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Specialists' perceptions of hereditary colorectal cancer screening in Newfoundland and Labrador

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ABSTRACT

Purpose

Colorectal cancer (CRC) screening is particularly valuable in Newfoundland and Labrador (NL), where a substantial proportion of CRC cases have a hereditary link. We examined the perceptions of gastroenterologists and general surgeons with respect to screening practices for patients with hereditary CRC.

Methods

We surveyed all gastroenterologists and general surgeons in NL to determine demographic and professional practice characteristics and screening knowledge, practices, and attitudes for four groups of patients with hereditary CRC.

Results

Of the 43 eligible physicians, 36 (83.7%) responded. Most of the physicians surveyed knew the correct age to start screening, preferred screening by colonoscopy, had a systematic means in their own practice of prioritizing patients for screening, and felt that family doctors or patients (or both) should be responsible for monitoring screening compliance. Most physicians reported that patients with hereditary nonpolyposis CRC and familial adenomatous polyposis waited 3 months for screening; patients with a family history of CRC or adenomatous polyp waited 6 months or longer. Although respondents agreed on the need for a province-wide CRC registry [4.36 on a 5-point Likert scale (1 = strongly disagree; 5 = strongly agree)], they disagreed that wait times were reasonable (2.81) and that other health professionals should perform colonoscopies (2.86). They were equivocal about the need for centralized bookings (3.25) and about whether genetic testing is useful for prioritizing patients (3.25).

Conclusions

Gastroenterologists and general surgeons in NL were knowledgeable about screening, but had varying opinions about individual roles in screening, wait times, and the means for prioritizing and providing screening for patients with hereditary CRC.

KEY WORDS

Colorectal cancer, familial, hereditary, specialists, screening

1. INTRODUCTION

Colorectal cancer (CRC) is the fourth most commonly diagnosed cancer and the second leading cause of cancer death for both men and women in Canada [1]. In 2011, an estimated 22,200 Canadians were expected to be diagnosed with CRC and 8900 to die from the disease [2]. Currently, Newfoundland and Labrador (NL) has the highest age-standardized incidence rates of CRC among men (89 per 100,000) and women (52 per 100,000) [2]. Based on the 2011 NL cancer statistics estimates, a total of 310 men and 200 women were expected to be diagnosed with CRC, with 150 men and 90 women being expected die from the disease [2].

With regular screening, CRC is one of the most preventable forms of cancer. Screening reduces CRC incidence and mortality by identifying premalignant polyps so that they can be removed before cancerous tumors develop. With advancements in genetics research, high-risk individuals can be identified at an earlier age and screened more frequently. Screening has the potential to be particularly valuable in NL, where researchers have found that almost 4% of CRC cases come from families with hereditary nonpolyposis CRC (HNPCC) and that 0.9% of cases involve familial adenomatous polyposis (FAP). A further 43% of patients appear to have a familial link to CRC [3].

Despite higher rates of CRC incidence and mortality in NL, screening rates in the province are low. Based

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on data from the Canadian Community Health Survey Cycle 2.1, the proportion of people who reported up-to-date CRC screening among the four provinces assessed (Ontario, British Columbia, Saskatchewan, and NL) was lowest in NL at 12.6%. As few as 4% of women in NL reported taking a fecal occult blood test in the 2 years before the survey was conducted [4].

Gastroenterologists and surgeons play a critical role in screening for CRC in NL. These specialists are trained to do colonoscopies, the modality most commonly used for screening in high-risk CRC populations [5,6]. We surveyed these physicians to determine their demographic and professional practice characteristics, screening knowledge, screening practices, and attitudes about current CRC screening services available in NL, particularly for high-risk patients. Understanding the perspectives of physicians involved in CRC screening is an important first step to improving screening rates in the province.

2. METHODS

Our study was approved by Memorial University's Human Investigation Committee.

Survey questions were based on questions used in a similar study in the United States [7], on screening guidelines proposed by the Canadian Association of Gastroenterology [5] and the Alberta Cancer Board [8], and on feedback from local experts, including a surgeon and a medical geneticist. The 20-question survey had three parts:

- Physician demographic and practice characteristics
- Screening practices for general and high-risk patients
- Attitudes about current CRC screening services

We defined HNPCC as "previously known as Lynch syndrome," FAP as "adenomatous polyp diagnosed at younger than age 60," family history of adenomatous polyp as "single first-degree relative with adenomatous polyp diagnosed at younger than age 60," and family history of CRC as "single first-degree relative with CRC diagnosed at younger than age 55." Those definitions had been used in a previous survey of high-risk CRC patients [7].

The survey was piloted by a gastroenterologist and a surgeon. Based on their feedback and the advice of the experts, we revised the survey questions to reflect local practice. For example, we used age cut-offs adapted locally from screening guidelines.

We used the College of Physicians and Surgeons of Newfoundland and Labrador Web site to identify all gastroenterologists and general surgeons in the province. Using a modified Dillman method [9], we mailed surveys in January 2009 and followed up with a second mailing in February 2009. Although the regular Dillman method suggests three mailings of the survey with reminders, we mailed the survey twice and then reminded non-respondents by telephone. Each survey package included the survey, a cover letter that described the purpose of the study, a prepaid return envelope, and a postcard (which was returned separately and used to track respondents).

To be included in the study, physicians had to be practicing in NL and performing colonoscopies as of December 31, 2008. We excluded pediatric specialists and postgraduate residents.

Survey responses were entered into SPSS, a database for statistical analysis (SPSS, Chicago, IL, U.S.A.). To assess the representativeness of the sample, chi-square tests were used to compare respondents to non-respondents in terms of specialty, sex, and size of community practice. Frequencies were used for categorical variables, and means and standard deviations were used for continuous variables (for example, responses to 5-point Likert scale questions).

3. RESULTS

Of the 43 gastroenterologists and general surgeons in NL who were eligible for the study, 36 returned a survey (83.7% response rate). The sample was representative in terms of sex and specialty, but not community size. The sample slightly overrepresented physicians practicing in rural and small urban communities (populations less than 100,000).

As shown in Table I, gastroenterologists made up one quarter of the sample. Most of the respondents were male (82.9%), had graduated from medical school more than 10 years earlier (64.7%), had practiced in NL for fewer than 10 years (57.1%), were certified by the Royal College of Physicians and Surgeons of Canada (82.9%), worked in urban or small urban communities (62.9%), and performed more than 250 colonoscopies annually (73.5%).

Most respondents begin screening patients with a family history of CRC or adenomatous polyposis at 40–49 years (or 10 years before the youngest family member at diagnosis); of FAP, at 15–24 years; and of HNPCC, at 25–39 years (Table II). Colonoscopy was the most commonly used screening method for all four high-risk groups. Roughly one third to one half of the physicians surveyed reported involving family doctors in the care of all four groups of patients. Two thirds of physicians surveyed involved the Provincial Medical Genetics Program in the screening of FAP and HNPCC patients. Nearly all respondents routinely recommend genetic testing for patients suspected to be at risk of FAP (97.0%) and HNPCC (90.6%). Just more than half (55.9%) reported wait times of 3 months for colonoscopies in FAP and HNPCC patients; for patients with a family history of CRC (76.5%) or adenomatous polyp (69.7%), the respondents expected a wait of 6 months or longer. By contrast, two thirds of the physicians surveyed (66.7%) reported that the general population waited 6 months or more for a colonoscopy. Five physicians (15.2%) reported that the general population waited fewer than 3 months.

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TABLE I Characteristics of specialists who perform colonoscopies in Newfoundland and Labrador (NL)

Characteristic	*Value (n)*[a]	*(%)*
Specialty		
Gastroenterology	9	25.0
Surgery	27	75.0
Sex		
Women	6	17.1
Men	29	82.9
Years since graduation from medical school		
<10	12	35.3
10–20	7	20.6
20–30	8	23.5
>30	7	20.6
Years practicing in NL		
<10	20	57.1
10–30	12	34.3
>30	3	8.6
Professional certification[b]		
RCPSC	29	82.9
American Board of Surgery	3	8.6
Non-certified specialist	4	11.4
Other	3	8.4
Community size		
Rural (<10,000)	5	14.3
Small urban (10,000–100,000)	17	48.6
Urban (>100,000)	13	37.1
Colonoscopies performed annually		
<100	2	5.9
101–250	7	20.6
251–500	12	35.3
501–750	6	17.6
>750	7	20.6

[a] Responses may not total to 36 because of unanswered questions.
[b] May total to more than 36 and 100% because more than one answer could be selected.
RCPSC = Royal College of Physicians and Surgeons of Canada.

More than three quarters of specialists (80.0%) reported having a systematic approach to prioritizing their colonoscopy service (Table III). More than half (52.8%) said that they prioritized on the basis of presenting symptoms (for example, abnormal lab data, occult blood, change in stool pattern, weight loss). When asked who should be responsible for monitoring patient compliance to screening, the most common answers were the patient (22.2%), the family doctor (11.1%), or a combination of the patient and the family doctor (22.2%).

The physicians surveyed were asked to use a 5-point Likert scale (1 = strongly disagree; 5 = strongly agree) to rate their agreement with a number of statements (Table IV). The results showed general agreement on the need in NL for a province-wide CRC registry and for more continuing education on CRC screening for family physicians. Although respondents generally disagreed that wait times were reasonable, they did not agree with other health professionals (besides gastroenterologists and surgeons) performing colonoscopies, with centralized bookings, or with the usefulness of genetic testing for prioritizing patients.

4. DISCUSSION

We surveyed gastroenterologists and general surgeons in NL to gain a better understanding of CRC screening practices in NL, particularly for high-risk patients. In general, it appears most specialists know the recommended ages to begin screening for patients with a hereditary link to CRC. A number of studies have examined the knowledge, practices, and attitudes of physicians with respect to CRC screening for average-risk patients, but we were unable to find any Canadian study examining screening for high-risk patients. A U.S. study found that, among surveyed gastroenterologists, more than 70% knew the correct age to begin screening for patients with a family history of CRC, of FAP, and of HNPCC, but fewer than 40% knew the correct age for screening patients for adenomatous polyposis [7].

Currently, no Canadian consensus for screening populations at high risk for familial or hereditary CRC has been developed (Green J. Memorial University of Newfoundland. Personal communication, 2009). The Canadian Association of Gastroenterology and the Canadian Digestive Health Foundation recommend that individuals with a family history of CRC or adenomatous polyps have a colonoscopy every 5 years, or 10 years earlier than the youngest diagnosis of polyp or cancer in the family, whichever comes first [5]. For HNPCC patients, colonoscopy is recommended every 2 years beginning at age 20, or 10 years earlier than the youngest case in the family, whichever comes first. For FAP patients, sigmoidoscopy is recommended annually, beginning at age 10–12 years [5].

Colonoscopy was the preferred method of screening for the high-risk patients addressed in the present study. Although guidelines recommend flexible sigmoidoscopy for screening patients with FAP, only 23% of specialists selected that screening modality for those patients. The latter finding may be a result of polyp locations in FAP families in NL. Unlike typical FAP patients, the polyps in many NL patients appear only in the right colon, making colonoscopy the preferred screening test (Green J. Memorial University of Newfoundland. Personal communication, 2009).

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TABLE II Specialists' preferred modalities for screening high-risk patients

Variable	*Family history*							
	CRC		*AP*		*FAP*		*HNPCC*	
	(n)	*(%)*	*(n)*	*(%)*	*(n)*	*(%)*	*(n)*	*(%)*
Age screening starts								
15–24 Years	0	0.0	1	2.8	31	86.1	12	35.3
25–39 Years	4	11.8	2	5.6	5	13.9	20	58.8
40–49 Years or 10 years earlier than youngest relative diagnosed	29	85.2	25	69.4	0	0.0	2	5.9
50+ Years	1	2.9	8	22.2	0	0.0	0	0.0
Most commonly used screening modality[a]								
Digital rectal exam	7	20.0	5	13.9	5	13.9	5	13.9
Flexible sigmoidoscopy	1	2.9	1	2.8	8	22.2	1	2.8
Colonoscopy	33	94.3	34	94.4	29	80.6	34	94.4
Fecal occult blood test	5	14.3	5	13.9	4	11.1	4	11.1
Fecal occult blood test plus flexible sigmoidoscopy	0	0.0	1	2.8	0	0.0	2	5.6
Double-contrast barium enema	2	5.7	2	5.6	2	5.6	3	8.3
Do not screen	1	2.9	1	2.8	1	2.8	0	0.0
Involve other health professionals[a]								
Other gastroenterologists/surgeons	8	22.9	8	22.2	13	36.1	13	36.1
Family doctor	16	45.9	14	38.9	16	44.4	14	38.9
Provincial medical genetics program	9	25.7	5	13.9	26	72.2	26	66.7
Gynecologists/urologists	1	2.8	0	0.0	3	8.3	9	25.0
None	11	31.4	13	3.61	2	5.6	2	5.6
Genetic testing								
Yes	1	3.0	3	9.4	32	97.0	25	80.6
No	32	97.0	29	90.6	1	3.0	6	19.4
Wait time for colonoscopy								
<1 Month	2	5.9	3	9.1	5		14.7	
1–3 Months	6	17.6	7	21.2	14		41.2	
3–6 Months	9	26.5	7	21.2	5		14.7	
6–12 Months	9	26.5	11	33.3	9		26.5	
>12 Months	8	23.5	5	15.2	1		2.9	

[a] May total to more than 36 and 100% because all applicable answers could be selected. Percentages are based on number of respondents selecting each item.

CRC = colorectal cancer; AP = adenomatous polyposis; FAP = familial adenomatous polyposis; HNPCC = hereditary nonpolyposis colorectal cancer.

Our study found low agreement with the proposition that genetic testing is useful for prioritizing patient care. Few of the surveyed physicians reported that they involved the Provincial Medical Genetics Program in the care of patients with a family history of CRC or adenomatous polyposis. Almost all the specialists involve the Provincial Medical Genetics Program for patients with FAP, but a lower proportion of physicians involve the Program for HNPCC patients. Likewise, of the surveyed specialists, a smaller proportion refer suspected HNPCC patients than refer FAP patients for genetic testing. A U.S. study reported similar results: 91% of gastroenterologists surveyed referred FAP patients for genetic testing, but only 72% referred HNPCC patients [7]. The difference in referral rates for HNPCC and FAP has been attributed to the difficulty of differentiating patients with a strong family history of CRC from those who carry a

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TABLE III Specialists' criteria for prioritizing colonoscopy service and monitoring compliance to screening by patients with familial hereditary colorectal cancer

Criterion	*Value* (n)	*(%)*
Do you have a systematic approach to prioritization?		
Yes	28	80.0
No	7	20.0
On what basis do you prioritize?		
Symptoms	19	52.8
Referral from family doctor/nurse practitioner	3	8.3
Referral from PMGP/results of genetic testing	2	5.6
Family history (CRC, FAP, HNPCC, polyps)	11	30.6
Personal history of CRC or polyps	3	8.3
Past-heir screening interval in FAP/HNPCC patients	2	5.6
Age	4	11.1
Who should be responsible for monitoring?		
Patient	8	22.2
Gastroenterologist/surgeon	1	2.8
PMGP	2	5.6
Family doctor	4	11.1
Patient and gastroenterologist/surgeon	2	5.6
Patient and PMGP	1	2.8
Patient and family doctor	2	22.2
Patient, gastroenterologist/surgeon, and family doctor	6	16.7
Gastroenterologist/surgeon and family doctor	2	5.6
Patient, gastroenterologist/surgeon, family doctor, and PMGP	2	5.6

PMGP = provincial medical genetics program; CRC = colorectal cancer; FAP = familial adenomatous polyposis; HNPCC = hereditary nonpolyposis colorectal cancer.

gene mutation associated with HNPCC, given that all possible gene mutations associated with HNPCC have yet to be identified (Green J. Memorial University of Newfoundland. Personal communication, 2009). Genetic confirmation is shown to enhance adherence to screening recommendations; it also helps genetic counsellors to ensure that appropriate information and support is provided to patients [10–12].

Most physicians in our study indicated that they had a systematic approach to prioritizing patients for colonoscopy; however, they do not share a standardized methodology for prioritizing patients. Moreover, most agree that wait times for screening are too long, but show little support for centralized colonoscopy booking or for allowing other health professionals to provide colonoscopy—two approaches that may reduce wait times or prioritize patients [13,14].

TABLE IV Specialists' attitude about current colorectal cancer (CRC) screening services in Newfoundland and Labrador

Item	*Score (mean±SD)*
There is a need for a province-wide CRC registry	4.36±0.72
There is a need for a province-wide CRC screening central booking centre	3.25±1.23
Gastroenterologists need more continuing education around family history and CRC screening	3.03±0.87
Surgeons need more continuing education around family history of CRC screening	3.34±0.97
Family physicians need more continuing education around family history of CRC screening	4.00±0.80
High-risk patients (that is, FAP, HNPCC) should be seeing the same physician for follow-up colonoscopies	3.75±1.13
Other health professionals besides gastroenterologists/surgeons should be trained to do colonoscopies	2.36±1.13
Wait times for your colonoscopy service is reasonable	2.81±1.28
Genetic testing is useful in prioritizing patient care	3.25±1.00
More patients are being referred for genetic testing than 5 years ago	3.12±1.01
There is sufficient support given to those patients who undergo genetic testing	3.51±0.70

SD = standard deviation; FAP = familial adenomatous polyposis; HNPCC = hereditary nonpolyposis colorectal cancer.

Our study also suggests that the gastroenterologists and general surgeons surveyed do not generally consider themselves to be responsible for monitoring screening compliance by high-risk familial and hereditary CRC patients. Interestingly, although more than 60% of specialists surveyed felt that family physicians should be involved in monitoring the compliance of high-risk CRC patients to screening, there was high agreement that family physicians need more continuing education about family history and CRC screening guidelines.

This descriptive study has a number of limitations. First, despite the high response rate, the small sample size restricts our ability to compare groups of respondents. The survey was adapted to provide valid reflection of local practices, but that adaptation may limit its generalizability to other jurisdictions. As noted earlier, the sample slightly overrepresents specialists working in rural regions of NL. Rural physicians generally have less access to continuing medical education, but visits by medical geneticists to rural areas of the province to inform specialists

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about familial and hereditary CRC and screening recommendations have recently increased (Green J. Memorial University of Newfoundland. Personal communication, 2009). Those visits lessens the likelihood of urban-versus-rural differences in specialist knowledge of CRC screening. Lastly, our survey captures the perceptions and attitudes of physicians. Some respondents may have felt pressured to answer questions based on socially accepted standards or published clinical practice guidelines rather than based on reflection about personal practice. Further research on the perceptions of patients, family doctors, and other health professionals and on actual service utilization patterns will provide a more rounded understanding of the issues related to screening of patients at high risk for CRC in NL.

5. CONCLUSIONS

Gaining a better understanding of the knowledge, practice patterns, and attitudes of gastroenterologists and general surgeons, the primary providers of colonoscopies in NL, is a key initial step in improving CRC screening service for the province, particularly for high-risk patients. Our cross-sectional descriptive survey captures the perceptions of these specialist physicians and describes inconsistencies in CRC screening practices in the province. Most of the specialists surveyed were knowledgeable about screening recommendations for high-risk patients, but they do not use a systematic means of prioritizing patients. Moreover, agreement on two approaches (centralized booking and the provision of colonoscopies by other health professionals) that have been used to improve access to CRC screening in other jurisdictions is low. Our study also highlights the need to clarify roles to be able to improve screening monitoring and compliance.

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7. CONFLICT OF INTEREST DISCLOSURES

The authors have no financial conflicts of interest to declare.

8. REFERENCES

1. Health Canada. Home > Healthy Living > It's Your Health > Diseases > Screening for colorectal cancer [Web page]. Ottawa, ON: Health Canada; 2007. [Available at: http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/diseases-maladies/colorectal-eng.php; cited April 23, 2012]
2. Canadian Cancer Society's Steering Committee on Cancer Statistics. *Canadian Cancer Statistics 2011.* Toronto, ON: Canadian Cancer Society; 2011.
3. Green RC, Green JS, Buehler SK, *et al.* Very high incidence of familial colorectal cancer in Newfoundland: a comparison with Ontario and 13 other population based studies. *Fam Cancer* 2007;6:53–62.
4. Zarychanski R, Chen Y, Bernstein CN, Hébert PC. Frequency of colorectal cancer screening and the impact of family physicians on screening behavior. *CMAJ* 2007;177:593–7.
5. Leddin D, Hunt R, Champion M, *et al.* Canadian Association of Gastroenterology and the Canadian Digestive Health Foundation: guidelines on colon cancer screening. *Can J Gastroenterol* 2004;18:93–9.
6. Levin B, Lieberman DA, McFarland B, *et al.* Screening surveillance for early detection of colorectal cancer and adenomatous polyps: a joint guideline from the American Cancer Society, the U.S. Multi-Society Task Force on Colorectal Cancer and the American College of Radiology. *CA Cancer J Clin* 2008;58:130–60.
7. Schroy PC 3rd, Barrison AF, Ling BS, Wilson S, Geller AC. Family history and colorectal cancer screening: a survey of physician knowledge and practice patterns. *Am J Gastroenterol* 2002;97:1031–6.
8. Alberta Health Services. Home > Information For > Health Professionals > Policies & Guidelines > Cancer Guidelines > Treatment Guidelines > Gastrointestinal > Screening for Colorectal Cancer [Web page]. [Available at: http://www.albertahealthservices.ca/hp/if-hp-cancer-guide-screening-colorectal.pdf; cited April 23, 2012]
9. Dillman DA. *Mail and Internet Surveys: the Tailored Design Method.* 2nd ed. New York, NY: John Wiley and Sons; 2007.
10. Wagner A, van Kessel I, Kriege MG, *et al.* Long term follow-up of HNPCC gene mutation carriers: compliance with screening and satisfaction with counseling and screening procedures. *Fam Cancer* 2005;4:295–300.
11. Halbert CH, Lynch H, Lynch J, *et al.* Colon cancer screening practices following genetic testing for hereditary nonpolyposis colon cancer (HNPCC) mutations. *Arch Intern Med* 2004;164:1881–7.
12. Hadley DW, Jenkins JF, Dimond E, de Carvalho M, Kirsch I, Palmer CG. Colon cancer screening practices after genetic counseling and testing for hereditary nonpolyposis colorectal cancer. *J Clin Oncol* 2004;22:39–44.
13. Rabeneck L, Adams PC. Colorectal cancer screening: opportunistic or organized? *Can J Gastroenterol* 2006;20:249–250.
14. Cotterill M, Gasparelli R, Kirby E. Colorectal cancer detection in a rural community. Development of a colonoscopy screening program. *Can Fam Physician* 2005;51:1224–8.

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