Short Communication

Accuracy of Colorectal Polyp Self-Reports: Findings from the Colon Cancer Family Registry

Lisa Madlensky,1 Darshana Daftary,2 Terrilea Burnett,4 Patricia Harmon,5 Mark Jenkins,6 Judi Maskiell,6 Sandra Nigon,7 Kerry Phillips,8 Allyson Templeton,9 Paul J. Limburg,7 Robert W. Haile,5 John D. Potter,9 Steven Gallinger,3 and John A. Baron10

1UCSD Moores Cancer Center, University of California, San Diego, California; 2Cancer Care Ontario; 3Samuel Lunenfeld Research Institute, University of Toronto, Toronto, Ontario, Canada; 4Epidemiology Program, Cancer Research Center of Hawaii, University of Hawaii, Manoa, Hawaii; 5Department of Preventive Medicine, University of Southern California-Keck School of Medicine, Los Angeles, California; 6Centre for Molecular, Environmental, Genetic and Analytic Epidemiology, The University of Melbourne, Melbourne, Victoria, Australia; 7Mayo Clinic, Rochester, Minnesota; 8South Australian Familial Cancer Unit, Women's and Children's Hospital, North Adelaide, Australia; 9Cancer Prevention Program, Fred Hutchinson Cancer Research Center, Seattle, Washington; and 10Departments of Medicine and Community and Family Medicine, Dartmouth Medical School, Hanover, New Hampshire

Abstract

Introduction: Colorectal adenomas and other types of polyps are commonly used as end points or risk factors in epidemiologic studies. However, it is not known how accurately patients are able to self-report the presence or absence of adenomas following colonoscopy.

Methods: Participants in the Colon Cancer Family Registry provided self-reports of recent colorectal cancer (CRC) screening activity, and whether or not they had ever been told they had a polyp. Positive and negative predictive values for polyp self-report were calculated by comparing medical records with self-reports from 488 participants.

Results: The positive predictive value for self-reported polyp was 80.9%, and the negative predictive value was 85.8%. The predictive values did not differ by age group or sex, but participants with a previous diagnosis of CRC had a lower negative predictive value (76.2%) than participants with no personal history of CRC (89.0%; P = 0.04).

Conclusions: Predictive values for self-reports of polyps are fairly high, but researchers needing accurate polyp data should obtain medical record confirmation. Pursuing medical records on only those participants self-reporting a polyp could result in an underestimation of the polyp prevalence in a study population.

(Cancer Epidemiol Biomarkers Prev 2007;16(9):1898–901)

Introduction

Colorectal adenomatous polyps (adenomas) are pre-malignant tumors with the potential to progress to invasive colorectal cancer (CRC; ref. 1). Other histologic types of polyps (such as serrated polyps) may also have malignant potential, although this remains controversial (2, 3). Adenomas are frequently an endpoint in clinical trials of CRC prevention, and several intervention studies have aimed to reduce adenoma incidence or recurrence (4, 5).

Several epidemiologic studies have relied on self-reports of “polyps” as an initial screen to determine which participants within a study will have medical records reviewed, which is a less costly practice than reviewing records for all participants (6-8).

The finding of an adenoma in a first-degree relative increases CRC risk, in some studies almost to the same extent as a family history of invasive CRC (9). As such, several authoritative guidelines treat a family history of adenoma exactly the same as a family history of CRC, and advise that individuals with either type of family history be screened more aggressively than the general population (10, 11). If such screening guidelines are to be advocated in an effort to reduce the incidence and mortality of CRC in the population, then accurate self-reporting of colorectal lesions will be of great importance for the successful identification of family members at increased-risk.

Whereas there is evidence that most individuals are able to report whether or not they have ever had a colonoscopy (12, 13), it is less clear whether those who have had a colonoscopy are able to accurately report whether or not a polyp was found during the procedure. The goal of this study was to determine the positive and
negative predictive values of self-reported polyps, using colonoscopy and pathology reports as a "gold standard" for comparison.

Materials and Methods

This study uses data from the Colorectal Cancer Family Registries (CCFR), an international collaborative resource that comprises family history, epidemiologic, medical, and genetic data, as well as biospecimens from more than 11,000 families affected by at least one case of CRC. Established with National Cancer Institute funding in 1997, the CCFR has six performance sites located in the United States, Canada, and Australasia (14). Three sites recruit participants through both population registries and high-risk clinics, and three sites recruit exclusively through population-based cancer registries. Two sites also collect data from randomly selected members of the general population as a control group.

The CCFR protocol includes follow-up questionnaires (administered 4-5 years after baseline data collection) for all participants, including self-reports of having undergone CRC screening and polyp diagnoses. Whereas some sites used telephone interviews and others mailed questionnaires, wording was very similar so that data from all sites could reasonably be combined. Participants were asked at follow-up if they had undergone any type of CRC screening since baseline. For polyp self-reports, participants were asked, "Since the date of your last interview (month/year), has a doctor told you that you had polyps in your large bowel or colon or rectum? Be sure to think about all polyps that were found in any of the procedures you had since your last interview—not just ones that may have been found during your most recent procedure."

For this pilot project, consent forms were mailed to consecutive CCFR participants who returned a follow-up questionnaire between 2003 and 2005 and met the eligibility criteria. Eligible participants reported at least one colonoscopy at follow-up that had taken place since baseline. In accordance with Institutional Review Board approvals at each site, eligible participants were sent a consent form to allow review of their colonoscopy records for five of the six sites, consent was requested from all eligible participants; for the remaining site, consent was requested only from those who self-reported a polyp. Thus, data from this site are included only in the calculations for positive predictive value.

Medical records (colonoscopy reports and, when appropriate and available, pathology reports) were reviewed and coded at each site. Data on age, sex, and cancer status (CRC patient versus unaffected relative) were obtained from the main CCFR database. Positive predictive values were calculated [along with 95% confidence intervals (95% CI)] as the percentage of participants with a verified polyp (of any histology) among those who responded "yes" to the polyp question. Negative predictive values were calculated as the proportion of participants with no mention of any type of polyp in their colonoscopy reports (or a clear statement that no polyps were identified) among those who responded "no" to the polyp question. We calculated positive predictive values and negative predictive values for the subset of participants for whom the self-reported number of colonoscopies was equal to the number of medically verified colonoscopies, to eliminate any inaccuracies due to faulty recall of the colonoscopic procedures themselves, as may occur with individuals undergoing frequent surveillance. Confidence intervals were calculated using a continuity-corrected efficient score method (15), and χ² tests of proportions were used to compare positive predictive values and negative predictive values across categories of age, sex, and cancer status.

A separate baseline data set consisting of 1,084 CCFR participants (unaffected by CRC and recruited between 1997 and 2003) from the Toronto and Seattle sites who self-reported a previous polyp diagnosis was used to evaluate the types of polyps that individuals self-reported. Response options were "benign", "adenomatous (precancerous)", "hyperplastic", "other (specify)", and "don't know". None of these subjects had their records reviewed. To determine whether family history of CRC is associated with self-reported polyp type, we classified these 1,084 individuals according to the numbers of CRC-affected first- and second-degree relatives (FDRs and SDRs, respectively) as having (a) no family history of CRC, (b) a moderate family history (no FDRs + up to 2 SDRs, or 1 FDR + up to 1 SDR), or (c) a strong family history (2 or more FDRs, 3 or more SDRs, or 1 FDR + 2 SDRs).

Results

A total of 808 CCFR participants were eligible for this study, having returned a questionnaire within the pilot time frame of each performance site, and indicating that a colonoscopy had been done during the follow-up period. Of these, 100 did not have medical records available for review, 10 responded "don't know" to the question about polyps, and 210 (30%) had more self-reported colonoscopies than were medically verified. Individuals with a previous CRC diagnosis were less likely than non-CRC patients (P < 0.001) to have medical records available, and they were also more likely to

<p>| Table 1. Positive and negative predictive values (95% CIs) of self-reported colorectal polyps from the CCR follow-up questionnaire |
|-----------------|-----------------|-----------------|-----------------|</p>
<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>PPV</th>
<th>NPV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;50</td>
<td>240</td>
<td>82.7 (76.2-87.8)</td>
<td>80.3 (76.1-89.0)</td>
</tr>
<tr>
<td>50-59</td>
<td>120</td>
<td>78.0 (70.1-85.9)</td>
<td>80.2 (76.1-89.0)</td>
</tr>
<tr>
<td>60-69</td>
<td>100</td>
<td>82.1 (78.1-86.7)</td>
<td>76.3 (72.1-81.0)</td>
</tr>
<tr>
<td>70+</td>
<td>100</td>
<td>85.9 (80.0-91.9)</td>
<td>80.0 (75.9-89.9)</td>
</tr>
<tr>
<td>CCFR site type</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Population based</td>
<td>332</td>
<td>81.6 (75.6-87.6)</td>
<td>84.3 (76.6-89.8)</td>
</tr>
<tr>
<td>Population + clinic</td>
<td>160</td>
<td>78.3 (72.8-83.8)</td>
<td>76.3 (70.8-80.8)</td>
</tr>
<tr>
<td>CRC cancer diagnosis*</td>
<td>196</td>
<td>82.5 (75.3-87.9)</td>
<td>76.2 (60.2-87.4)</td>
</tr>
<tr>
<td>No CRC</td>
<td>291</td>
<td>78.6 (70.1-84.9)</td>
<td>88.9 (81.0-93.9)</td>
</tr>
</tbody>
</table>

Abbreviations: PPV, positive predictive values; NPV, negative predictive value. *P = 0.04 for negative predictive value by χ² test.
self-report more colonoscopies than were verifiable \( (P < 0.001) \). Of the remaining 488 participants, 319 (65%) reported having had a polyp.

The positive predictive value of a self-reported polyp was 80.9% (95% CI, 76.0-85.0%), and the negative predictive value was 85.8% (95% CI, 79.4-90.5%). The comparisons of predictive values for various subgroups are shown in Table 1. There were no differences in positive predictive value or negative predictive value between men and women, between different age groups, or by CCFR site (three population-based sites versus three population-based and high-risk clinic sites). A lower negative predictive value was found among participants who had a previous cancer diagnosis (76% versus 89% for noncancer patients; \( P = 0.04 \)) but there was no difference in positive predictive value. Sensitivity and specificity were 91.5% (95% CI, 87.4-94.4%) and 70.4% (95% CI, 63.6-76.4%), respectively.

Twenty-four individuals self-reported not having a polyp but had colonoscopy reports indicating that at least one polyp was found; of these, 17 also had a pathology report. The sizes and types of lesions found are summarized in Table 2; 10 of the 17 polyps were adenomatous (2 were >10 mm). Of the 61 individuals who self-reported a polyp but did not have a polyp identified in their medical records, 12 (20%) had other findings reported, including hemorrhoids (4), diverticulosis (3), inflamed tissue (1), lymphoid hyperplasia (1), angiolipoma (1), hemangioma (1), and tumor masses (2). One individual had both hemorrhoids and diverticulae noted.

From the separate baseline data set of 1,084 non-CRC participants who reported their specific type of polyp, only 8% indicated a specific polyp type (adenoma) whereas 71% indicated that their polyps were benign. No respondents selected hyperplastic, and the remainder selected either other or don’t know, or had a missing response. Table 3 summarizes the self-reported type of polyp according to level of familial CRC risk; there were no differences in reporting across risk levels (Pearson \( \chi^2 = 9.9, P = 0.13)\).

**Discussion**

Based on these results, most colonoscoped individuals self-report the presence or absence of colorectal polyps with reasonable accuracy. However, the finding that 15% of individuals who do not self-report a polyp do, in fact, have a medically verified polyp is important for researchers who use self-reports as an initial screen to determine which individuals will have medical records requested for verification. We have examined only the accuracy of reporting the presence or absence of any type of polyp. Results from our separate baseline data set suggest that individuals with polyps are unable to accurately report polyp histology regardless of family history classification. Thus, it is important for researchers to pursue medical records when the specific type of polyp is needed.

In the context of behavioral research, our results present an interesting situation because \( \sim 13\% \) of colonoscoped individuals believe that they have had a polyp but, in fact, have not. Researchers who plan to study any behavioral responses to a polyp diagnosis will need to determine whether the appropriate variable to choose for any particular study is the actual diagnosis of a polyp or the belief that someone has or has not had a polyp.

We have identified a single publication that we can compare our results to. The investigators of the Health Professional Follow-up Study described medical records from men with self-reported colorectal polyps and reported a positive predictive value of 88% (8). They also reported that in a random sample of 200 participants who self-reported that they did not have a polyp, no medical reports of adenomas were identified. It is not known how many other types of polyps were found on review of medical records, if any, so their negative predictive value is not directly comparable to the present study.

Accuracy of polyp self-reporting did not differ significantly by age or sex; however, CRC patients were less likely to accurately report the absence of a polyp than subjects without cancer. This may be due to polyps being considered more of an incidental finding relative to the seriousness of the cancer that the patient has previously experienced. Alternatively, the finding could also be due to different communication patterns that occur between health professionals and cancer patients versus noncancer patients. Interestingly, CRC patients were also less likely to be included in this study due to unavailable medical records or discrepant numbers of self-reported and medically verified colonoscopies. Thus, our findings pertaining to CRC patients may be somewhat biased because their records were less likely to be evaluated; those who had better recall of their colonoscopy history were more likely to be included in this study and likely had better recall of their polyp status as well. Thus, our predictive values for CRC patients are likely ceiling estimates. We did not find that accuracy of self-reports varied by the recruitment sites; however, this analysis was done at the site level rather than by individual participants. It may be that individuals recruited through high-risk clinics differ from

---

**Table 2. Lesions identified in medical records of 24 participants incorrectly self-reporting no polyp history on the CCR follow-up questionnaire**

<table>
<thead>
<tr>
<th>Type of lesion</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adenoma of unknown size</td>
<td>1</td>
</tr>
<tr>
<td>Adenoma 1-5 mm</td>
<td>6</td>
</tr>
<tr>
<td>Adenoma 6-10 mm</td>
<td>1</td>
</tr>
<tr>
<td>Adenoma &gt;10 mm</td>
<td>2</td>
</tr>
<tr>
<td>Hyperplastic polyp</td>
<td>7</td>
</tr>
<tr>
<td>Polyp on colonoscopy report only</td>
<td>7</td>
</tr>
</tbody>
</table>

---

**Table 3. Self-reported type of polyp by strength of family history from the Seattle and Toronto CFR sites at baseline**

<table>
<thead>
<tr>
<th>Type of lesion</th>
<th>None</th>
<th>Moderate</th>
<th>Strong</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adenoma</td>
<td>17 (6.4)</td>
<td>46 (16.6)</td>
<td>24 (8.4)</td>
<td>87 (8.0)</td>
</tr>
<tr>
<td>Benign</td>
<td>190 (71.4)</td>
<td>383 (71.9)</td>
<td>201 (70.5)</td>
<td>774 (71.4)</td>
</tr>
<tr>
<td>Other</td>
<td>18 (6.8)</td>
<td>43 (8.1)</td>
<td>12 (4.2)</td>
<td>73 (6.7)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>41 (15.4)</td>
<td>61 (11.4)</td>
<td>48 (16.8)</td>
<td>150 (13.8)</td>
</tr>
</tbody>
</table>

NOTE: Data are presented as \( n (\%) \).
those recruited through population-based strategies; however, the present study is unable to address this.

We chose to focus on the predictive values of self-reports rather than the sensitivity and specificity test statistics because these may be of more use to researchers who have patient self-reports as their starting point (16) and need to decide whether or not to pursue medical records. Polyps were a common occurrence in our population, and thus the negative predictive values are not artificially inflated by a low prevalence.

Health professionals have the opportunity to communicate the finding of a polyp to the patient immediately following an endoscopic procedure. However, the pathology of the polyp normally takes several additional days to be reported, and physician practice patterns may vary. One survey of gastroenterologists found that the finding of polyps would be reported to 92% of unsedated and 79% of sedated patients (17). The nature of the sedation that is commonly used during colonoscopies (midazolam) poses an important problem for doctor-patient communication: it causes a transient amnesia, and whereas many patients seem coherent following their endoscopy, it is not uncommon for patients to forget their post-endoscopy conversation with medical staff (18).

A limitation of this study may be an above-average familiarity with CRC in our study cohort. Every participant either had CRC in the past or was a family member of someone with CRC. As such, awareness of CRC and polyps may be higher in this group than in the general population. However, our separate analysis of self-reported polyp type showed that individuals randomly selected from the general population had identical reporting patterns to CCFR participants with a moderate or strong CRC family history. These data provide compelling evidence that the majority of colonoscopy patients do not know the specific histology of their polyp. Whereas the CCFR participants are not necessarily representative of the general population, our results are applicable to those involved in the research or clinical care of individuals at increased familial risk. Another limitation is that we did not pursue medical records on those individuals who responded “don’t know” to the polyp question; thus, we were not able to provide any information on the actual polyp prevalence among this group. Finally, other variables relating to education, medical knowledge, or health communication that may be associated with accuracy of self-report were not explored in this study because this was a secondary analysis of data already collected by the CCFR. Comparisons across CCFR sites were not possible due to small cell sizes.

In summary, the accuracy of self-reports of polyps is fair, but most epidemiologic studies will still need to rely on medical records for definitive diagnoses. Using self-reports as an initial screen to determine which medical records are pursued may be appropriate and cost-effective for some studies. For other studies in which polyps are the main outcome of interest, relying on self-reports as an initial screen would lead to ~9% of polyps being missed.

Acknowledgments

We thank Graeme Suthe and John Hopper of the Australasian Colorectal Cancer Family Registry, Noralane Lindor of the Mayo Colorectal Cancer Family Registry, and Loic Le Marchand of the Hawaii Colorectal Cancer Family Registry for their support of this project.

References

Accuracy of Colorectal Polyp Self-Reports: Findings from the Colon Cancer Family Registry

Lisa Madlensky, Darshana Daftary, Terrilea Burnett, et al.


Updated version
Access the most recent version of this article at:
http://cebp.aacrjournals.org/content/16/9/1898

Cited articles
This article cites 17 articles, 5 of which you can access for free at:
http://cebp.aacrjournals.org/content/16/9/1898.full#ref-list-1

Citing articles
This article has been cited by 2 HighWire-hosted articles. Access the articles at:
http://cebp.aacrjournals.org/content/16/9/1898.full#related-urls

E-mail alerts
Sign up to receive free email-alerts related to this article or journal.

Reprints and Subscriptions
To order reprints of this article or to subscribe to the journal, contact the AACR Publications Department at pubs@aacr.org.

Permissions
To request permission to re-use all or part of this article, use this link
http://cebp.aacrjournals.org/content/16/9/1898.
Click on "Request Permissions" which will take you to the Copyright Clearance Center’s (CCC) Rightslink site.