Estimating the Prevalence of Cancer in the United States

Anthony P. Polednak, Ph.D.

Connecticut Department of Public Health, Hartford, Connecticut.

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Address for reprints: Anthony P. Polednak, Ph.D., Connecticut Tumor Registry, Connecticut Department of Public Health, 410 Capitol Avenue, Hartford, CT 06134-0308.

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BACKGROUND. Few reports have estimated the prevalence of persons in the U.S. ever diagnosed with invasive cancer.

METHODS. The Connecticut Tumor Registry was used to identify all Connecticut residents ever diagnosed (1935–1994) with invasive cancer who were known to be alive in 1994. Estimated prevalence rates for Connecticut were compared with those for 1982, and were applied to the total U.S. population for selected years.

RESULTS. Some 95,361 persons ever diagnosed with invasive cancer(s) were confirmed as being alive at the end of 1994. The age-standardized prevalence rate had increased by 40% in males and 13% in females since 1982, due in part to large increases for breast, prostate, and (in females) lung carcinoma. Using the data for Connecticut, an estimated 7.1 million Americans in 1995 had ever been diagnosed with invasive cancer; projected numbers were 7.7 million for 2000 and 13.2 million for 2030.

CONCLUSIONS. The prevalence of persons ever diagnosed with invasive cancer could increase considerably in the coming decades, and numbers for elderly males could surpass those for elderly females by 2020. Although projections must be interpreted with caution, these data emphasize the need for primary prevention of cancer and for studies of cancer survivors. ***Cancer* 1997;80:136–41.**
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Estimates of ''cancer prevalence'' (or the number of living persons ever diagnosed with cancer), which take into account both incidence and survival, are especially useful in planning for health care and other needs of cancer survivors. Using age specific cancer prevalence rates in Connecticut in 1982, derived from the Connecticut Tumor Registry (CTR), an estimated 5 million of the 241 million Americans alive in 1986 had ever received a diagnosis of invasive cancer.[1] Since 1982, incidence rates for many types of cancer have increased in Connecticut[2] and in other parts of the U.S. with cancer registries,[3] along with survival rates.[3] The proportion of elderly Americans, who are at higher risk for cancer, has also increased. In view of these temporal trends, the estimates based on 1982 data should be updated.

METHODS

Although the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program has collected high quality data on cancer incidence from several population-based registries (including the CTR) since 1973, the CTR includes cancers diagnosed since 1935. For this study, 1994 was the most recent year for which reporting of incident cancers to the CTR was considered complete; also, follow-

up information was available through 1994 for many patients diagnosed in the distant past. Using International Classification of Diseases for Oncology (ICD-O-2) morphology codes, the study included invasive cancers. In situ cancers were excluded, but (following the procedure used in SEER reports)[3] in situ bladder carcinomas were included because of difficulties in distinguishing (pathologically) in situ from invasive bladder carcinomas. In analyses of specific types of cancer, lymphomas are coded separately (as Hodgkin's disease or non-Hodgkin's lymphoma).[3,4]

Bilateral cancers of paired organs are usually coded as separate tumors, as are tumors of different subsite (e.g., colon) or different histology occurring at the same site or paired organ (e.g., breast). These separate tumors were included in estimating the prevalence of multiple primary cancers.

Methods for vital status determination involve (since 1941) contacts with Connecticut hospitals and linkage of all CTR cases with state death records (including deaths through 1995). CTR cases diagnosed since 1973 have been linked with the National Death Index (NDI), which covers death since 1979[5]; the last CTR-NDI linkage covered deaths through 1990. Annual linkage with Health Care Financing Administration files since 1984 ascertains the vital status of elderly or disabled persons (last linkage in 1996), including those residing out of state. In linking annually with Connecticut Department of Motor Vehicle (DMV) records, CTR patients are presumed to be alive as of the date of last license renewal, but the 4-year renewal cycle results in underestimation of survivors.

Some 117,454 persons in the CTR were diagnosed with an invasive cancer while residing in Connecticut and were not known to have died as of Jan. 1, 1995; 98.7% had a histologically confirmed cancer. For patients whose records also mentioned a prior history of another cancer, tumor behavior and stage are often unavailable or of uncertain accuracy; the earlier tumor was excluded if place of residence at the time of diagnosis was out of state or unknown. Only the 95,361 persons (81% of 117,454) who were last ''contacted'' in 1994 (or later) were included. This could have underestimated the number of survivors in 1994 by as much as 19%. However, overestimation of prevalence rates also may have occurred, because follow-up in SEER registries is intended only for ascertaining vital status and not tracking place of residence. Only 69% of the 95,361 confirmed survivors were successfully linked with the latest Connecticut DMV computer file of license renewals (almost all having a last renewal date between 1992–1996), but some residents (e.g., children and some elderly individuals) do not have a driver's license. Because overestimation of prevalence may have offset underestimation, no adjustment was made to the prevalence rates based on the 95,361 persons confirmed as alive in 1994. Current residence is not relevant to examining long term survivorship.

Age specific prevalence rates of survivors in 1994 were estimated (0–14 years, 10-year intervals from 15–24 to 75–84, and 85+ years), using as denominators the U.S. Bureau of the Census population estimates by age and gender for Connecticut in July 1994.[6] Age-standardized rates (ASRs) were calculated by the direct method, using (as in a previous report)[1] the age distribution of the total U.S. population in 1980 as the standard. The age specific Connecticut prevalence rates were applied to the estimated U.S. population in these age groups in 1995, 2000, 2010, 2020,[7] and 2030[8] to project the prevalence of Americans alive in these years who had ever been diagnosed with invasive cancer.

RESULTS

Using the same age groups as in the previous study[1] (Table 1), the ASR of persons ever diagnosed with an invasive cancer(s) increased from 1982 to 1994 by 40% for males and 13% for females; the increase was greater for individuals age 70+ years. Data are shown for the most common cancer sites (breast, prostate, and lung). The 24,188 women in 1994 ever diagnosed with breast carcinoma comprised 44.5% of all 54,350 females, reflecting a substantial increase in ASR from 1982. The largest temporal increases in ASRs were for prostate carcinoma (126%) and lung carcinoma in women (78%); noteworthy also were the declines for lung carcinoma in younger men. By 1994 the ASR for the prevalence of persons with any cancer among males had almost reached that for females, despite lung carcinoma prevalence rates that increased for females and declined slightly for younger males (Table 1). The higher cancer prevalence rates for any cancer in males than females at age $\geq$70 years were due in large part to prostate carcinoma (Table 1).

Using additional age groupings (Fig. 1), age specific prevalence rates in 1994 for persons with 1 cancer diagnosed, and with multiple cancers, were higher for females than males in the middle-aged groups (age 35–44 to 55–59 years) but higher for males after age 65–74 years.

Using the latest year of diagnosis for persons with a history of $>$1 invasive cancer, 7847 of all 95,361 confirmed survivors in 1994 (8.2%) would have been missed if only years of diagnosis covered by the SEER Program (1973–1994) had been used (Table 2). This proportion reached 9% for breast carcinoma, 14% for testicular carcinoma, 16% for ovarian carcinoma, and 18% for carcinoma of the uterus (cervix or corpus), but only 0.7% for prostate carcinoma (reflecting the relatively late age at diag-

TABLE 1
Age Specific Cancer Prevalence Rates (per 100,000) in Connecticut in 1982[a] and 1994

	Age group (yrs)					
Site(s)	0–29	30–49	50–59	60–69	70+	Age-standardized rate[b]
Any Male						
1982[a]	134.4	597.6	2296.3	5380.3	11,809.7	1789.0
1994	160.9	697.7	2587.5	8082.1	17,818.6	2504.0 (41,006)[c]
% change[d]	+20%	+17%	+13%	+50%	+51%	+40%
Female						
1982	142.7	1169.8	4538.0	7530.7	10,635.0	2221.6
1994	161.9	1205.5	4414.6	8474.9	13,419.5	2521.4 (54,350)
% change	+14%	+3%	−3%	+13%	+26%	+13%
Breast						
1982	4.2	413.3	2067.3	2983.4	3888.7	847.6
1994	3.6	480.8	2217.3	4069.0	5924.4	1121.7 (24,188)
% change	−14%	+16%	+7%	+36%	+52%	+32%
Prostate						
1982	0.1	2.6	129.2	960.3	3696.8	372.3
1994	0.3	6.0	379.8	2657.1	7852.8	841.6 (13,762)
% change	+200%	+131%	+194%	+177%	+112%	+126%
Lung Male						
1982	0.8	27.7	238.6	564.5	757.6	134.8
1994	0.3	17.8	199.9	621.2	1085.5	156.9 (2529)
% change	−63%	−36%	−16%	+10%	+43%	+16%
Female						
1982	0.3	24.5	143.3	272.2	233.6	61.1
1994	0.3	23.8	191.2	497.4	569.6	109.0 (2319)
% change	0%	−3%	+33%	+83%	+144%	+78%

[a] Data for 1982 are from Feldman AR, Kessler L, Myers MH, Naughton MD. The prevalence of cancer. Estimates based on the Connecticut Tumor Registry. *N Engl J Med* 1986;315:1394–7.
[b] Age-standardized rate, direct method, using the age distribution of the total U.S. population in 1980 as the standard.
[c] Estimated number of persons in Connecticut in 1994 with a history of invasive cancer; gender was not recorded for 5 of 95,361 cases.
[d] Percentage change.

nosis) (data not shown). There were few survivors at 55–59 years after being diagnosed (not surprisingly, at a relatively young age), but 180 survivors were diagnosed in the 1940s and 891 in the 1950s. These long term survivors included persons with breast, ovarian, testicular, colorectal, and uterine carcinomas, as well as parotid gland, connective tissue, bone, thyroid, and Hodgkin's disease.

Applying the estimated gender and age specific prevalence rates for Connecticut in 1994 (Fig. 1) to the U.S. population in 1995 yielded an estimated 7.1 million Americans (3.1 million males and 4.0 million females) in 1995 with a history of invasive cancer. Projected numbers of Americans with a history of invasive cancer(s) are shown in broad age groups in Table 3 reflecting interest in the growing numbers of elderly (including persons age $\geq$ 85 years). The prevalence could be 7.7 million in 2000 and, reflecting the aging of the baby boom generation, 13.2 million in 2030 (Table 3). These figures are higher than the corresponding estimates made in 1986 (i.e., 6.2 million in 2000 and 9.6 million in 2030).[1] The number of Americans with multiple primary (invasive) cancers, apparently not previously estimated, could reach 0.8 million in 2000 and 1.4 million in 2030 (data not shown).

DISCUSSION

Problems in Estimating Cancer Prevalence

Errors in the estimated prevalence rates for 1994 would have occurred if underascertainment of survivors due to loss to follow-up, along with incomplete ascertainment of nonfatal cancers in the earlier years of CTR's operation,[4] were not exactly offset by the inclusion of persons no longer residing in Connecticut (an issue not considered in the previous study using Connecticut data).[1] Applying Connecticut prevalence rates to the entire U.S. is also problematic. Although Connecticut incidence rates for certain cancers may approximate those for the U.S. more closely than SEER-wide data (at least since 1973 and for the elderly),[9] prevalence in 1994 was influenced by incidence and survival rates in the past. The proportions of minorities in the past and current population of

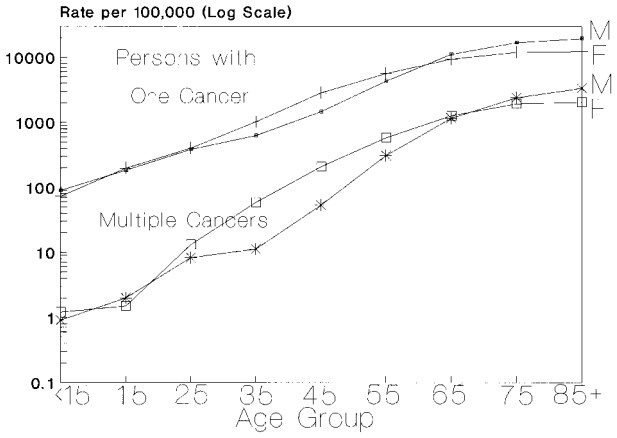

FIGURE 1. Estimated prevalence (per 100,000) of Connecticut residents in 1994 ever diagnosed with one invasive cancer and ≥ two invasive cancers by age and gender M: male; F: female.

Connecticut differ from those for the U.S. (e.g., in 1990, African Americans and Hispanics comprised 8.3% and 6.5%, respectively, of the Connecticut population versus 12.1% and 9.0%, respectively, of the U.S. population. However, 5-year relative survival rates for cancer patients diagnosed in recent years and residing in Connecticut are similar to those for all SEER registries.[3]

The National Health Interview Survey (NHIS) is a potential source for obtaining or validating prevalence estimates. However, the average annual number of U.S. women with breast carcinoma between 1990–1992 was 802,000 (unpublished data, National Center for Health Statistics) or a crude annual rate of only approximately 620 per 100,000 females. This low rate may reflect the ambiguity of the NHIS question (''During the past 12 months, did anyone in the family have breast cancer?'').[10] Also, a history of cancer may be underreported by patients (relative to physician reports),[11] especially when proxy respondents are included[12] (as in the NHIS). Identifying long term survivors requires questions on the date of diagnosis of each cancer, as in the 1992 NHIS special supplement,[10] which included only 12,000 respondents (adults only) with 730 (or 6083 per 100,000) reporting a history of cancer[13]; age specific prevalence rates would be subject to considerable statistical uncertainty. Although involving a larger total sample nationwide, the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System has not included questions (in all states) on cancer survivorship.

It is uncertain if expansion of national surveys (with their limitations involving self-reported and proxy data on history of cancer) would provide more accurate estimates of the prevalence of persons with a history of cancer than estimates based on data in cancer registries (with missing information on current residence, loss to follow-up, and varying years of registry operation). The special value of older registries, such as the CTR (Table 2), in estimating survivors will diminish over time. Finally, these methods could be replaced or supplemented by modeling approaches using age-period-cohort models of cancer incidence and survival rates, along with population projections.

Temporal Trends in Estimated Prevalence Rates

With the above-mentioned limitations in mind, the estimate of 7.1 million Americans with a history of invasive cancer in 1995 is lower than the American Cancer Society's figure of 10 million with ''cancer'' in 1996.[14] The latter estimate could reflect (in part) extrapolation of prostate carcinoma incidence rates, which actually peaked in 1992 and then declined (for elderly men).[15–17] Increases in prevalence rates between 1982 and 1994 for breast and prostate carcinoma reflect increases in incidence rates, largely due to trends in cancer screening rates.[18,19]

Projections of Prevalence

The prevalence of Americans ever diagnosed with invasive cancer could surpass 11 million by 2020 (Table 3). However, such projections should be interpreted with caution in view of future changes in cancer incidence and survival rates. The near disappearance of the gender difference in total prevalence by 2030 for all ages combined, and an actual reversal in the gender ratio for individuals age ≥ age 65 years by 2020 (Table 3), reflect gender differences in projected trends in life expectancy.[7,8] However, excluding in situ (mainly breast and cervical) carcinomas from this study has a greater impact on women than men.

Implications

The proportion of persons ever diagnosed with cancer who currently experience residual health effects is unknown. A recent report on the prevalence of Americans with chronic conditions that require the use of medical services and supplies or involve disability was based on a survey in 1987, because more recent surveys (i.e., the NHIS) undercounted persons with chronic conditions; data on cancer were not included, and the limitations of self-reported information also were acknowledged.[20]

Residual effects of having been diagnosed with cancer include risks for future events, and the psychosocial impact of perceptions of such risks. In a National Coalition for Cancer Survivorship survey of a self-selected group of survivors, with a response rate of only 57% (of 1200 sampled), fears of recurrence reportedly persisted.[21] Although recurrence, and rere-

TABLE 2
Numbers of Persons Ever Diagnosed with Invasive Cancer(s) in Connecticut and Confirmed Alive in 1994, by Year of Diagnosis[a]

			Mean age (yrs)	
Calendar years of diagnosis	No. of years to 1994	No. of survivors	Diagnosis	In 1994
Pre-SEER era (Connecticut Registry)				
1935–1939	55–59	16	25.8	82.8
1940–1944	50–54	53	30.0	82.3
1945–1949	45–49	127	31.6	78.8
1950–1954	40–44	314	34.5	76.8
1955–1959	35–39	577	37.1	74.2
1960–1964	30–34	1110	41.1	72.6
1965–1969	25–29	1768	44.5	71.8
1970–1972	22–24	3882	48.3	70.4
SEER program period				
1973–1994	0–21	87,514 (91.8%)[a]	61.1	67.1
Total period				
1935–1994	0–59	95,361	59.7	67.5

SEER: Surveillance, Epidemiology, and End Results Program, sponsored by the National Cancer Institute.
[a] If a survivor had more than one invasive cancer, the latest year of diagnosis was selected.
[b] Proportion of all 95,361 survivors.

TABLE 3
Projected Prevalences (Millions) of Persons Living in the U.S. in Selected Year Who Had Ever Been Diagnosed with Invasive Cancer

		Year			
Age group (yrs)	Gender	2000 (no.)	2010 (no.)	2020 (no.)	2030 (no.)
<65	Male	1.074	1.365	1.514	1.412
	Female	1.719	2.226	2.343	2.199
65+	Male	2.280	2.703	3.650	4.997
	Female	2.581	2.860	3.632	4.560
65–84	Male	(1.997)	(2.279)	(3.124)	(4.341)
	Female	(2.134)	(2.267)	(2.959)	(3.892)
85+	Male	(0.283)	(0.424)	(0.526)	(0.656)
	Female	(0.447)	(0.594)	(0.673)	(0.668)
Total	Male	3.354	4.068	5.164	6.409
	Female	4.300	5.087	5.975	6.759
	Total	7.654	9.154	11.139	13.168

currence (such as for colorectal carcinomas),[22] among cancer survivors are not readily studied by cancer registries, risks of multiple primary cancers have been studied.[22–25] Persons ever diagnosed with certain cancers are at elevated risk of additional cancer(s), reflecting both the operation of shared causes (e.g., inherited genetic factors and smoking history) and the effects of cancer treatment. Excess risks (based on cancer rates for the general population) are small,[26] but explaining such relative risks to patients may be challenging.

Cancer ''cure'' sometimes refers to survival to a point at which the relative survival rate (i.e., adjusted for death rates in the general population) no longer declines. Relative survival rates stabilize early after diagnosis for some cancers (e.g., testicular carcinoma) but somewhat later for others (e.g., Hodgkin's disease),[27] and only after at least 20 years for breast carcinoma.[5,28,29] However, many patients considered cured (e.g., of prostate carcinoma) may not only need further treatment[30] but also have lives ''permanently altered'' by diminished functioning and specific complications of treatment.[31] Some trends in treatment should be leading to improvements in quality of life for survivors. Examples include fewer colostomies for colorectal carcinoma patients,[32] and the increasing use of breast-conserving surgery (associated with fewer problems with clothing and body image).[33]

In conclusion, projected increases in the numbers of incident cancers (due largely to an aging population)[34] do not take into account the long survival of some patients. Although improvements in survival rates are desirable, prevalence estimates and projections support the need for expanding primary prevention efforts (e.g., involving smoking, alcohol, diet, body weight, and excessive sun exposure) in which primary care physicians could play a greater role,[35,36] as well as studies of the quality of life of survivors and (as for other chronic diseases)[20] their caregivers and families.

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