Mountain States Genetics Collaborative
Final Project Report

Project Title: Educational outreach about genetic testing to individuals at-risk of having hereditary colon cancer

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Abstract

Background. Colon cancer accounts for over 150,000 new cancer cases and 52,000 deaths each year in the U.S. About 3% of all colon cancer is attributed to Lynch syndrome, also called Hereditary Non-Polyposis Colon Cancer. Individuals with Lynch Syndrome have significant lifetime risk of developing colon cancer, upwards of 80%. Thus, identification of these individuals is important for reducing morbidity and mortality from colon cancer. Genetic counseling and testing for Lynch syndrome are under-utilized in Colorado. The purpose of this project was to educate Coloradans at-risk for hereditary colon cancer about the potential benefits of cancer risk assessment and to provide risk assessment via telephone to individuals without access to these services. A secondary aim was to determine the feasibility of utilizing a cancer registry for identifying at-risk individuals and conducting educational outreach. *Methods.* At-risk individuals were identified through the Colorado Central Cancer Registry. Cases included individuals diagnosed with colon cancer in the last five years who met one of the revised Bethesda criteria, clinical guidelines established to determine who may be at risk for hereditary cancer. The physician of record was mailed an educational brochure about hereditary cancer, a brief survey and asked to provide written consent to contact their patient(s). Eligible cases were mailed the educational brochure and a one-page survey to elicit reactions to being contacted via the registry. Follow-up surveys were mailed to cases about 4 months after the initial mailing. *Results.* In total, 575 cases and 412 physicians were identified by the cancer registry. About 40% of physicians (169) representing 226 patients provided consent to contact patients. Among physicians who completed the survey, the majority felt the educational information was clearly presented and useful. Most (77%) reported that they currently provide their patients with information about cancer and genetics and 90% felt that the registry should provide this information to at-risk patients, with (30%) or without (60%) physician consent. Forty-three of the 181 cases successfully contacted by mail returned a completed initial survey (23%). Cases were generally glad to have received the information and wanted to know more. Only 4 cases reported concern or worry in response to the information sent. The majority agreed that the registry should send this information, however most preferred that their physicians be contacted first. At follow-up, 20 cases reported having had a cancer risk assessment in the past 4 months or had intentions to have a cancer risk assessment, and about 45% reported having discussed a cancer risk assessment with someone. No individuals contacted called the toll-free information line to speak with a genetic counselor, thus no referrals were made. *Conclusions.* Response from physicians and cases regarding both the content of the

materials and the mode of delivery was positive suggesting that targeted outreach using the cancer registry, in combination with physician notification, may be a viable approach to disseminating genetic information. A sizeable proportion of cases either sought risk assessment or discussed it with others, suggesting that mail-based outreach may be effective in increasing uptake of information and/or genetic services. The lack of calls to the information line may reflect patients' preference to confer first with providers and/or persons of trust regarding these issues. Uptake for telephone risk assessment may be improved after establishing clinical relationships with patients.

Background

Colorectal cancer (CRC) is a significant cause of morbidity and mortality in the United States. An estimated 153,000 Americans are diagnosed with colorectal cancer (CRC) and 52,000 people die from this disease each year [1]. The lifetime risk of CRC in the general population is 5-6 percent. This risk is much higher, upwards of 80% among individuals with Lynch syndrome, an inherited susceptibility for colon cancer [4]. Individuals in these families are also at-risk for developing multiple primary CRC in addition to several other cancer types. Lynch syndrome, also called Hereditary Non-Polyposis Colon Cancer, accounts for about 3% of all CRC [4].

Colon cancer can be prevented by screening. Thus, identification of individuals and families genetically predisposed to CRC can lead to a reduction in morbidity and mortality from CRC. Genetic counseling and testing services for identification of Lynch syndrome are under-utilized in the state of Colorado. Though the amount of CRC attributed to Lynch syndrome is comparable to the number of breast cancers due to germline mutations in BRCA1/2, only 10% of patients seen seek testing for Lynch syndrome (personal communication, genetic counselor, University Colorado Hereditary Cancer Clinic). This disparity is likely due to reduced awareness about genetic susceptibility for CRC in the general population and among physicians resulting in low demand for services. It was shown in a nationally representative sample of physicians that knowledge was limited about key cancer genetics concepts particularly among general primary care physicians [4].

The purpose of this project was to educate physicians and individuals at-risk for hereditary colon cancer about the potential benefits of cancer risk assessment and genetic testing and to provide risk assessment to individuals without access to these services. The target population for outreach was at-risk individuals previously diagnosed with CRC that could be identified through the Colorado Central Cancer Registry. The focus on cases was intentional in order to optimize the potential benefit of genetic testing that is most informative when performed on individuals affected with cancer. A secondary aim was to determine the feasibility of utilizing a cancer registry for identifying at-risk individuals and conducting educational outreach Use of the registry for this purpose is unprecedented and thus determining the feasibility of this approach for future efforts was an important focus of this project.

Methods

Target Population. Individuals targeted for the educational outreach were identified using the Colorado Central Cancer Registry (CCCR). CCCR is a population-based cancer registry that collects information on all cancer cases diagnosed and/or treated in the state of Colorado. Colorado law mandates that all cancer diagnoses be reported to the CCCR within 6 months of diagnosis. Case ascertainment in Colorado approaches 98%. Routine follow-up on cases is performed by individual hospital registries and forwarded to CCCR. For this project, at-risk individuals were defined as those that had a recent diagnosis of colon cancer (2001-2005) and met one of the revised Bethesda criteria, which are clinical criteria for identifying individuals with hereditary non-polyposis colon cancer (HNPCC) [5]. The Bethesda criteria that were available to query through the registry included the following: diagnosis of CRC under age 50, 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, diagnosis of CRC under age 60 that exhibits MSI-high histology (mucinous/signet ring, medullary types). All cases aged 18 or older were included.

Prior to sending educational materials to cases, physician consent was obtained. The physician of record for eligible cases was contacted by mail and asked for permission to contact their patient(s). Only cases for which physician consent was provided were included in the outreach.

Educational Materials and Surveys. An educational brochure was developed by genetic counselors that provided in lay terms an overview of hereditary colon cancer including who may be at risk, what cancer risk assessment is and who might benefit from risk assessment. The brochure also provided contact information for cancer genetic counselors across Colorado and a toll-free number that individuals could call to speak with a genetic counselor for more information about hereditary cancer or to obtain referrals to a genetic counselor in their area. Prior to finalizing the outreach materials, a focus group was assembled, mailed the materials and asked to provide feedback. The focus group consisted of 15 colon cancer survivors currently enrolled in the Colorectal Cancer Family Registry, a local and national registry of colon cancer families. Suggestions emanating from the focus group were incorporated into the final materials. A laminated 5x6 card was created for physicians that outlined the Amsterdam and the revised Bethesda criteria for identifying at-risk patients and the current screening recommendations for these individuals.

In addition to the brochure and introductory letter, physicians and patients were mailed a brief survey. The purpose of the survey was to elicit reaction to the outreach materials and to the method of delivery (using the registry). Patients were allowed the opportunity to opt out of future contact related to this project. A second survey was mailed to all patients, excluding those that opted out of future contact, about 4 months after the initial mailing to assess whether and/or how the outreach may have affected behaviors related to cancer risk assessment. All surveys 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 or to obtain referrals to counselors in their area. Patients were also offered to receive telephone risk assessment with a genetic counselor if they did not have medical insurance or did not have access to a counselor near their home.

Results

The cancer registry identified 575 at-risk cases and 412 physicians of record. In total, 207 physicians (50%) responded to the mailing and among those who responded, 169 (81%) provided consent to contact their patients (n=226 patients). There were 34 physicians that responded but did not consent to patient contact. The most common reasons given for non-consent were that the physician no longer followed the patient (15), the patient had died (4), the patient had already been tested (3), or was too old to be tested (3).

Responses to the physician survey are presented in Table 1. The majority of physicians thought that the information provided was clear and potentially useful for their patients. Most said that they currently talk with their patients about cancer and genetics. Most physicians felt that the cancer registry should provide education to at-risk cases either with (30%) or without (60%) seeking prior physician consent. Only 3% of physicians did not support the registry doing this type of outreach. Of the 150 physicians that reported their specialty, 59 were in family practice, 26 in internal medicine, 24 in oncology, 16 in gastroenterology, 13 in surgery and 12 reported other disciplines. 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. Responses to Provider Survey

	Yes	No	Not Sure
Was the information 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 not necessary	99 (60%)		
Yes, only after getting physician consent	51 (30%)		

Overall, 226 at-risk individuals were included in the outreach and mailed educational materials. Forty-five packets were returned without a forwarding address leaving 181 cases that were successfully contacted. Surveys were completed and returned by 43

cases giving a response rate of 23%. The respondents were equally split between males (23) and females (20) and ranged in age from 33 to 91 years. The majority of respondents lived in urban versus rural areas (79% vs. 21%). Most cases thought that the information was clear and potentially useful though 21% were not sure. Over 90% of respondents agreed that the registry should send out information about hereditary cancer, however, the majority preferred to have their physician involved.

Table 2. Case Response to Initial Survey

	Yes	No	Not sure
Was the information clear?	42 (98%)	1 (2%)	
Do you think this information will be useful?	30 (71%)	3 (7%)	9 (21%)
Do you think the registry should send information to individuals at risk for hereditary cancer?		3 (7%)	
Yes, with physician consent	31 (71%)		
Yes, physician consent is not necessary	10 (22%)		

When asked how they felt about getting the information, 77% of respondents were glad, 42% indicated they wanted to know more, 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.

Response to the 4-month follow-up survey improved to 40% (67 of 166 mailed were returned) due in part to a second mailing to non-responders. Survey responses are shown in Table 3. Most respondents remembered getting and reading the brochure. About one-third reported that they had had a cancer risk assessment since the mailing or had intentions to have risk assessment in the near future. Nine respondents said they had genetic testing in the past 4 months and 8 reported having been tested in the past.

Table 3: Case Response to Follow-up Survey

	Yes	No	Not sure	Already been tested
Do you remember getting the brochure?	48 (74%)	7 (11%)	10 (15%)	
Did you read the brochure?	40 (64%)	14 (22%)	9 (14%)	
In the past 4 months, have you had a cancer risk assessment or 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%)	8 (12%)

When asked whether they had discussed cancer risk assessment with anyone in the past 4 months, 40% of respondents indicated they had spoken with one or more of the following: their doctor (24%), a genetic counselor (3%), family members (16%), or friends (16%). When asked again how they felt about receiving the educational materials, 56% were glad, 23% wanted to know more, 37% had no strong feelings. One respondent was angry and one was worried or concerned. Nearly 80% of respondents agreed that the registry should send out information about cancer and genetics to

individuals who may be at risk for hereditary cancer. Though similar to the response from the initial survey, the majority, 55%, preferred their physicians be involved. Among the 14 respondents who did *not* want the registry sending this information, 10 (71%) indicated they would rather get the information from their doctor.

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

Conclusions

This project sought to increase awareness about hereditary colon cancer and utilization of cancer risk assessment among providers and their at-risk patients through a mail-based educational outreach. To this end, the project successfully contacted over 400 providers and 180 colon cancer cases identified through the Colorado Central Cancer Registry. The response to the material was generally positive both in terms of readability and usefulness. The majority of cases that 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, and in particular 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 a brochure intended for a wide audience. Furthermore, risk assessment and genetic testing can have implications for other family members so including them in the decision-making process is critical. 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 that they had had or had made plans to have risk assessment since receiving the materials and 9 had already undergone risk assessment. Though confirmation of services rendered was not possible, it is intriguing that 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 that was implemented in order 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. As discussed earlier, most respondents surveyed preferred to have their physician involved in the dissemination of this type of information. 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 interesting 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. An a priori concern was that individuals would be upset or offended by having been contacted by the 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. This was not entirely surprising given the sensitive nature of the information provided. 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 content 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. The rationale for targeting cases for this outreach was to maximize the benefit of genetic counseling and testing. Genetic testing is most informative when done in an affected individual first as results from these tests can direct the need for testing in other family members. 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 percent 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 criteria 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.

There are some limitations to using the cancer registry and to this project as a whole that are worth noting. The registry does not routinely collect information on family history of cancer. Since having a family history of colon or other Lynch-related cancers is part of the revised Bethesda criteria, the lack of this information limited the number of at-risk cases that could be identified. A second limitation was physician response as this affected the number of patients that could be contacted. The 180 cases for whom 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 inability to conduct follow-up. As with any survey, low response rates may affect the generalizability of survey responses. It is notable however, that

respondents represented a wide age-range, were equally divided between males and females and time since diagnosis.

In conclusion, this project represented a novel approach to conducting outreach about hereditary cancer to at-risk persons among the general population. Results suggest that future efforts using this method would be well-received and effective for increasing awareness and uptake of genetic information among those most likely to benefit.

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References

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