

Factors associated with delays to medical assessment and diagnosis for patients with colorectal cancer

Corey Tomlinson MD Clarence Wong MD FRCPC Heather-Jane Au MD FRCPC MPH Dan Schiller FRCSC MSc MD

Abstract

Objective To identify factors associated with delays to medical assessment and diagnosis for patients with colorectal cancer (CRC).

Design Data were collected through a standardized questionnaire. Clinical records were also reviewed. When necessary, patients were contacted by a member of the study team to collect missing data and confirm information.

Setting Cross Cancer Institute in Edmonton, Alta.

Participants Patients newly diagnosed with a histologically proven colorectal adenocarcinoma were identified and eligible for the study.

Main outcome measures Associations between symptoms, tumour stage at operation, symptom duration, and tumour location were sought to identify factors associated with a delay in diagnosis of CRC.

Results Surveys were completed by 93 patients. A total of 49% of patients had symptoms of CRC present for 1 month or less before seeing a physician, and 51% had symptoms for longer than 1 month. Seventy-five (86%) patients initially presented to family physicians for assessment, while 12 (14%) patients presented to the emergency department for their first physician encounters. Only 33 (38%) patients had digital rectal examinations during their first visits. Women were more likely to present to physicians with longer than 1 month of symptoms, while men were more likely to present with less than 1 month of symptoms ($P = .03$). Abdominal pain, blood in the stool, and change in stool size were the most frequent symptoms encountered. Twenty-two (26%) patients delayed seeking treatment because they thought their symptoms were not serious and 12 (14%) believed that their family physicians had taken inappropriate action. Fifteen (18%) patients attributed their delays to waiting too long for specialist referral and diagnostic tests.

Conclusion This study highlights the important role patients and physicians both play in delays in the diagnosis of CRC. Efforts to diminish future delays must focus on educating the public and practising physicians about important symptoms and signs of CRC. Additionally, the value of a digital rectal examination must be emphasized, along with continued promotion of CRC screening.

EDITOR'S KEY POINTS

- Prospective studies have shown that the most important prognostic factor for colorectal cancer (CRC) is the stage of the disease at the time of diagnosis. This study aimed to understand the factors associated with delays to medical assessment and diagnosis of CRC.
- The most common symptoms reported by patients in this study included abdominal pain, rectal bleeding, change in the size of the stool, and new onset of either constipation or diarrhea. Only 38% of patients had digital rectal examinations performed at their initial physician visits.
- In addition to delays caused by waiting for referrals and tests, some patients delayed seeking medical care because of a failure to recognize the seriousness of their symptoms. Efforts to increase public awareness and education about the signs and symptoms of CRC are necessary.

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Facteurs pouvant l'évaluation médicale et le diagnostic du cancer colorectal

Corey Tomlinson MD Clarence Wong MD FRCPC Heather-Jane Au MD FRCPC MPH Dan Schiller FRCSC MSc MD

Résumé

Objectif Identifier les facteurs qui peuvent entraîner des retards dans l'évaluation médicale et le diagnostic du cancer colorectal (CCR).

Type d'étude Les données ont été recueillies à l'aide d'un questionnaire standardisé. On a également révisé des dossiers cliniques. Lorsque nécessaire, les patients ont été contactés par un membre de l'équipe afin d'obtenir les données manquantes et confirmer les informations.

Contexte Le Cross Cancer Institute à Edmonton, Alberta.

Participants Patients ayant reçu un nouveau diagnostic d'adénocarcinome colorectal histologiquement prouvé et éligibles à l'étude.

Principaux paramètres à l'étude On a tenté d'établir des associations entre les symptômes, le stade de la tumeur à l'opération, la durée des symptômes et la localisation de la tumeur afin d'identifier les facteurs pouvant entraîner des retards dans le diagnostic du CCR.

Résultats Le questionnaire a été complété par 93 patients. Un total de 49% d'entre eux avait présenté des symptômes de CCR un mois ou moins avant de consulter et 51% avaient des symptômes depuis plus d'un mois. Soixante-quinze patients (86%) ont d'abord consulté un médecin de famille pour être évalués, tandis que 12 (14%) sont allés à l'urgence pour leur première rencontre avec un médecin. Seulement 33 patients (38%) ont eu un toucher rectal à leur première consultation. Les femmes étaient plus susceptibles de consulter après plus d'un mois de symptômes, alors que les hommes étaient plus susceptibles de consulter moins d'un mois après le début des symptômes ($p = ,03$). Les symptômes les plus fréquents étaient la douleur abdominale, la présence de sang dans les selles et des changements dans la taille des selles. Trente-deux patients (26%) ont tardé à se faire traiter parce qu'ils croyaient que leurs symptômes n'étaient pas graves et 12 (14%) croyaient que leur médecin de famille avait pris les mesures nécessaires. Quinze patients (18%) attribuaient le retard au fait d'avoir trop longtemps attendu pour voir un spécialiste et pour subir les tests diagnostiques.

Conclusion Cette étude montre bien que patient et médecin ont une part importante responsabilité dans le retard à poser un diagnostic de CCR. Afin de diminuer les retards à l'avenir, on devra s'efforcer d'éduquer le public et les médecins en pratique sur les principaux symptômes et signes du CCR. En outre, il faudra insister sur du toucher rectal, tout en poursuivant la promotion du dépistage du CCR.

POINTS DE REPÈRE DU RÉDACTEUR

- Selon certaines études prospectives, le facteur de pronostic le plus important pour le cancer colorectal (CCR) est le stade de la maladie au moment du diagnostic. Cette étude voulait identifier les facteurs susceptibles d'entraîner des délais dans l'évaluation médicale et le diagnostic de ce cancer.
- Les symptômes le plus fréquemment rapportés par les participants à cette étude incluait les douleurs abdominales, le saignement rectal, un changement dans la taille des selles et l'apparition récente de constipation ou de diarrhée. Seulement 38% des patients avaient eu un toucher rectal dès la première consultation médicale.
- En plus des retards causés par l'attente requise pour voir un spécialiste ou pour subir les tests, certains patients ont tardé à consulter parce qu'ils ne croyaient pas que leurs symptômes étaient graves. On devra prendre des mesures pour éduquer le public et le rendre plus conscient des signes et symptômes du CCR.

Cet article a fait l'objet d'une révision par des pairs.
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Colorectal cancer (CRC) is a leading cause of cancer morbidity and mortality in Canada. It is the second most common cause of cancer death among Canadians.¹ Prospective studies have shown that the most important prognostic factor for CRC is the stage of the disease at the time of diagnosis.²⁻⁴ Five-year survival for stage I CRC approximates 90% with surgery alone, whereas nonresectable stage IV CRC carries a median survival of 24 months with intensive chemoradiotherapy. The ultimate goal in CRC screening is to identify lesions earlier and remove precancerous polyps before they become invasive cancers. Unfortunately, the nonspecific nature of gastrointestinal (GI) symptoms can lead to patient delays in seeking care, inappropriate physician advice, out-of-place testing, and ultimately delays in CRC diagnosis. The purpose of this study was to identify patient variables associated with delays in medical access and treatment for CRC.

METHODS

Patient population

Following ethics approval from the Alberta Cancer Board, a convenience sample of postsurgical patients with histologically proven colorectal adenocarcinoma was recruited from a tertiary cancer centre in Edmonton, Alta. Patients were recruited through new-patient GI oncology clinics between August 2008 and June 2009. Patients were approached for study inclusion by their oncologists or surgeons.

Survey instrument and data collection

Surveys were constructed and revised through multiple focus groups with medical specialists in oncology and surgery. Surveys were then piloted and reviewed to test content validity and ease of administration, and to ensure unbiased questions. The survey was provided to patients at the time of consent. Surveys were returned by mail in preaddressed, prestamped envelopes. Data collected from the questionnaires included age, sex, marital status, level of education, symptoms before diagnosis, duration of symptoms before seeking medical advice, patient's initial response to symptoms, investigations and procedures completed, and overall patient satisfaction. Location of neoplasm, tumour stage, and confirmation of patient-recalled dates were obtained from the laboratory, imaging, endoscopy, pathology, and operative reports.

Statistical analysis

The duration of symptoms was defined as the number of days between when a patient first noted the onset of symptoms and the first physician assessment. Patients

were divided into 2 groups: those with less than 1 month of symptoms before seeking medical attention and those with more than 1 month of symptoms. The division of 30 days was used following Khattak and colleagues' 2006 prospective evaluation of symptom duration that demonstrated that the median time before patients first seek medical advice is 30 days.⁵ As necessary, questionnaires were reviewed in person or via telephone to address concerns and clarify unclear responses.

Percentages were used to describe the study population. Fisher exact or χ^2 tests were used to assess associations between symptom duration, stage and tumour location, demographic characteristics, and clinical variables. All tests were 2-sided. A value of $P < .05$ was considered to be statistically significant.

RESULTS

Ninety-three participants were recruited into the study during a 10-month period. Six patients were excluded from analysis owing to incomplete consent forms or missing identification. The remaining 87 patients represent approximately 15% of the patients diagnosed with CRC during the recruitment period who were expected to receive treatment at our institution.

Table 1 displays the demographic and clinical characteristics of the study participants. The study population consisted of 56 men and 31 women. The average age was 65 years. Forty-three (49%) patients had CRC symptoms for 1 month or less before seeing a physician, and 44 (51%) had symptoms for longer than 1 month before seeing a physician (**Figure 1**). There were no statistical differences between these groups with respect to marital status, education, or TNM (primary tumour, regional lymph nodes, and distant metastasis) stage. Women were more likely than men to present to a physician with longer symptom duration ($P = .03$). The location

Figure 1. Flow of patients involved in the study

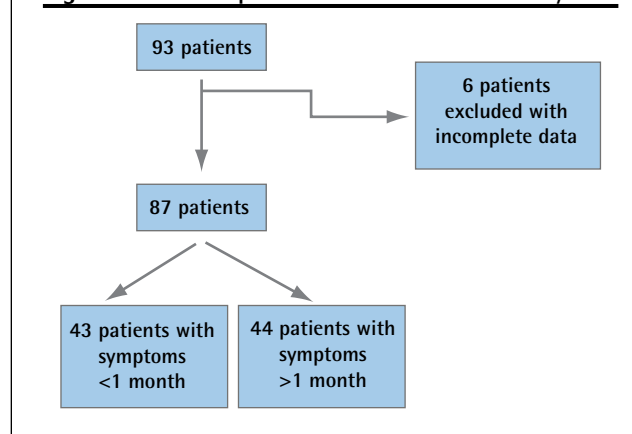


Table 1. Demographic and clinical characteristics of the patient study group: The average age of patients was 65.8 years in the group with < 1 month of symptoms and 65.0 years in the group with > 1 month of symptoms.

CHARACTERISTIC	TOTAL (N = 87), N (%)	TIME FROM SYMPTOM ONSET TO PHYSICIAN ASSESSMENT		P VALUE*
		< 1 MONTH (N = 43), N (%)	> 1 MONTH (N = 44), N (%)	
Sex				.03
• Male	56 (64)	30 (70)	26 (59)	
• Female	31 (36)	13 (30)	18 (41)	
Marital status				.53
• Married	60 (69)	31 (72)	29 (66)	
• Not married	27 (31)	12 (28)	15 (34)	
Education				.75
• Less than high school	27 (31)	11 (26)	16 (36)	
• High school	35 (40)	17 (40)	18 (41)	
• College degree	25 (29)	15 (35)	10 (23)	
TNM stage				.98
• I or II	32 (37)	16 (37)	16 (36)	
• III	30 (34)	16 (37)	14 (32)	
• IV	25 (29)	11 (26)	14 (32)	
Tumour location				.05
• Cecum or ascending colon	36 (41)	20 (47)	16 (36)	
• Transverse colon	3 (3)	1 (2)	2 (5)	
• Descending colon	5 (6)	3 (7)	2 (5)	
• Sigmoid colon	24 (28)	15 (35)	9 (20)	
• Rectum	19 (22)	4 (9)	15 (34)	

TNM—primary tumour, regional lymph nodes, and distant metastasis.
*Based on Fisher exact test.

of tumours was as follows: ascending colon (41%), transverse colon (3%), descending colon (6%), sigmoid colon (28%), and rectum (22%). Significantly more patients with rectal tumours presented with duration of symptoms longer than 1 month ($P = .05$). Sixteen patients presented to a physician for assessment with signs and symptoms of intestinal obstruction or perforation. Five of these patients had symptoms of CRC for longer than 1 month.

After the onset of symptoms, 75 (86%) patients initially presented to family physicians for assessment, while 12 (14%) patients first presented to the emergency department. Only 33 (38%) patients had digital rectal examinations (DREs) during their first physician visits. Nineteen (22%) patients had rectal cancer within 10 cm of the anal verge, and only 11 (58%) patients with these potentially palpable rectal cancers underwent DRE.

Table 2 presents the relationships between initial symptoms and how long patients delayed before seeing physicians. Abdominal pain, blood in the stool, and change in stool size were the most frequent symptoms. Patients who had symptoms for longer than 1 month were more likely to present to physicians with smaller stool size ($P = .02$) and constitutional symptoms ($P = .01$). There

was no statistical association between the most frequently observed symptoms and the TNM stage (**Table 3**).

Of the 44 patients who had symptoms for longer than 1 month, 30% had tried over-the-counter medications or herbal remedies, while 56% reported their response to symptoms was to wait for spontaneous resolution. Only 5% of the patients with symptoms of less than 1 month's duration tried over-the-counter medications before seeing a doctor.

Table 4 displays the relationship between duration of symptoms and patient-perceived delays. Thirty-five (42%) patients believed there was no delay in their CRC diagnosis. Twenty-two (26%) delayed seeking treatment because they believed their symptoms were not serious. Twelve (14%) thought that their family physicians had taken inappropriate action, and 15 (18%) patients attributed their delays to waiting for specialist consultation and diagnostic tests. Seventeen (40%) patients with symptoms for more than 1 month stated that their delays were owing to their failure to understand the seriousness of their symptoms. The duration of symptoms and perception of delay was significantly different between the 2 groups ($P = .02$).

Table 2. Relationship between the reported symptoms and patient delay in seeking medical assessment

PATIENT SYMPTOM	TIME FROM SYMPTOM ONSET TO PHYSICIAN ASSESSMENT			P VALUE*
	TOTAL (N=87), N (%)	<1 MONTH (N=43), N (%)	>1 MONTH (N=44), N (%)	
Rectal bleeding with wiping	31 (36)	12 (28)	19 (43)	.14
Blood in or on stool	36 (41)	18 (42)	18 (41)	.93
Smaller size of stool	35 (40)	12 (28)	23 (52)	.02
Abdominal pain	40 (46)	20 (47)	20 (45)	.92
Constipation or diarrhea	26 (30)	9 (21)	17 (39)	.07
Constitutional symptoms	25 (29)	7 (16)	18 (41)	.01
Rectal pain	12 (14)	4 (9)	8 (18)	.23
Black stool	9 (10)	2 (5)	7 (16)	.16

*Based on Fisher exact test.

Table 4 also reveals the relationship between the duration of symptoms and patient satisfaction with care. Of 85 patients who completed this portion of the survey, 71 (84%) reported that they were either somewhat satisfied or very satisfied with their care. Twelve (14%) patients reported that they were either somewhat unsatisfied or very unsatisfied with their care. Of these 12 patients, 10 reported either doctor error or wait time for tests and specialists as their source of delay.

DISCUSSION

This study examined 93 patients with a new histologic diagnosis of CRC in an effort to identify factors from the

Table 3. Relationship between the most frequently observed symptoms and TNM stage

PARAMETER	TNM STAGE		P VALUE
	I OR II (N=32), N (%)	III OR IV (N=55), N (%)	
Rectal bleeding with wiping	11 (34)	20 (36)	.85
Blood in or on stool	13 (41)	24 (44)	.78
Smaller size of stool	13 (41)	23 (42)	.91
Abdominal pain	15 (47)	24 (44)	.77
Constipation or diarrhea	9 (28)	15 (27)	.93
Constitutional symptoms	6 (19)	13 (24)	.60

TNM—primary tumour, regional lymph nodes, and distant metastasis.

patient perspective that contributed to delays in diagnosis of CRC. A relationship between the duration of symptoms and prognosis of CRC has been suggested.⁶ Detection of the disease during the asymptomatic or preclinical period might improve the prognosis.⁷ Studies on rectal cancer have suggested that if the interval between onset of symptoms and the start of treatment is longer than 60 days, the risk of having an advanced rectal cancer is doubled.⁸ Winawer and colleagues, in the National Polyp Study Workgroup, showed that identification and removal of precancerous polyps leads to decreased mortality from colorectal cancer.⁷ In the absence of a population-based screening program, a large percentage of CRC is diagnosed in patients who present with symptoms. It is often difficult for physicians to determine which presenting symptoms are related to CRC and which are related to other, often benign, pathologies. This ambiguity might lead patients and physicians to disregard or overlook important cancer-related symptoms. More important, the nonspecific nature of GI symptoms can

Table 4. Relationship between the duration of symptoms and patient-perceived diagnostic delays and patient satisfaction with care

PATIENT PERCEPTION	DURATION OF SYMPTOMS			P VALUE
	TOTAL (N=84)	<1 MONTH (N=41)	>1 MONTH (N=43)	
Reason for delay				.02
• No delay	35 (42)	19 (46)	16 (37)	
• Thought symptoms were not serious	22 (26)	5 (12)	17 (40)	
• Inappropriate FP action	12 (14)	6 (15)	6 (14)	
• Waited too long for tests or specialists	15 (18)	11 (27)	4 (9)	
Satisfaction*				.20
• Satisfied or somewhat satisfied	71 (84)	33 (79)	38 (88)	
• Unsatisfied or somewhat unsatisfied	12 (14)	8 (19)	4 (9)	

TNM—primary tumour, regional lymph nodes, and distant metastasis.

*Eighty-five patients completed the portion of the survey on satisfaction with care.

lead to patient delays in seeking care, inappropriate physician advice, out-of-place testing, and ultimately delays in CRC diagnosis.

We found that the most common symptoms reported by these patients included abdominal pain, rectal bleeding, change in the size of the stool, and new onset of either constipation or diarrhea. Patients presenting with these symptoms should undergo a detailed history and physical examination to rule out CRC. The importance of a DRE for any patient with these symptoms cannot be overemphasized, and a DRE must be included when examining this patient population. This study found that only 38% of patients had DREs performed at their initial physician visits while presenting with GI symptoms. This is unacceptably low and is an important focus point for improving the delivery of care for our patients.

Compared with patients with colon cancer, we found that patients with rectal cancer were more likely to wait for more than 1 month after the onset of symptoms before seeking medical advice. The exact reason for this is unclear but might be explained by the knowledge that rectal bleeding is associated with many benign anorectal disorders. One study found that 12% of healthy adults might complain of rectal bleeding.⁹ Rectal bleeding is often attributed to hemorrhoids, and this has been implicated in leading to a delay in diagnosis.¹⁰

The results of our study highlight the fact that patient factors contribute to the delay in diagnosis in patients with CRC. We found that 51% of patients with CRC symptoms delayed seeking medical advice for longer than 1 month. Of these, 17 (40%) stated that they did not initially seek medical advice because they did not think their symptoms were serious. Almost a third of patients initially tried over-the-counter medications before seeking medical advice. This provides insight into limited patient knowledge of CRC symptoms and provides an opportunity for intervention by the medical community. Efforts to increase public awareness and education about the signs and symptoms of CRC are necessary and are likely to have a considerable effect on early detection of this disease.

In addition to patient factors, wait times for appointments and tests also play a role in the delay of diagnosis and treatment. Eighteen percent of patients attributed their delay in diagnosis to excessive wait times for specialist appointments or tests. Long wait times have been previously cited as a potential weakness of universal-coverage socialized health care systems like the Canadian health care system.


Colorectal cancer is thought to be a largely preventable and curable disease given the time interval from polyp formation to the development of invasive cancer. With several sensitive screening tests available and

such a long “window” to detect and remove precancerous lesions, we should expect to detect by far most of these lesions at an early or precancerous stage. Unfortunately, less than half the cancers detected in our cohort were stage I or II. In the province of Alberta, it is estimated that the number of patients eligible for CRC screening who are actually undergoing screening is approximately 15%.¹¹ Our health care system must find ways to improve the number of eligible patients who are actually undergoing screening for CRC.

Limitations

Weaknesses of this study can be attributed to patient recall, lack of resources, and absence of a dedicated study nurse. The exact start date for symptoms is difficult to pinpoint, as is the date at which a physician is first contacted. We therefore must interpret the data from this study with care, as these dates form the crux of the argument. There is often a disagreement between the dates of a clinical history and the information the patient gives during an interview, and this fact holds true even for structured interviews specially designed to identify symptoms and dates.⁴ Additionally, our team lacked the resources required to run an intensive interview process for every new CRC patient who attended the Cross Cancer Institute for assessment, which functionally led to the accrual of a smaller sample size. The limited resources and absence of a dedicated research nurse made it difficult to accurately record the number of surveys distributed and impossible to calculate a true response rate. This could affect the generalizability of our results and might be a source of selection bias.

Conclusion

This study reveals that efforts to increase the knowledge of the general public about symptoms and appropriate workup for CRC are needed. Efforts to increase the working knowledge of the general practitioners in our community regarding CRC symptoms are also needed. Patients presenting with vague CRC symptoms such as a smaller stool size or constitutional symptoms are substantially more likely to have a delayed diagnosis. Therefore, an extensive history and physical examination querying a possible colorectal neoplasm must be completed on any patient presenting with a change in bowel routine or stool size, rectal bleeding, abdominal pain, or constitutional symptoms. In addition, a renewed emphasis on the importance of annual or semiannual DRE is required, as is continued support for the implementation of provincial CRC screening programs. 

Dr Tomlinson is Chief Resident in the Department of Surgery at the University of Alberta in Edmonton. **Dr Wong** is Assistant Professor in the Department of Gastroenterology at the University of Alberta. **Dr Au** is Assistant Professor in the Department of Medicine at the University of Alberta. **Dr Schiller** is Assistant Professor in the Department of Surgery at the University of Alberta.

Contributors

All authors contributed to concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

Correspondence

Dr Dan Schiller, Department of Surgery, University of Alberta, Room 407, Community Services Centre, Royal Alexandra Hospital, 10240 Kingsway Ave, Edmonton, AB T5H 3V9, telephone 780 413-7766; fax 780 944-8652; e-mail ds9@ualberta.ca

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