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Improving the Quality of Colorectal Cancer Screening: Assessment of Familial Risk

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Abstract

Background—Accuracy of familial risk assessment by endoscopists in determining colonoscopic screening and surveillance intervals is unknown.

Aims—To investigate follow-up recommended by endoscopists for individuals at average or increased familial risk, following colonoscopies that were normal or yielded hyperplastic polyps only.

Methods—Colonoscopy registry data was analyzed on 5,982 patients who had colonoscopy between 2004 and 2006. Patient information was linked with colonoscopy procedure information and pathology results. Patients with a personal or family history of colorectal cancer (CRC) or polyps, inflammatory bowel disease, or who had diagnostic, incomplete or suboptimally prepped examinations were excluded. The final analysis, which included 2,414 patients, investigated concordance of risk assessment between patient and endoscopist, and resulting endoscopist follow-up recommendations.

Results—Following normal colonoscopy, 76% of average-risk individuals were told to follow-up in 10 years, but if a hyperplastic polyp was found, less than 10 years was suggested for 76%. Many patients reporting a known familial cancer syndrome or a very strong family history did not have that history indicated on the endoscopist's procedure form, and recommended follow-up intervals were beyond guideline recommendations for 60.4% of the very high-risk group.

Conclusions—Endoscopists may sometimes be unaware of the presence of familial risk factors, even for individuals at very high familial risk. Greater consistency and accuracy in familial risk assessments could significantly increase the efficacy of screening in preventing colorectal cancer.

Keywords

Colonoscopy; Screening; Colorectal cancer; Endoscopy; Quality; Familial risk

Introduction

Colorectal cancer (CRC) is the second most common cancer-related cause of death for men and women combined in the USA [1]. Since most colorectal cancers arise from polyps, colonoscopy, as the only screening test that affords polypectomy, is a critical resource for CRC screening and prevention. The process of polypectomy interrupts the 5- to 10-year course by which some adenomas develop into cancer and confers the benefit of decreased cancer incidence and mortality [2-4]. However, appropriate utilization of colonoscopy is vital to its effectiveness. Overutilization impacts available capacity, whereas underutilization leads to inadequate protection of individuals at increased risk. A key factor in effective utilization is the follow-up intervals that are recommended for screening and surveillance. Both accurate assessment of individual patient risk and knowledge of current guidelines are necessary to derive appropriate follow-up recommendations. The extent to which either of these factors is incorporated in clinical practice is not well known.

National surveys of colonoscopy capacity [5,6] as well as other assessments [7] have estimated colonoscopy procedures in the USA at between 4 and 14 million per year. A statewide assessment in New Hampshire estimated colonoscopy demand in 2002 to be approximately twice capacity [8]. Several factors influence demand for colonoscopy, including the follow-up intervals recommended by endoscopists. Guidelines for screening and surveillance have been published, describing optimal evidence-based utilization [9-11], but compliance with these guidelines appears to show wide variation.

Some studies indicate that average-risk patients with normal colonoscopy are recommended to follow up at intervals shorter than the published guidelines [12]; this practice could contribute to capacity issues due to overutilization of colonoscopy. On the other hand, underutilization of colonoscopy may not afford adequate protection. Family and personal history of CRC or adenomatous polyps are known to be associated with increased risk of CRC or polyps [9,13] and therefore are integral factors in determining appropriate follow-up intervals.

Guidelines for screening and surveillance address three groups of patients: average risk, comprised of individuals aged 50 years and older with no personal or family history of CRC or polyps; increased risk, comprised of individuals with a personal or family history of CRC or polyps or personal history of inflammatory bowel disease; and high risk, comprised of individuals with a known or suspected hereditary colon cancer syndrome, such as hereditary nonpolyposis colon cancer (HNPCC or Lynch syndrome) or familial adenomatous polyposis (FAP).

Published guidelines state that appropriate follow-up for average-risk individuals with normal complete colonoscopy or with colonoscopy yielding only a small hyperplastic polyp is to repeat the test at 10-year intervals [11]. For increased-risk individuals, those with one first-degree relative with CRC have been shown to be at an approximately two- to threefold increased lifetime risk of CRC compared with individuals at average risk (without family history). Those with two or more first-degree relatives with CRC or a first-degree relative who was 50 years or younger at CRC diagnosis have been shown to have an approximately three- to fourfold increased risk of colon cancer [9,14]. The multisociety guidelines for individuals with a first-degree relative with CRC or adenomatous polyps [9] consider relatives who are <60 years, or ≥ 60 years, at the time of diagnosis in order to determine appropriate follow-up (5 or 10 years, respectively). It is not yet firmly established that the longer interval will be adequate, which may contribute to some practice variation within that group. This recommendation should be distinguished from recommendations for an individual who has a first-degree relative younger

than age 45–50 years with CRC, for whom the possibility of a genetic syndrome would be a consideration.

Inappropriately long follow-up intervals for very high-risk individuals could lead to missed cancers [13,15–18]. While the normal adenoma-to-carcinoma sequence may follow a 5- to 10-year pattern, for individuals with HNPCC that pattern may follow an accelerated pace of only 2–3 years [15]; for this reason it is recommended that individuals with HNPCC undergo colonoscopy at 1- to 2-year intervals prior to age 40 years, and annually thereafter [13,16]. Awareness of the presence of familial risk factors in high-risk patients with a known or suspected hereditary colon cancer syndrome is essential to making appropriate follow-up recommendations, but the degree to which relevant history is obtained and incorporated into those recommendations is unknown. Understanding the frequency with which follow-up recommendations are based on endoscopy results alone, without incorporating family history, should lead to more effective colonoscopy practices.

Using data from the New Hampshire Colonoscopy Registry (NHCR), we investigated endoscopists' recommended follow-up for average, increased, and high-risk individuals, respectively, following colonoscopies that were normal or showed only a hyperplastic polyp. Since information on family history is essential in determining risk and therefore follow-up intervals, we assessed how often a discrepancy existed between a patient's report of family history and information reported by the endoscopist, including for patients with known HNPCC. Consistent and accurate performance in patient risk assessment, combined with knowledge of evidence-based guidelines, could significantly increase effectiveness of CRC screening.

Methods

Background

The NHCR records colonoscopy examinations with linkages to pathology for consenting individuals in New Hampshire. Approximately 85% of all patients receiving colonoscopy at participating sites consented to participate. The design and development of the registry are described elsewhere [19].

NHCR data collection includes three questionnaire forms. A self-administered patient form completed during the outpatient registration process ascertains demographic characteristics, previous experience with colonoscopy or sigmoidoscopy, detailed personal and family history of CRC or polyps, and other health history (including use of aspirin, calcium, alcohol, and smoking history). The family history includes specific questions about which (if any) first-degree relative(s) had CRC and whether those specific relatives were aged <50 years at diagnosis. Patients are asked whether they have been told that they have a family history of HNPCC or FAP; answer options include “yes,” “no,” and “I don't know.” Nurses and endoscopists are readily available to answer patients' questions about the survey form. A second form, the endoscopist's procedure report, records indication for the procedure (screening with and without family history, surveillance, or diagnostic examination for signs or symptoms), findings (location, size, and specific treatment of polyps or cancer), quality of bowel preparation, sedation medications, region reached during the procedure, follow-up recommendations, and immediate complications. The third form is a follow-up survey mailed to patients approximately 1 month after their procedure to assess follow-up recommendations and post-procedure complications. All data collection forms and procedures have been approved by our Committee for the Protection of Human Subjects.

Three risk categories were studied: average risk (individuals over age 50 years with no personal or family history of CRC or polyps), increased risk (individuals with one first-degree relative

with CRC), and high risk (individuals with a suspected or known familial syndrome such as HNPCC or FAP). Individuals with two or more first-degree relatives with CRC, or CRC in a first-degree relative aged less than 50 years, were categorized as high risk.

Study Population

The NHCR included data on 5,982 patients who underwent colonoscopy between 2004 and 2006.

Exclusion Criteria

Patients reporting personal history of CRC or polyps, inflammatory bowel disease, or those whose examination was for diagnostic purposes were excluded from the analysis ($n = 1,879$). An additional 1,062 patients found to have nonhyperplastic polyps were excluded, and 271 patients were excluded due to “poor” or “fair” bowel preparation (only individuals whose prep was described as “good” or “excellent” were included). Lastly, 355 patients were excluded because the examination did not reach the cecum or terminal ileum. Final analysis included 2,414 patients.

Analysis

Results are reported as descriptive statistics, and analysis was conducted using SAS analytic software.

Results

The demographic characteristics of the 2,414 analyzed patients (comprised of those remaining after applying the exclusion criteria described above) are shown in Table 1. Sixty-one percent were female and 39% were male, with the majority of participants being 50–69 years old. Two hundred and sixteen patients were excluded from the remaining tables and from Figure 1 because familial risk could not be assessed. Based on self-report of personal and family history of 2,198 patients, 1,787 (81.3%) patients were considered at average risk, 274 (12.5%) were at increased risk, and 137 (6.2%) were at high risk. Of the 137 high-risk patients, 35 (25.5%) reported known personal and/or family history of HNPCC or FAP.

Table 2 illustrates intervals recommended for average- and increased-risk patients for whom recommendation information was complete ($n = 1,564$). Of the patients for whom the recommendation was no further screening, 56.8% were over the age of 75 years, 38.6% were aged between 70 and 75 years, and the remaining 2.2% were under the age of 70 years (data not shown). Seventy-six percent of average-risk patients who had normal colonoscopy were told to follow-up in 10 years, although 20.2% of recommendations were for a shorter interval. For average-risk patients found to have a hyperplastic polyp, 75.8% of recommendations were for an interval shorter than 10 years. The majority (69.5%) of increased-risk patients who had a normal colonoscopy were told to follow up in 5 years or less. Nearly all (93.4%) increased-risk patients with a hyperplastic polyp were told to follow up in 5 years or less.

Table 3 illustrates follow-up intervals recommended for patients having two or more first-degree relatives with CRC, and/or colon cancer in a first-degree relative aged under 50 years (not including individuals with known personal or family history of HNPCC or FAP). Within the former group, 22.9% were recommended to follow-up in more than 5 years (20% in 10 years); of the latter group, 18% received a follow-up recommendation longer than 5 years (16% in 10 years).

Table 4 presents agreement between the patient report of personal or family history of HNPCC or FAP and the procedure indications on the corresponding endoscopist's report. Of the 35

patients who reported known HNPCC or FAP on the patient questionnaire, 33 (94%) patients did not have HNPCC or FAP noted on the endoscopist's report form questionnaire. Recommended follow-up interval for the HNPCC or FAP group was 10 years in 17.1% and 4–9 years for 48.6%; thus, for 65.7% of the very high-risk group, an interval of 4 years or longer was suggested.

One thousand five hundred and fourteen patients had complete family history and recommended follow-up information. Of these, 1,231 (81.3%) patients indicated that they did not have family history of CRC. Of those patient reports, 1,169 (94.9%) had concurring information on the endoscopist's report. Nearly 19% (283/1,514) of patients indicated that they did have family history; of these 283 patients, the endoscopist selected "screening with no family history" as the indication for 63 (22.2%).

Figure 1 provides information on the recommended follow-up for each of the "report concordance" situations. Of patients reporting no family history and for whom the endoscopist's report concurred, 79% received a recommendation for follow-up in 10 years or more or no further screening; 18% received a shorter recommendation. Of patients reporting no family history and for whom the endoscopist did note a family history, follow-up recommendations for the majority (74%) were for less than 10 years. Of patients who reported positive family history and for whom the endoscopist did not concur (noting no family history), 67% were recommended to have follow-up at an interval ≥ 10 years or no further screening.

Discussion

The capability for prevention and early detection of CRC has generated compelling support for CRC screening, with several organizations suggesting colonoscopy as the test of choice [20,21]. As the only screening test allowing polypectomy, colonoscopy is a critical resource. However, appropriate utilization of colonoscopy is essential.

Several notable findings arose from our study. Compared with previous reports [12], our analysis indicates greater adherence to the current guideline recommendation [11] for 10-year follow-up of average-risk individuals following normal colonoscopy. However, 76% of average-risk individuals with a hyperplastic polyp, for whom the same guideline recommendation applies, received a specific follow-up recommendation of less than 10 years (Table 2), despite the option of "follow-up per pending pathology" on the endoscopist's form. Variation from this guideline, involving the majority of average-risk patients in the hyperplastic subgroup, suggests an area for improvement in colonoscopy utilization.

A major focus of our investigation was the degree to which family history is incorporated in endoscopists' recommendations for follow-up screening and surveillance. As reflected in Tables 3 and 4, many high-risk individuals (both with and without known HNPCC) were recommended to follow-up at intervals longer than those indicated in guidelines [9]. In the known HNPCC or FAP group, the majority of patients were given a follow-up recommendation of 4–5 years or longer. Since the recommended surveillance for HNPCC is yearly follow-up after age 40 years, about 80% of recommendations were inconsistent with current guidelines. This information suggests that endoscopists may lack accurate information concerning their patients' familial risk, thereby resulting in inappropriate follow-up recommendations.

To further investigate our hypothesis, we analyzed the concordance of familial risk information between patients' forms and the corresponding endoscopists' forms, and reviewed recommended follow-up within this framework. We found that the majority (95%) of patients who reported no family history of colorectal cancer had concurring information noted by the endoscopist on the endoscopy form. However, of patients that did report a positive family history in at least one first-degree relative, 20% did not have family history noted on the

corresponding endoscopy form. The most striking finding was that, of the 35 patients reporting known HNPCC (Table 4), the endoscopist did not note this history for 33 (94%), which may have contributed to the deviation from guideline recommendations for this group.

Our results suggest that incorporation of family history into CRC screening recommendations may be inconsistent in clinical practice, resulting in inappropriate follow-up. A critical factor that can improve screening outcomes, particularly for high-risk patients, is consistently ascertaining detailed family history, and not just the polyp history, in making follow-up recommendations.

Limitations of this study include that only those patients for whom both patient and endoscopist forms were completed were analyzed. It should also be acknowledged that guidelines are just that, and individual judgment should take precedence when appropriate. Nonetheless, adherence to the published guidelines may be a reasonable place to begin assessment of best practices for colonoscopy. To allow clear focus on consideration of family history in determining follow-up recommendations, we intentionally studied the less controversial aspects of the guidelines (normal examination or hyperplastic polyp) for patients at average, increased, and high risk by virtue of their family history alone, rather than adenomatous polyp surveillance indications.

Clinical implications of this study suggest that one source of variation from “best practices” for CRC screening may be lack of accurate assessment of patients’ familial risk. Sweet et al. compared patient and physician reports of family history and found that moderate- and high-risk individuals were often not identified by physicians due to lack of detail in the physician family history assessment [22]. A later study showed that presence of risk factors which increase the likelihood of having a hereditary form of cancer (such as young age at onset of disease or a first-degree relative who also had cancer) did not improve accuracy of family history assessments [23]. The authors suggested that more systematic and standardized methods of obtaining family history could enhance efficiency, and more accurate risk assessment would improve the opportunity for cancer prevention for patients and their close relatives. These conclusions clearly apply to CRC screening, particularly given the potential for true prevention that exists for CRC.

A recent national survey of primary care providers (PCPs) found increased frequency of recommended surveillance compared with guidelines, including 61% of PCP’s recommending 5-year follow-up for a hyperplastic polyp [24]. Schroy et al. [25] noted that only 63% of PCPs routinely inquire about family history of CRC or polyps. Potentially successful methods for changing physician practices have been reviewed in depth elsewhere [26]. A recent quality improvement initiative significantly improved compliance with postpolypectomy surveillance guidelines through simple and inexpensive interventions [27], and implementation of a guideline-based triage system for colonoscopy has proven successful [28]. Thus, heightened awareness of the importance of familial risk assessment by endoscopists and PCPs appears to be an achievable and critically important goal that could significantly improve the performance and outcome of CRC screening.

In addition to interventions designed to increase physicians’ CRC risk assessments and appropriate screening recommendations for their patients, the electronic medical record may become an important tool for documenting, monitoring, and communicating patients’ familial risk. Accessibility of patient risk factors during every patient-provider encounter will help to ensure that each patient is screened and followed up appropriately.

This study shows that improvement is needed in the accuracy and integration of family history in patient risk assessments for CRC screening and surveillance. The variation from guideline recommendations demonstrated by this study, especially for high-risk patients, highlights

specific areas in which improvements could significantly enhance CRC screening and thereby improve patient care.

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¹Concordance between patient and colonoscopist report of no family history was 95%.

²Concordance between patient and colonoscopist report of positive family history was 80%.

Fig. 1.

Recommended follow-up intervals based on agreement between patient report and colonoscopist's documentation of family history (Figure does not include patients with HNPCC or FAP)

Table 1

Participant characteristics in the New Hampshire Colonoscopy Registry (2004–2006)

Characteristic	Participants, <i>n</i> (%)
Total	2,414 (100)
Age (years)	
<40	25 (1.0)
40–49	146 (6.1)
50–59	1,400 (58.0)
60–69	586 (24.3)
70+	25 (10.6)
Sex	
Male	933 (39.4)
Female	1,436 (60.6)
Education	
High school or less	49 (2.8)
Some college or technical school	323 (18.3)
College or post-college graduate	1,395 (78.9)
Health insurance	
Medicare	459 (20.3)
Medicaid	65 (2.9)
Private	1,275 (56.3)
HMO/PPO	609 (26.9)
Other	263 (11.6)
None	33 (1.5)
Smoking history	
Never smoked	1,145 (50.1)
Past smoker	988 (43.2)
Current smoker	152 (6.7)
Number of alcoholic drinks per week	
0	810 (35.8)
1–4	780 (34.5)
5–8	383 (16.9)
9–12	156 (6.9)
13+	132 (5.8)

Percentages do not include missing numbers: sex (45); age (2); Education (647); smoking (129); alcohol (153); insurance (150)

Colonoscopy follow-up recommendation for average-risk versus increased-risk patients with normal or hyperplastic findings upon examination

Table 2

Recommended follow-up interval	Average risk (no family history of colorectal cancer) <i>n</i> = 1,343		Increased risk (family history of colorectal cancer in a first-degree relative) <i>n</i> = 221	
	Normal (<i>n</i> = 1,244) <i>n</i> (%)	Hyperplastic (<i>n</i> = 99)	Normal (<i>n</i> = 206) <i>n</i> (%)	Hyperplastic (<i>n</i> = 15)
≤1 year	0 (0)	1 (1.0)	1 (0.5)	0 (0)
2–3 years	18 (1.4)	7 (7.1)	9 (4.4)	4 (26.7)
4–5 years	215 (17.3)	67 (67.7)	133 (64.6)	10 (66.7)
6–9 years	19 (1.5)	0 (0)	11 (5.3)	0 (0)
10 years	943 (75.8)	24 (24.2)	39 (18.9)	0 (0)
>10 years	14 (1.1)	0 (0)	5 (2.4)	0 (0)
No further screening	35 (2.8)	0 (0)	8 (3.9)	1 (6.7)

Table 3

Colonoscopy follow-up recommendations for high-risk patients with normal (or only hyperplastic) findings upon examination

Recommended follow-up interval	Family history risk factor	
	≥2 first-degree relatives with colon cancer ^a <i>n</i> = 35 <i>n</i> (%)	Colon cancer in relative <50 years of age ^a <i>n</i> = 50 <i>n</i> (%)
≤1 year	0	0
2–3 years	1 (2.9)	5 (10.0)
4–5 years	26 (74.2)	36 (72.0)
6–9 years	1 (2.9)	1 (2.0)
10 years	7 (20.0)	8 (16.0)
>10 years	0	0
No further screening	0	0

Excludes individuals with a history of HNPCC or FAP

^a Not mutually exclusive: nine individuals had both two or more first-degree relatives and a relative <50 years old with colorectal cancer

Table 4

Agreement between patient report of family history of HNPCC or FAP and colonoscopist's documentation

	NO Endoscopist did not indicate HX of HNPCC or FAP	YES Endoscopist indicated HX of HNPCC or FAP
Patient: Personal or Family History of HNPCC or FAP (n=35)	n=33 (94%)	n=2 (6%)
Recommended follow-up: <ul style="list-style-type: none"> • <1 year = 0 (0%) • 2-3 years = 3 (8.6%) • 4-5 years = 16 (45.7%) • 6-9 years = 1 (2.9%) • 10 years = 6 (17.1%) Follow-up recommendation was not indicated for 9 (25.7%) patients		

n = 35

The guideline recommendation is colonoscopy every 1–2 years until age 40 years, and annually thereafter