

# The Prevalence of Patients with Colorectal Carcinoma under Care in the U.S.

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**BACKGROUND.** Prevalence usually is defined as the proportion of individuals alive who previously had a diagnosis of the disease, regardless of whether the individuals still are receiving treatment or are *cured*. The objective of this study was to estimate the proportion of elderly patients with colorectal carcinoma (CRC) in the U.S. that actually were receiving care for their disease as a better quantification of the burden of CRC.

**METHODS.** The authors used data from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program linked to Medicare claims. Four phases of CRC care were defined: initial diagnosis and treatment, postdiagnostic monitoring, treatment for recurrent/metastatic disease, and terminal care. CRC care prevalence measures by phase were extrapolated to the U.S. population age 65 years and older.

**RESULTS.** For all patients with CRC who were diagnosed between 1975 and 1996, 62% received at least 1 service related to their CRC in 1996, and patients received an average of 2.1 months per person of CRC care. Among the U.S. population age 65 years and older, 1.81% had 1 diagnosis of CRC, and  $(1.81\% \times 0.62\%) = 1.12\%$  received at least 1 service related to their CRC. This translated to 380,783 individuals who received care and 1,210,121 person months of care during 1996.

**CONCLUSIONS.** To the authors' knowledge, this is the first report in which care prevalence has been estimated directly. The classification of CRC care by phases of care provides a very detailed picture of the amount of care delivered in the U.S. population. Person-month estimates can be used to estimate the cost of CRC. *Cancer* 2003;98:1253-61. Published 2003 by the American Cancer Society.\*

**KEYWORDS:** colorectal carcinoma, care prevalence, initial diagnosis, monitoring, recurrent/metastatic disease, terminal care.

Cancer prevalence is an indicator of importance from a public health perspective, because it measures the burden of cancer in a population and on the health care system. Prevalence usually is defined as the proportion of people alive on a certain date who previously had a diagnosis of the disease at any time in their life, regardless of whether the individuals still are under treatment or are *cured*. The major reason that prevalence estimates include persons with any prior diagnosis of cancer is the lack of data to estimate who currently is under care and the difficulty of defining who is cured. An additional justification is that, in general, the prevalent population may have greater health needs than the general population not only because they need treatment for their disease but also because the disease and/or treatment may lead to long-term or permanent impairment.

We define *care prevalence* as the prevalent cases under care. This prevalence measure is a better quantification of the burden of cancer.

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Care prevalence requires population-based information on cancer treatment. Cancer registries do not collect this type of information. The linked Surveillance, Epidemiology, and End Results (SEER)-Medicare data allow for longitudinal tracking of individuals with cancer and can be used to estimate the proportion of the prevalent population receiving cancer care in the U.S. Cancer care prevalence is of interest for several reasons. First, estimates of the proportion of individuals actually receiving care can be used to enhance assessment of the national burden of illness and to assess where resources can be allocated most effectively. Second, together with the costs of cancer care services, estimates of care prevalence can be used to calculate the total costs of cancer care at the population level. Third, care prevalence can be used to monitor the performance of the health care system in assuring that individuals in a community have access to treatment.

We chose colorectal carcinoma (CRC) as a case-study example for this analysis. CRC is the fourth most common malignancy in the U.S.<sup>1</sup> and there are a large number of prevalent cases. Also, many of the services received by patients with CRC are covered by Medicare. In this article, we used the SEER-Medicare data to provide estimates of care prevalence in 1996 for patients diagnosed with CRC between 1975 and 1996. We also used the data to classify the different types of prevalent care after a cancer diagnosis. To our knowledge, this article represents the first effort to directly estimate cancer care prevalence.

## **MATERIALS AND METHODS**

### **Data Sources**

We used data from the National Cancer Institute's SEER Program linked to Medicare data. The SEER Program (available from URL: <http://seer.cancer.gov/>) has collected data regarding cancer incidence since 1973. For each individual, the SEER data include month and year of diagnosis, cancer site, histology, extent of disease (stage), initial treatment, vital status information, and sociodemographic information. The data used in this analysis include SEER registries from 5 states (Connecticut, Hawaii, Iowa, New Mexico, and Utah) and 5 metropolitan areas (Atlanta, Detroit, San Francisco-Oakland, and Seattle), which account for approximately 10% of the U.S. population.

Medicare is the primary health insurance for 97% of the U.S. population age 65 years and older. All Medicare beneficiaries receive Part A benefits, which cover inpatient care in hospitals, skilled nursing facilities, home health, and hospice care. About 95% of beneficiaries also subscribe to Part B services of Medicare to obtain benefits that cover physician services,

outpatient care, durable medical equipment, and home health care in some instances. Medicare data are collected by the Centers for Medicare and Medicaid Services (CMS) and contain information regarding each beneficiary's enrollment and entitlement, demographics, and health maintenance organization (HMO) membership. In addition, Medicare claims are available for the services covered by Part A and Part B benefits. Services provided to Medicare beneficiaries can be identified from codes reported on bills submitted by providers. Medicare hospitalization data contain up to 10 International Classification of Diseases, Ninth Edition-Clinical Modification (ICD-9-CM) diagnoses and 10 ICD-9-CM procedures. Medicare outpatient services files, physician claims, and hospice files contain both ICD-9-CM diagnoses as well as Current Procedural Terminology-4 codes for all billed claims. All files contain fields with date of service. The Medicare data contain claims only for fee-for-service care. Until recently, HMOs have not been required by CMS to submit claims for specific services received by their Medicare enrollees. Approximately 20% of the SEER Medicare populations in 1996 were enrolled in HMOs.<sup>2</sup>

SEER data for patients diagnosed through 1996 have been linked to Medicare claims data through 1998. The linkage procedure is described by Potosky et al.<sup>3</sup> and Warren et al.<sup>2</sup> For individuals age 65 years and older who appeared in the SEER data, 93% could be identified as Medicare beneficiaries.

### **Exclusions and the CRC Study Population**

Patients are included in the study population if they are diagnosed with adenocarcinoma of the colon or rectum between 1975 and 1996 and are alive and age 65 years or older as of January 1, 1996, as reported by a SEER registry. Only patients with malignant CRC are considered. Patients diagnosed with a second or later primary malignancy other than CRC before December, 1996 (11,362 patients) are excluded, because it would be difficult to distinguish whether treatment was related to CRC. To have their complete treatment history during 1996, we have excluded patients who do not have claims in the Medicare files, either because they had an HMO entitlement in 1996 (8404 patients) and/or did not have a continuous Medicare Part A and Part B entitlement in 1996 (2047 patients). Patients who died or were lost to follow-up in 1996 are included in the analysis, although only the months in 1996 for which they were alive or were not lost to follow-up are included. The final study population includes 43,217 patients age 65 years and older who were diagnosed with CRC in the SEER areas and had complete Medicare coverage through 1996.

### Phases of Care

We define four phases of care: 1) *initial* diagnosis treated with curative intent, 2) postdiagnostic *monitoring*, 3) treatment for *recurrent/metastatic* disease or second primaries, and 4) *terminal* care. The words in italics are the short names used to reference the phases of care. In each month of 1996, each patient is assigned to one phase of care according to an algorithm that includes the date and stage at diagnosis; the timing of any health care received, if any, relative to the date of diagnosis; the type of care received, if any; and a hierarchy of phases of care. The hierarchy is necessary to place patients in unique phases of care and works through backward interaction. For each month in 1996, the algorithm first checks whether the patient is in the initial diagnosis phase. If not, then it checks whether the patient may be assigned to terminal care and, if not, then it checks whether the patient may be assigned to the recurrent/metastatic phase. Finally, if the patient is in none of these phases, then he or she is considered to be in the postdiagnostic monitoring phase. The algorithm in detail in Figure 1. The assignment of a patient into a potential phase of care means only that any care associated with CRC that a patient may have received would be assigned to that phase. After a patient is assigned to a care phase, Medicare claims are reviewed further to determine whether the patient actually received CRC care in that phase and the value assigned to a second variable. The types of diagnoses and services, with respective codes, used to define care associated with a specific CRC phase of care are described in Table 1.

### Care Prevalence Measures

*Person* and *person-months* measures of care prevalence were developed. *Person measures* refers to the proportion of individuals receiving care, or a certain phase of care, in the given period, i.e., 1996. Although this is a useful measure, it does not take into account the length of time the patient received care during the year; that, in a given year, an individual patient may receive care in several phases (i.e., the proportions for each phase may sum to more than one); and that a patient may not have been eligible for care for the entire year (because they may have been diagnosed after the beginning of the year or may have died during the year). *Person-month measures* estimate the proportion of person-months in which the respective populations receive care or, equivalently, the average number of months during the year that the population received care. For both person and person-months care prevalence, two denominators are considered.

We calculate care prevalence among individuals with CRC as well as among the population age 65 years and older residing in the SEER areas. First, we will define the quantities of interest and, later, the methods for estimating them.

### Person Measures of Care and Care Prevalence

Let  $N_{CRC}$  represent the number of patients with CRC, let  $N_{care}$  indicate the number of patients with CRC receiving care for any portion of 1996, let  $N_{care(i)}$  represent the number of patients with CRC receiving care in phase (i) for any portion of 1996, and let  $N_{alive}$  represent the respective total population alive for any portion of 1996, including persons with and without CRC. Thus, for example, to measure care prevalence among patients with CRC age 65 years and older with complete Medicare coverage in 1996 in the SEER areas, then its denominator,  $N_{alive}$ , represent the population age 65 years and older residing in the SEER area with complete Medicare coverage. Because an individual may receive care in more than one phase during a year,  $N_{care} \neq \sum_{i=1}^4 N_{care(i)}$ . The person measures of interest are as follows:  $N_{care}/N_{CRC}$ , the proportion of people diagnosed with CRC receiving CRC care;  $N_{care(i)}/N_{CRC}$ , the proportion of people diagnosed with CRC receiving CRC care in phase (i);  $N_{care}/N_{alive}$ , the prevalence of CRC care among the total population; and  $N_{care(i)}/N_{alive}$ , the prevalence of phase (i) CRC care among the total population.

### Person-Month Measures of Care

Let  $PM_{CRC}$  represent the total number of person-months that patients with CRC are alive during 1996, and let  $PM_{alive}$  represent the total number of months that the  $N_{alive}$  patients are alive during 1996. We further define  $PM_{care}$  as the number of person-months that patients with CRC in the cohort received care during 1996 and  $PM_{care(i)}$  as the number person-months that patients with CRC in the cohort received care in phase (i) in 1996. Because, in any 1-month period, we only allow an individual to be in a single phase,  $PM_{care} = \sum_{i=1}^4 PM_{care(i)}$ . The person-month measures of care prevalence are as follows:  $12*(PM_{care}/PM_{CRC})$ , the average number of months in CRC care among patients with CRC;  $12 * (PM_{care(i)}/PM_{CRC})$ , the average number of months in CRC care in phase (i) among patients with CRC;  $PM_{care}/PM_{alive}$ , the average number of months in CRC care among the total population; and  $12*(PM_{care(i)}/PM_{alive})$ , the average number of months in phase (i) CRC care among the total population.

### **Definition of phases of care in hierarchical order.**

- (1) Initial diagnosis treated with curative intent: The initial care phase includes persons diagnosed with CRC from July 1995–December 1996. The beginning of the phase is the mid-point of the SEER month of diagnosis. If the SEER date of diagnosis occurs prior to 1996, then only the portion of the phase occurring in 1996 is included.
  - i. Care for patients diagnosed with Stage I CRC is included in the initial care phase for the period from the index date to 6 months later or the end of 1996, whichever comes first.
  - ii. For patients with Stages II–III CRC, care included in the initial care phase varies depending on whether the patient receives adjuvant radiation (RT) or chemotherapy.
    - a. For patients who do not receive adjuvant therapy, the initial care phase is the same as for patients with Stage I CRC.
    - b. For patients who receive adjuvant therapy within three months of the index date, the initial care period lasts 18 months following the index date or until the end of 1996, whichever comes first.
- (4) Terminal care is defined as:
  - i. All care for persons enrolled in a hospice program in 1996, from the time of enrollment until death or the end of 1996, whichever comes first.
  - ii. Care provided during the last 6 months of life for persons who died from January 1996 throughout May 1997 with cancer as the cause of death as reported by SEER. For persons who died in 1997, then only the portion of the phase occurring in 1996 is included.
- (3) Treatment for recurrent/metastatic disease or second primaries Persons are considered as being treated for a recurrence/metastasis or second primary if they are not classified as terminal care and have during 1996:
  - i. a second cancer directed colorectal surgery after the initial care phase;
  - ii. chemotherapy or RT after the initial care phase;
  - iii. have a second CRC primary that does not present as stage IV;
  - iv. have a claim with an ICD-9 diagnosis of 197xx or 198xx (metastasis).
- (2) Post-diagnostic monitoring: any colorectal related care that does not fall into the three categories above.

Below are some examples of assignment of phases of care.

Patient A, diagnosed in 1990 and alive through 1/1/1997 has a Medicare claim for hospitalization due to a bone fracture. Although the patient is in the monitoring phase (2) for all months of 1996, the care he is receiving is not related to CRC and would not be included in the care prevalence estimates.

Patient B, diagnosed with stage II CRC in 2/1995, with a radiation claim in 4/1995, is in the initial phase (2) for the 18 months following 2/1995 and is placed in the initial phase (1) from 1/1996 through 8/1996. For the remainder of the time, 9/1996 through 12/1996, he is assigned to the post-diagnostic monitoring phase (2), since he did not have any claims in that period and did not die in 1996 or 1997. In 1996, we find CRC related claims in 1/1996, 3/1996 and 7/1996, thus he received initial care only in those months.

Patient C, diagnosed with stage IV CRC in 1/1996 dies of cancer in 3/1997. All CRC care from 1/1996 through 10/1996 is placed in the recurrent/metastatic phase (3) while CRC care received in 11/1996 through 12/1996 is placed in terminal phase (4).

Patient D is diagnosed with CRC in 1992 and dies of cancer in 2/1997. Any care provided from 9/1996 to 12/1996 would be classified as terminal care (4)

**FIGURE 1.** Definition of phases of care in hierarchical order. Procedures and diagnosis, used to define care received in each phase of care, with respect relevant codes are presented in Table 2. CRC: colorectal carcinoma; ICD-9: International Classification of Diseases, Ninth Revision.

**TABLE 1**  
**Diagnostic and Procedure Codes Used to Determine Colorectal Carcinoma Care in SEER-Medicare Patients Age 65 and Older by Phase of Care<sup>a</sup>**

Description	ICD-9 dx codes	ICD-9 procedure codes	HCFA common procedure-coding system/revenue center codes	Phases of care
Surgery				
Surgical removal of CRC	-	45.7, 45.73-45.76, 45.8, 45.9, 45.92-45.95, 48.5, 48.6X, 46.10-46.13, 46.4X, 46.52	-	1,3
Metastectomy/lobectomy/wedge-resection of liver or lung metastasis	-	32.3, 32.4, 50.22, 50.3,	32480, 32482, 32484, 32500, 47120, 47125, 47130	3
Laparotomy with lysis of adhesions	-	54.11, 54.5X	49000, 44005	4
Procedures				
Liver biopsy	-	50.1-50.19	47000, 47100	1,2,3
Lung biopsy	-	33.26, 33.28	32405, 32095	2,3
Endoscopy with biopsy/laser photoablation	-	45.25, 45.42, 45.43, 48.23, 48.24, 48.31-48.36	45300, 45302, 45305, 45308, 45309, 45315, 45320, 45331, 45333, 45338, 45339, 45380,, 45383-45385	1,2,3
Colonoscopy	-	45.23, 45.24	45300, 45330, 45355, 45336, 44388, 44389, 45378, 45360, 44392-44394 74270, 74280	2
Barium enema with contrast	-	87.64	74270, 74280	2,3
Thoracentesis	-	34.91	32000	3,4
Paracentesis	-	54.91	49080-49081	3,4
Scans/laboratory tests				
CT/MRI abdomen/pelvis	-	88.97, 88.01	72192-72196, 74150-74170, 74181	1,2,3,4
CT/MRI head/brain	-	88.91, 87.03	70450-70470	1,4
CT/MRI chest/lung	-	88.92, 87.41	71250-71270	1,2,3,4
Bone scan	-	92.14	78300-78320	1,2,4
Liver ultrasound	-	88.74, 88.76	76700, 76705	1,2,3,4
Carcinoembryonic antigen	-	-	82378, 86149, 86151	1,2,3,4
Office visits				
CPT-4 code for an office visits with ICD-9 dx code for CRC in the same trailer	CRC dx: 153XX, 1540, 1541	-	Office visits: 99201-99215, 99241-99245; revenue center codes: 0510, 0520-0523, 0529	1,2,3 <sup>b</sup>
Any hospice claim (for nonhospice users, an office visit with ICD-9 dx code for CRC) and a home health claim with ICD-9 dx code for CRC	-	-	-	4
Radiotherapy	V580, V661, V671	92.2-92.29	77XXX; revenue center codes: 0330, 0333	1,3,4
Chemotherapy	81, V662, V672	9.25	J9000-J9999, 964XX, 965XX, Q0083-Q0085	1,3,4
Second-line chemotherapy (irinotecan)	-	J9206	-	3,4

SEER: Surveillance, Epidemiology and End Results program; ICD-9-CM: International Classification of Diseases, Ninth Revision-Clinical Modification; dx: diagnosis; HCFA: Health Care Financing Administration; CRC: colorectal carcinoma; CT: computed tomography; MRI: magnetic resonance imaging; CPT-4: Current Procedural Terminology-4;

<sup>a</sup> The Phases of care were 1) pretreatment evaluation, 2) initial diagnosis treated with curative intent, (3) postdiagnostic monitoring, (4) treatment for recurrent/metastatic disease or second primaries and (5) terminal care.

<sup>b</sup> Office visit with Health Care Financing Administration provider specialty code of gastroenterology (10), colorectal surgeon (28), medical oncology (90), surgical oncology (91), or radiation oncology (92). Office visit to primary care physician (PCP) with carcinoembryonic antigen (CEA) measurement performed then or followed by a carcinoembryonic antigen or endoscopy within 30 days. PCP includes family practice (08), internist (11), general practitioner (01), and general surgeon (02).

**Extrapolating Care Prevalence Measures to SEER and to the U.S.**

Both the person measures and the person-month measures defined above can be estimated directly from the study population that represents individuals age 65 years and older as of January 1, 1996 with complete Medicare coverage in 1996. To extrapolate

care prevalence to more general populations, such as the SEER population of individuals age 65 years and older, we consider the following decomposition of the CRC care prevalence:

$$N_{care}/N_{Alive} = (N_{care}/N_{CRC}) \times (N_{CRC}/N_{Alive}), \quad (1)$$

$$12^*(PM_{care}/PM_{Alive}) = 12^*(PM_{care}/PM_{CRC}) \times (PM_{CRC}/PM_{Alive}). \quad (2)$$

The first parenthesis, representing the proportion receiving care, can be measured only among individuals with complete Medicare coverage. The second parenthesis, representing the prevalence of CRC, also can be measured in the SEER population. Although  $N_{care}/N_{alive}$  can be measured directly in the study population, Equations 1 and 2 are better estimates of care prevalence in the general population, especially if the prevalence of CRC ( $N_{CRC}/N_{alive}$  and  $PM_{CRC}/PM_{alive}$ ) estimated from individuals with complete Medicare coverage (the study population) is different compared with the prevalence of CRC estimated from the general population (the SEER population). An underlying assumption in Equations 1 and 2 is that the pattern of care in the study population is the same as in the general population. Because there is no direct estimate of the total number of person-months alive in the SEER population ( $PM_{alive}$ ), as an approximation, we have used  $12 N_{alive}$ , with  $N_{alive}$  representing the 1996 midyear SEER population. To estimate the total number of persons and person-months in the U.S. receiving CRC care, we multiply the SEER CRC care prevalence measures calculated from Equations 1 and 2 by the 1996 U.S. population older than 65 years. The underlying assumption is that the prevalence of CRC and patterns of care in SEER and the U.S. are the same.

## RESULTS

Table 2 shows the person measures (Table 2A) and person-month measures (Table 2B) of CRC care prevalence among patients with CRC in the study population. The percentage of patients with CRC in the study population who received at least one care procedure in any phase related to their CRC care in 1996 (Table 2A, column 4) is greater for patients who were diagnosed with CRC in more recent years, as expected. For patients who were diagnosed > 15 years prior to the index year (1996), a large percentage (41%) still were receiving some kind of CRC-related care, although it was mostly monitoring. For all patients who were diagnosed with CRC between 1975 and 1996, 62% received at least one service related to their CRC in 1996. The percentage of patients with CRC who received CRC-related care in each phase also is displayed in Table 2A (columns 5–9). The percentage of patients with CRC who received care for recurrent/metastatic CRC reaches a peak in the fourth year after diagnosis; whereas, for postdiagnostic monitoring care, the percentage is highest between 4 years and 5 years after-

diagnosis and decreases after that. To have an idea of the intensity of care, the person-month measures of care are presented in Table 2B. On average, a patient diagnosed with CRC during 1996 received 7.2 months of care, and patients diagnosed 15–21 years earlier received on average < 1 month of care during 1996 (Table 2B, column 4). Time in care is partitioned further by phases of care in Table 2B (columns 5–9). Although there is usually a greater percentage of patients with CRC who receive postdiagnostic monitoring care compared with recurrent/metastatic care (Table 2A), this difference diminishes when considering the average number of months in both phases (Table 2B). Both the proportion treated and the duration of treatment increases with more advanced stages of the disease.

Among the population age 65 years and older who resided in the SEER areas in 1996, the percent of people alive previously diagnosed with CRC is 1.81% and the percent of person-months alive with CRC is 1.68%. Using Equations 1 and 2, we calculate the CRC care prevalence in the SEER areas and in the U.S. (Table 3). The percentages of persons and person-months among the SEER population age 65 years and older who received CRC care in 1996 are estimated at 1.12% and 0.30%, respectively (Table 3, columns c and g). This is equivalent to approximately 381,000 patients older than 65 years receiving at least 1 type of CRC care (Table 3, column d) and approximately 1.2 million person-months, or equivalently, 100,000 person-years of CRC care (Table 3, column h) during 1996.

## DISCUSSION

This article provides what to our knowledge is the first national, population-based estimates of the prevalence of CRC care by phases of treatment for elderly patients. The results suggest that treatment for prevalent CRC is a significant care burden, with > 380,000 individuals receiving such care in 1996. We showed that a sizeable portion of patients receive care for their CRC long after 5 years postdiagnosis, the time that most CRC survivors are considered cured.<sup>4</sup> Of the care provided for long-term survivors, the vast majority is cancer surveillance. We estimate that in excess of 230,000 individuals undergo postdiagnostic surveillance, although the absolute benefit of follow-up surveillance, the appropriate methods, and the ideal periodicity for postdiagnostic surveillance continue to be debated.<sup>5–7</sup> At some point after diagnosis, procedures such as colonoscopy may be considered more for screening reasons rather than as active treatment for CRC. However, it is difficult to distinguish between the two, and the estimates of postdiagnostic monitoring

**TABLE 2**  
**Percent of Persons (A) and Average Number of Months (B) Care was Received for Colorectal Carcinoma in 1996 by Years from Diagnosis, Stage at Diagnosis, and Phases of Care among SEER-Medicare Patients Diagnosed with Colorectal Carcinoma from 1975 to 1996<sup>a</sup>**

A. Persons			Persons receiving care (%) <sup>b</sup>					
Variable	No. of persons		$N_{\text{care}}/N_{\text{CRC}}$ (any phase)	$N_{\text{care}(i)}/N_{\text{CRC}}$				
	With CRC ( $N_{\text{CRC}}$ )	With CRC receiving care ( $N_{\text{care}}$ )		Initial phase	Monitoring phase	Recurrent/mets phase	Terminal phase	Not in in-care
Yrs since dx								
< 1	4581	4462	97.4	70.6	8.5	21.8	16.7	2.6
1 to < 2	3920	3288	83.9	28.1	37.6	26.1	16.1	16.1
2 to < 3	3478	2638	75.8	4.9	44.6	26.0	12.4	24.2
3 to < 4	3077	2166	70.4	—	39.2	28.0	7.8	29.6
4 to < 5	2880	1946	67.6	—	48.0	18.0	5.5	32.4
5 to < 10	11,509	6370	55.3	—	45.1	9.5	3.0	44.7
10 to < 15	7878	3545	45.0	—	39.5	5.4	1.3	55.0
15 to < 21	5894	2404	40.8	—	36.5	4.7	0.8	59.2
< 21	43,217	26,819	62.1	10.4	38.1	14.1	6.3	37.9
Stage								
I	14,262	8046	56.4	8.2	43.2	7.5	1.7	43.6
II	16,396	9872	60.2	10.5	39.4	12.5	3.7	39.8
III	9328	6425	68.9	15.4	36.6	18.8	8.7	31.1
IV	1891	1627	86.0	—	—	53.6	48.6	14.0
Unstaged	1340	849	63.4	12.9	31.1	15.8	11.6	36.6
B. Person-months			Average no. of months of phase(i) care among patients with CRC					
Variable	Persons years (PM/12)		$PM_{\text{care}}/PM_{\text{CRC}}$ (any phase)	$PM_{\text{care}(i)}/PM_{\text{CRC}}$				
	With CRC ( $PM_{\text{CRC}}$ )	With CRC receiving care ( $PM_{\text{care}}$ )		Initial phase	Monitoring phase	Recurrent/mets phase	Terminal phase	Not in in care
Yrs since dx								
< 1	2256	1359	7.2	4.5	0.3	1.6	0.9	4.8
1 to < 2	3557	1343	4.5	1.4	1.0	1.5	0.6	7.5
2 to < 3	3221	779	2.9	0.1	1.2	1.1	0.5	9.1
3 to < 4	2912	571	2.4	—	1.0	1.1	0.3	9.6
4 to < 5	2744	460	2.0	—	1.1	0.7	0.2	10.0
5 to < 10	11,092	1335	1.4	—	1.0	0.3	0.1	10.6
10 to < 15	7614	666	1.0	—	0.8	0.2	0.0	11.0
15 to < 21	5703	441	0.9	—	0.8	0.1	0.0	11.1
< 21	39,099	6954	2.1	0.4	0.9	0.6	0.2	9.9
Stage								
I	13,320	1638	1.5	0.2	1.0	0.3	0.1	10.5
II	15,087	2403	1.9	0.4	0.9	0.5	0.1	10.1
III	8364	2064	3.0	0.8	0.9	0.9	0.3	9.0
IV	1200	625	6.2	—	—	3.8	2.4	5.8
Unstaged	1129	225	2.4	0.3	0.8	0.8	0.4	9.6

SEER: Surveillance, Epidemiology, and End Results program; CRC: colorectal carcinoma; dx: diagnosis; mets; metastasis; PM: person-months.

<sup>a</sup> Surveillance, Epidemiology, and End Results (SEER) program-Medicare patients were patients with colorectal carcinoma age 65 years and older alive on January 1, 1996 who had complete Medicare coverage.

<sup>b</sup> Percentages by phase do not sum to the percentage in any phase because, in 1 year patients, may receive treatment in multiple phases.

CRC care may slightly overestimate the number of patients who are monitored. The estimates also indicate that, after 15 years postdiagnosis, 5% of patients received treatment for recurrent/metastatic disease. Because recurrence is uncommon > 6 years postdiagnosis,<sup>4</sup> such patients may represent a later CRC pri-

mary or metastatic CRC with an occult or undiagnosed primary. However, the percentage of individuals diagnosed with CRC between 1975 and 1981 who had a later CRC primary after 15 years was very small. Among 47,353 patients in the SEER areas who were diagnosed with CRC between 1975 and 1981, 5% were

**TABLE 3**  
**Estimated Percent and Number of Persons and Person-Months Age 65 Years and Older Receiving Care for Colorectal Carcinoma by Phases of Care in the U.S. in 1996**

Phases of care	Persons receiving care for CRC							
	Persons <sup>a</sup>				Person-mos (person-yrs) <sup>b</sup>			
	(a) No. of patients in the study cohort <sup>c</sup>	(b) Patients in the study cohort (%) <sup>c</sup>	(c) SEER population (%)	(d) Estimated no. in the U.S. population	(e) No. of person-yrs in the study cohort <sup>c</sup>	(f) Person-mos in the study cohort (%) <sup>c</sup>	(g) Person-mos in the SEER population (%)	(h) Estimated no. of person-mos in the U.S.
Phase of CRC								
Initial	4504	10	0.19	63,949	1290	3	0.06	224,414
Surveillance	16451	38	0.69	233,576	2975	8	0.13	517,650
Recurrence	6094	14	0.25	86,524	1994	5	0.09	346,932
Terminal	2719	6	0.11	38,605	696	2	0.03	121,125
All phases of care	26,819	62	1.12	380,783	6954	18	0.30	1,210,121
No care	16,398	38	0.69	232,823	32,145	82	1.38	5,593,480
Total <sup>d</sup>	43,217	100	1.81	613,607	39,099	100	1.68	6,803,601

CRC: colorectal carcinoma; SEER: Surveillance, Epidemiology, and End Results program. PM: person-months; N: number of persons.

<sup>a</sup> (b) =  $N_{\text{care}(i)} / N_{\text{CRC}}$ ; (c) = (b) \* total % of persons in SEER with CRC (1.807%); (d) = (c) \* total 1996 U.S. midyear population of persons age 65 years and older (33,957,198).

<sup>b</sup> (f) =  $PM_{\text{care}(i)} / PM_{\text{CRC}}$ ; (g) = (f) \* total % of PM in SEER with CRC (1.678%) during 1996; (h) = (g) \* total number of PM alive in the U.S. ( $12 * N_{\text{US}} = 12 * 33,957,198$ ).

<sup>c</sup> The study cohort was SEER-Medicare patients diagnosed with CRC from 1975 to 1996, age 65 years and older and with complete Medicare coverage in 1996.

<sup>d</sup> The total is the sum of all phases of care and no care.

diagnosed with a second or later primary CRC between 1975 and 1996, but only 0.2% had a second or later CRC primary diagnosis between 1992 and 1996.

The estimates of prevalent care are subject to the assumptions made in our design and may result in over or under estimates of true care prevalence. We used an algorithm to classify each patient in a unique phase of care for each month in 1996 that included disease stage at diagnosis, time from diagnosis, and a broad spectrum of claims. This method is a more accurate way to identify phases of care compared with looking at individual claims. A single claim may be associated with more than one phase. After reconstructing the history of the disease for each patient, we further determined whether care actually was received by reexamining claims. A similar but simpler algorithm was used by Brown et al.<sup>8</sup> to calculate the long-term costs of care. Their algorithm was based solely on the time from diagnosis and on disease stage, whereas ours also was based on individual patterns of care as well as time from diagnosis and disease stage, providing more accurate estimates of the proportion treated. With this approach, we were able to identify cancer care through a set of diagnoses and procedures. However, there may be circumstances in which the algorithm does not capture care that is related directly or indirectly to cancer treatment. For example, if a patient sought medical care for nausea and emesis, then it may not be possible to determine whether the care was related to cancer treatment or to another cause,

thus, resulting in an under estimate of CRC care. Conversely, it is also possible that some of the procedures associated with CRC care were being used for other conditions, for example, chemotherapy, which may be used for the treatment of arthritis. However, we believe this effect is very small.

Two main assumptions are made to extrapolate care prevalence to the U.S. We assumed that the prevalence of CRC in the SEER Program and in the U.S. was the same. Comparisons of 1996 cancer mortality rates for individuals age 65 years and older show that colorectal cancer mortality rates in the U.S. are 10% higher compared with rates in the SEER areas. Ecologic regression analyses on CRC survival data also indicate that patients with CRC in the U.S. have a poorer survival compared with patients with CRC in the SEER areas.<sup>9</sup> These results suggest a slightly lower prevalence of CRC in the U.S. compared with the SEER areas; thus, our estimates may slightly overestimate care prevalence. We also assumed that patterns of care observed in the study population were similar for all patients with CRC in the U.S. Merrill et al.<sup>10</sup> showed similar patterns of care between Medicare beneficiaries enrolled in HMOs and patients in the fee-for-service setting. Another study<sup>11</sup> showed low disenrollment rates of HMO enrollees who were diagnosed with cancer after enrollment, suggesting that patients with cancer in HMOs are somewhat satisfied with the services received. Because HMO enrollees represent < 20% of the population of Medicare beneficiaries, the

impact of a different care pattern for HMO enrollees would be small.

Prevalence can be measured in different ways. The most common definition of prevalence is point prevalence, i.e., the number of affected persons in a population at a specific point in time. Throughout this work, we have used period prevalence, i.e., the number of individuals with a condition at any time during a certain period, such as a single calendar year.<sup>12</sup> A measure of period prevalence is useful to quantify time as well as costs associated with it. By considering prevalence during a year, we were able to estimate the number of person-months in CRC care prevalence. These estimates, together with costs of monthly care by phase, can be used as an alternative to the method of Brown et al.<sup>8</sup> to calculate the total cost of CRC care in the U.S.

Our estimate of CRC prevalence differs from usual estimates of CRC prevalence. First, it is a period prevalence, representing individuals diagnosed with CRC between 1975 and 1996 who were alive at any time during 1996. The standard SEER point estimate (available from URL: <http://srab.cancer.gov/prevalence/methods>) of CRC prevalence on January 1, 1997 for individuals age 65 years and older who were diagnosed between 1975 and 1997 was 1.94%, higher than the 1.81% estimated here. This standard method counts the first CRC cancer for each individual but does not exclude individuals with a later primary cancer other than CRC, patients who we excluded from our estimate to match the CRC care prevalence. We believe that the use of care prevalence by phases of care provides a better estimate of the impact of CRC care on cancer resources, which is important both for resource allocation and for studying the patterns of care among the population.

## REFERENCES

1. Ries LA, Wingo PA, Miller DS, et al. The annual report to the nation on the status of cancer, 1973–1997, with a special section on colorectal cancer. *Cancer*. 2000;88:2398–2424.
2. Warren JL, Klabunde CN, Schrag D, Bach PB, Riley GF. Overview of the SEER-Medicare data: content, research applications, and generalizability to the United States elderly population. *Med Care*. 2002;40(8 Suppl):IV–18.
3. Potosky AL, Riley GF, Lubitz JD, Mentnech RM, Kessler LG. Potential for cancer related health services research using a linked Medicare-tumor registry database. *Med Care*. 1993;31:732–748.
4. Knopf KB, Warren JL, Feuer EJ, Brown ML. Bowel surveillance patterns after a diagnosis of colorectal cancer in Medicare beneficiaries. *Gastrointest Endosc*. 2001;54:563–571.
5. Goldberg RM, Fleming TR, Tangen CM, et al. Surgery for recurrent colon cancer: strategies for identifying resectable recurrence and success rates after resection. Eastern Cooperative Oncology Group, the North Central Cancer Treatment Group, and the Southwest Oncology Group. *Ann Intern Med*. 1998;129:27–35.
6. Smith TJ, Bear HD. Standard follow-up of colorectal cancer patients: finally, we can make practice guidelines based on evidence. *Gastroenterology*. 1998;114:211–213.
7. Safi F, Link KH, Beger HG. Is follow-up of colorectal cancer patients worthwhile? *Dis Colon Rectum*. 1993;36:636–643.
8. Brown ML, Riley GF, Potosky AL, Etzioni RD. Obtaining long-term disease specific costs of care: application to Medicare enrollees diagnosed with colorectal cancer. *Med Care*. 1999;37:1249–1259.
9. Mariotto A, Capocaccia R, Verdecchia A, et al. Projecting SEER cancer survival rates to the US: an ecological regression approach. *Cancer Causes Control*. 2002;13:101–111.
10. Merrill RM, Brown ML, Potosky AL, et al. Survival and treatment for colorectal cancer Medicare patients in two group/staff health maintenance organizations and the fee-for-service setting. *Med Care Res Rev*. 1999;56:177–196.
11. Riley GF, Feuer EJ, Lubitz JD. Disenrollment of Medicare cancer patients from health maintenance organizations. *Med Care*. 1996;34:826–836.
12. Kleinbaum DG, Kupper LL, Morgenstern H. Epidemiologic research: principles and quantitative methods. Belmont: Lifetime Learning Publications, 1982.