In contrast, most physicians did not feel it was necessary to obtain their consent before contacting their patients. Future outreach efforts using a cancer registry may consider a hybrid approach that would optimize the number of patients that could be contacted while maintaining some level of physician consent or notification. For example, future projects may consider allowing for passive consent from physicians, asking only those opposed to the project to respond, or obtaining a priori consent from physicians to contact patients for this purpose at the time their patient is enrolled into the local or state cancer registry.

There are many benefits to using the state cancer registry for conducting outreach. First and foremost, the registry provides the most comprehensive resource of all colon cancer cases diagnosed in Colorado. Having access to virtually all colon cancer cases across the state is important for assuring that all at-risk individuals regardless of age, insurance status, or residence, have an opportunity to receive the information. Although most physicians indicated that they currently discuss cancer and genetics with their patients, 23% of physicians surveyed do not, leaving a significant gap in access to information. In addition to providing a comprehensive resource of cases, the registry provides a means of identifying at-risk cases. Based on clinical criteria routinely collected by the registry, a subset of at-risk cases defined by the first three Bethesda guidelines could be identified. For this project, the registry was able to identify 575 at-risk cases, which represents about 10% of all colon cancer cases diagnosed in Colorado during the 5-year ascertainment period.[15]

There are some inherent limitations to using the cancer registry, mainly that the registry does not systematically collect information on family history of cancer. Because having a family history of colon or other HNPCC-related cancers is part of the Bethesda guidelines, the lack of this information limited the number of at-risk cases that could be identified. A second limitation was physician response, which affected the number of patients that could be contacted. The 180 cases, for which consent was obtained, represented only one third of all at-risk cases identified by the registry. As discussed above, altering the process by which physician consent is obtained may help to increase response. Patient response to the initial mailing and survey was relatively low (23% and 40%) but reasonable given the anonymous nature of the survey and the inability to conduct follow-up on nonresponders (due to confidentiality issues). As with any survey, low response rates may affect the ability to generalize survey responses. We did not have data available for this study on nonresponding patients with which to compare factors such as age, gender, and other socio-demographic information between responders and nonresponders. This type of analysis would be valuable not only for assessing representativeness of our sample but also for identifying predictors of response and nonresponse to inform future outreach projects. It is notable, however, that our respondents represented a wide age-range, were equally divided between males and females and time since diagnosis suggested a broad-based desire among patients to have this information.

Identification of individuals with genetic predisposition for cancer is critical for reducing their cancer risk and that of their family members. Current methods for identifying at-risk individuals are limited and not widely used at present. Multiple approaches must be employed to assure that individuals with genetic susceptibility are adequately identified and given proper recommendations for medical management. These approaches should include efforts to educate both providers and patients about the characteristics of Lynch syndrome and about the benefits of cancer risk assessment. Important is having the ability to reach a large, yet targeted population who would most benefit from these efforts. Results from this project suggest that using a cancer registry to target and conduct an outreach program would be well received and effective for increasing awareness and uptake of genetic services.

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