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Delayed Treatment for Rectal Cancer

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Abstract

PURPOSE—Reports of the relationship between length of delay before diagnosis of rectal cancer and stage of the disease have been mixed. The present study documented the magnitude and medical ramifications of delay in diagnosing rectal cancer.

METHODS—One hundred twenty patients who had been recently diagnosed with rectal cancer provided information regarding history of symptoms and initial perceptions of those symptoms. Patients also estimated the time elapsed from onset of symptoms until their first consultation with a physician, as well as time elapsed from consultation until the diagnosis of rectal cancer was made. Stage information was gathered from patient charts.

RESULTS—For 106 of the patients, the first sign of rectal cancer was in the form of symptoms, and the most common first symptom was rectal bleeding. For the remaining 14 patients, their cancer was first discovered through routine examination. Over 75 percent of patients with symptoms did not initially believe that they were caused by cancer or any other serious problem, and over 50 percent attributed their symptoms to hemorrhoids. There was a clear trend, albeit statistically nonsignificant, toward worsening disease with longer delays. Median delay times in weeks were Stage I (10.0 weeks), Stage II (14.0 weeks), Stage III (18.5 weeks), and Stage IV (26.0 weeks).

CONCLUSIONS—Delayed diagnosis for rectal cancer remains a significant problem, with instances of delay attributable to both patient and physician. Delayed diagnosis can result in more serious disease and, when attributable to the physician, can result in damaged trust and sometimes legal action.

Keywords

Rectal neoplasms; Diagnosis; Early diagnosis; Neoplasm staging

While it is estimated that 40,570 Americans will have been diagnosed with rectal cancer in 2004, it is also widely recognized that early diagnosis and effective treatment can result in a survival rate of greater than 90 percent.[1,2] Unfortunately, early diagnosis has been a significant challenge. Rates of participation in routine screening are low.[3] More alarming is the fact that even though most people who develop symptoms do act fairly quickly, many

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wait inordinate amounts of time before seeking medical help. Irvin and Greaney[4] found that 32 of 166 (19 percent) patients with rectal cancer delayed seeking treatment one year or more, and MacArthur and Smith[5] found that 12 of 48 (25 percent) patients with rectal cancer waited one year or more before seeking help. Other investigations of patient delay in rectal cancer have found mean patient delay times ranging from 4.0 to 10.3 months.[6–8] In addition, undue delay is sometimes attributable to the physician who misdiagnoses the symptoms, typically without adequate examination or appropriate referral.[6–10] This can have the unfortunate consequence of reassuring patients that their concerns are unwarranted, thus further extending the time before appropriate medical consultation is sought. In two more recent studies, the total median time between symptom onset and diagnosis of rectal cancer was found to be around three months in a group of 180 patients[11] and around four months in a sample of 66 patients.[12]

There has been mixed evidence regarding whether a delay in the diagnosis of rectal cancer translates into clinically significant worsening of disease. Rowe-Jones and Aylett found a significant relationship between total delay and Dukes stage of the disease.[7] Robinson *et al.* also found a significant relationship between delay and rectal tumor stage, with a mean duration of delay of 4.6 months in Stage I patients compared with a mean duration of delay of 8.9 months in Stage III patients.[13] Arbman *et al.* found that patients who were diagnosed less than a month after symptom onset had a significantly larger proportion of Dukes A tumors than those patients with a longer delay.[14] On the other hand, a few studies have found no relation between total duration of delay and stage of the rectal tumor.[8,11,12] The purpose of the present study was to document the magnitude and medical ramifications of delayed help-seeking among patients who have begun to experience symptoms of rectal cancer. The data reported here were gathered as part of a study of patient factors that contribute to delays in seeking help.[15]

MATERIALS AND METHODS

Participants and Procedure

Participants were patients who had been diagnosed with primary rectal tumors and treated in the Section of Colon and Rectal Surgery at the Washington University School of Medicine. Patients were recruited during a follow-up office visit soon after initial treatment but were excluded if there were evidence of cognitive deficits that would have precluded reliable recall of the events of interest or that would have interfered with completion of the study questionnaires. Informed consent was obtained at that time. An IRB-approved structured interview was developed and conducted with the first 12 participants by two clinic nurses and the first author. The interview was subsequently converted to a self-report paper-and-pencil format that could be completed at home and returned by mail, which resulted in a marked increase in participation. Interview and questionnaire data were combined for analyses.

Materials

The interview and the subsequent paper-and-pencil questionnaire were designed to collect information about history of symptoms, initial perceptions of those symptoms, pertinent decision-making, and behaviors during the time period before medical consultation, as well as more general health behavior history. The structured interview/questionnaire was made up of several multiple-choice or checklist questions. The first questions were about the initial symptoms and the patients' reactions to them: *"What was your first symptom?" "When you first noticed it, how serious did you think it was?" "Did you think at that time that it might be related to cancer?"* and *"If you didn't think that it might be cancer, what did you think was causing it?"*

Questions were also included about the circumstances surrounding the pursuit of medical help. We specifically wanted to estimate (1) the amount of time elapsed from onset of symptoms until the first pursuit of medical help (*"About how long was it after your very first symptom that you first saw a doctor about it?"*) and (2) the amount of time elapsed from first medical consultation about the symptoms until the diagnosis of rectal cancer was made (*"How long after that was the diagnosis of cancer made?"*). Delay times were measured as continuous variables (in weeks) to capture the most information.[16] Finally, we documented demographic information (age, education, ethnic background, gender), and medical information was obtained from patients' charts.

RESULTS

The patients who participated in this study were all diagnosed with the first occurrence of a rectal tumor. Of the 120 patients who completed the study, 48 were females and 72 were males, 110 were Caucasian, 9 were African-American, and 1 was Hispanic. Age at diagnosis ranged from 23 to 85 years, with a mean of 62.6 (SD = 12.7) and a median age of 64.0 years. Of the 101 patients in this sample who were over the age of 50, only 24 (23.8 percent) had previously been screened for colorectal cancer or polyps according to current recommendations.

First Symptoms

For 14 of the patients, the first sign of trouble was detected during a routine examination or screening. For these patients, the problem was revealed through a routine fecal occult blood test (n = 5), routine screening with flexible sigmoidoscopy (n = 4), prostate examination (n = 3), or digital rectal examination (n = 2). For the remaining 106 patients, the first sign of trouble came in the form of symptoms. As seen in Table 1, the most frequent first symptom was rectal bleeding, followed by change in bowel habits, rectal pressure, diarrhea, and difficult elimination. Those patients who indicated a "change in bowel habits" were asked to specify the change, which included increased frequency of bowel movements (n = 8), a change in volume or consistency of stool (n = 4), or increased urgency (n = 1). The remaining subjects did not specify the change in bowel habits that they experienced.

As seen in Table 2, over 75 percent of the patients thought that their symptoms were either "not" (n = 56; 52.8 percent) or "a little" (n = 26; 24.5 percent) serious. Also, over 75 percent thought that their symptoms were not related to cancer (n = 78; 73.6 percent), and over 50 percent thought that their symptoms were attributable to hemorrhoids (n = 55; 51.9 percent).

Time From Symptom Onset to Diagnosis

Nineteen of the subjects were not able to provide confident estimates of times between onset of symptoms, visits to the physician, and date of diagnosis, so the following statistics are based on the remaining 87 subjects. As seen in Table 3, total length of time from onset of symptoms to accurate medical diagnosis ranged from around two weeks to over seven years, with a mean of 36.3 weeks (SD = 60.2) and a median of 14.0 weeks. For 28 of 87 patients (32.2 percent), this time was six months or more, and for 21 of 87 (24.1 percent) patients, this time was one year or more. Delay times attributable to the patient (from symptom onset to first consultation with a physician) ranged from less than a week to around five years, with a mean of 24.2 weeks (SD = 36.5) and a median of 12.0 weeks. Delay times of six months or more were reported by 25 of 87 (28.7 percent) patients and 16 of 87 (18.4 percent) patients waited one year or more before actively seeking help. Length of time from first physician visit to accurate diagnosis of rectal cancer ranged from less than a week to around seven years, with a mean of 12.2 weeks (SD = 36.5) and a median of 2.0 weeks. The time from first medical consultation until accurate diagnosis was six months or more in 6 of

87 (6.9 percent) patients and 4 of 87 (4.6 percent) patients were delayed one year or more. Comparison of the mean and median delay times indicates a substantial positive skew to these distributions, indicating that the majority of patients were diagnosed fairly soon after symptom onset (approximately one-half within three months), although many were still delayed.

It can also be seen in Table 3 that for six of our subjects, the delay between initial consultation with a physician and accurate diagnosis was six months or more. It was the case for these six patients that their symptoms were either dismissed or misdiagnosed by their physician, and always without adequate examination. One of these patients related that his physician's misdiagnosis of hemorrhoids caused him to hesitate seeking additional medical advice, even although his symptoms persisted and worsened for some time after that consultation. Five of these patients were older than 50, one was 42 years old at the time of diagnosis, and none of them had a family history of colorectal cancer. Only one of the six had been previously screened for colorectal cancer and that was a 63-year-old woman who had been screened 18 years earlier around the time of a hysterectomy and appendectomy.

Medical Ramifications of Delay

Finally, we looked at the relationship between total delay times (*i.e.*, from symptom onset to accurate diagnosis) and stage of the disease. As seen in Table 4, 33 of the 87 patients who were able to estimate delay times were diagnosed with Stage I disease, 26 with Stage II, 24 with Stage III, and 4 with Stage IV. The mean statistics reveal no discernible trend toward worsening disease with longer delays. However, given the non-normal distribution of these data, as mentioned previously, the median statistic provides a better representation of the central tendency of delay time. Inspection of the median statistics reveals a clear trend toward worsening disease with longer delays (10.0 weeks delay for Stage I disease, 14.0 for Stage II, 18.5 for Stage III, and 26.0 for Stage IV). To test this trend statistically, we first combined the patients with Stage III and Stage IV tumors into one group, given that there were only four patients with Stage IV tumors. However, the Kruskal–Wallis test of this trend was not significant.

DISCUSSION

The purpose of this study was to document and report the magnitude and medical ramifications of delayed diagnosis of rectal cancer. We found several troubling findings. First, only a very small proportion (14/120) of the participants reported that their tumor was found on routine examination; most were discovered after symptoms had previously developed. Second, the great majority of these patients initially downplayed the significance of their symptoms, attributing them to some benign ailment that would get better with time. Third, a sizable number of these patients waited inordinate amounts of time before seeking help, probably because of the erroneous self-diagnosis that had been made. Perhaps because of the slow-growing nature of most colorectal polyps and tumors,[17,18] many patients who delayed long periods were spared a worse outcome. As reported elsewhere, the most significant underlying cause of patients' delay is the time spent in determining whether their symptoms represent a problem serious enough to warrant medical consultation.[15] Fourth, even after medical consultation, several of these patients were misdiagnosed following cursory examination and were led to believe that they were experiencing some benign problem, usually hemorrhoids.

The more troubling findings have to do with the potentially serious ramifications of delayed diagnosis of rectal cancer. This study does provide some evidence to suggest that longer delay times are associated with worsening of disease. Even though the statistical test was not significant, the trend is clear. Parenthetically, a methodologic issue related to this finding is

the fact that the median (*vs*. mean) statistic is the more accurate reflection of central tendency when studying the problem of delay in diagnosis, because delay time tends to be positively skewed. In part, this could explain why some previous studies using mean statistics have found no trend toward worsening disease with longer delays.

There are also other damaging ramifications of delayed diagnosis of this disease. On discovering the true cause of their symptoms, many of the patients who had delayed coming in were significantly distraught by the fact that it had not been caught sooner. And for those patients whose delay was attributable in part to a physician, their distress was compounded with anger and a feeling of betrayal. In a review of 98 malpractice cases involving colon and rectal disease, the most common allegation (43 percent) was a "failure to timely diagnose disease," and 46 percent (20/44) of those delayed diagnosis cases involved colon and rectal cancers.[19] The negative emotional sequelae that come in the wake of a delayed diagnosis could serve only to distract these patients from the critical need to focus all of their resources on the illness itself.

Several weaknesses of the study are worth noting. First, it is retrospective, which presents challenges to the collection of maximally reliable data and the drawing of valid causal inferences. The reliability of these data depends on patients' recall of events that may have occurred up to several years in the past. However, because patient delay is, by definition, a time period during which important physical symptoms are occurring without the benefit of appropriate clinical attention, it is a phenomenon for which retrospective investigation is the only reasonable alternative. The second limitation to this study is that all data are provided by patients' self-reports. The biggest threat to validity posed by the self-report format is that those patients who took the longest to seek help may have tended to underreport their delay times out of shame or embarrassment.[20] However, the present findings regarding lengths of delay times are consistent with many other studies,[4,5,8,10] and the fact that a fair number of these patients reported very long delay times suggests that they were probably not intentionally minimizing the facts. Third, the original symptoms experienced by some of these patients may have been unrelated to the cancer that was eventually diagnosed. Again, because of the self-report format of the study, we cannot know for which subjects this might have been true. Fourth, all of these subjects were seen in the same university-based surgery group so we do not know how these findings will generalize to other settings. However, the patients who are treated in this setting come from a wide variety of urban, suburban, and rural settings in the Midwestern United States.

In 1942, Braund and Binkley published a paper entitled "A plea for the earlier diagnosis of rectal cancer," in which they reported mean delay times of over eight months for patients and over nine months for physicians.[21] The data in the present study indicate significant improvements in achieving expeditious diagnoses of rectal cancer, although these improvements are still insufficient. Greater efforts need to be put into education of the public and their physicians while there is still needless morbidity and mortality from this disease. The public needs to be made aware of the potential danger that these symptoms might represent and they should not be too quick to dismiss such symptoms as benign. Likewise, physicians need to follow through with adequate examinations or appropriate referrals when such symptoms are reported.

CONCLUSION

There appears to be a relationship between time to diagnosis following onset of rectal cancer symptoms and increased stage of disease. Most patients who delayed seeking help attributed their symptoms to a less critical cause. Physicians who were responsible for delay had failed

to perform adequate workup in a timely fashion. Adherence to current screening recommendations would limit time to diagnosis in the majority of patients.

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Table 1

First Signs and Symptoms of Rectal Cancer

Symptom	n (%) of Cases
Bleeding	78 (73.6)
Change in bowel habits	17 (16.0)
Rectal pressure	17 (16.0)
Diarrhea	13 (12.3)
Difficult elimination	12 (11.3)
Constipation	12 (11.3)
Dark stools	9 (8.5)
Mucous in the stools	9 (8.5)
Pain	9 (8.5)
Weight loss	8 (7.5)
Loss of appetite	6 (5.7)
Vomiting	2 (1.9)
Nausea	1 (0.9)

Percentages do not add up to 100 because many of the patients experienced multiple symptoms at onset.

Table 2

Patients' First Reactions to Symptoms of Rectal Cancer

Question	n (%) of Cases
"*When you first noticed it, how serious did you think it was?*"	
not serious	56 (52.8)
a little serious	26 (24.5)
somewhat serious	17 (16.0)
very serious	3 (2.8)
extremely serious	4 (3.8)
"*Did you think at that time that it might be related to cancer?*"	
yes	6 (5.7)
no	78 (73.6)
maybe	13 (12.3)
didn't know/didn't answer	9 (8.4)
"*If you didn't think that it might be cancer, what did you think was causing it?*"	
hemorrhoids	55 (51.9)
diet	4 (3.8)
physical injury or stress	6 (5.7)
other	15 (14.2)
didn't know/didn't answer	26 (24.5)

Table 3

Delay Times Before *vs*. Subsequent to First Physician Consultation

	Delay Time		
Delay	**Before Consultation n (cum. %)**	**Subsequent to Consultation n (cum. %)**	**Total Delay n (cum. %)**
0–1 month	26 (29.9)	71 (81.6)	18 (20.7)
1–3 months	18 (50.6)	9 (92.0)	23 (47.1)
3–6 months	18 (71.3)	1 (93.1)	18 (67.8)
6–12 months	9 (81.6)	2 (95.4)	7 (75.9)
≥12 months	16 (100)	4 (100)	21 (100)
Delay time (weeks)			
Mean (SD)	24.2 (36.5)	12.2 (48.8)	36.3 (60.2)
Median	12.0	2.0	14.0
Range	1–260	1–364	2–382

SD = standard deviation.

Table 4

Association Between Total Delay and Rectal Tumor Stage at Diagnosis

Total Delay	Stage I n = 33 n (cum. %)	Stage II n = 26 n (cum. %)	Stage III n = 24 n (cum. %)	Stage IV n = 4 n (cum. %)
0–1 month	5 (15.2%)	7 (26.9%)	5 (20.8%)	1 (25.0%)
1–3 months	14 (57.6%)	3 (38.5%)	6 (45.8%)	0 (25.0%)
3–6 months	4 (69.7%)	9 (73.1%)	4 (62.5%)	1 (50.0%)
6–12 months	4 (81.8%)	1 (76.9%)	1 (66.7%)	1 (75.0%)
≥12 months	6 (100%)	6 (100%)	8 (100%)	1 (100%)
Total delay time (weeks)				
Mean (SD)	27.1 (32.7)	44.5 (73.7)	40.8 (76.2)	32.8 (31.8)
Median	10.0	14.0	18.5	26.0
Range	3–117	3–273	3–382	2–77

SD = standard deviation.