Burden of Illness in Cancer Survivors: Findings From a Population-Based National Sample

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Background: **Population trends in aging and improved cancer survival are likely to result in increased cancer prevalence in the United States, but few estimates of the burden of illness among cancer survivors are currently available. The purpose of this study was to estimate the burden of illness in cancer survivors in a national, population-based sample.** *Methods:* **A total of 1823 cancer survivors and 5469 age-, sex-, and educational attainment–matched control subjects were identified from the 2000 National Health Interview Survey. Multiple measures of burden, including utility, a summary measure of health, and days lost from work, were compared using two-sided tests of statistical significance for the two groups overall and for subgroups stratified by tumor site and time since diagnosis.** *Results:* **Compared with matched control subjects, cancer survivors had poorer outcomes across all burden measures ($P<.01$). Cancer survivors had lower utility values (0.74 versus 0.80; $P<.001$) and higher levels of lost productivity and were more likely to report their health as fair or poor (31.0% versus 17.9%; $P<.001$) than matched control subjects. Cancer survivors reported statistically significantly higher burden than did control subjects across tumor sites and across time since diagnosis (i.e., within the past year, 2–5 years, 6–10 years, and ≥11 years for the majority of measures.** *Conclusions:* **Cancer survivors have poorer health outcomes than do similar individuals without cancer across multiple burden measures. These decrements are consistent across tumor sites and are found in patients many years following reported diagnosis. Improved measurement of long-term burden of illness will be important for future prospective research. [J Natl Cancer Inst 2004;96:1322–30]**

Currently, more than 1 million people a year are diagnosed with cancer in the United States *(1)*. This number is expected to double by the year 2050, reflecting an aging population and an increase in population size *(2)*. In addition, improvements in early diagnosis and treatment have led to improved survival following diagnosis for many tumor sites *(3,4)*. Thus, over the next several decades, the prevalence of cancer survivors is also likely to increase. This population will consist of individuals cured of their disease and no longer undergoing active treatment as well as individuals with recurrences or resistant disease requiring ongoing treatment. Regardless of disease status, all survivors may experience lasting effects of treatment.

Prior research in estimating the burden of cancer in the United States has focused on the direct medical costs of treating illness, including hospitalization, outpatient care, and physician services *(5–10)*. Other components of cancer burden—productivity and intangible costs—have received less attention. Productivity costs are the time and economic output lost or forgone by the patient, family, and friends from usual activities as a result of disease and its treatment *(11)*. These costs are typically measured by forgone earnings among the currently employed (morbidity costs) and by the present value of future output lost because of premature death (mortality costs) *(12,13)*. Intangible or psychosocial costs are pain and suffering from disease and its treatment that affect health and well-being not reflected in the categories of direct or productivity costs *(10)*. For the purposes of cost-effectiveness analysis, psychosocial or intangible costs are conceptualized as a summary of health-related quality of life outcome and are measured by patient preference or utility. These utility values can be combined with survival to estimate quality-adjusted life-years that reflect both morbidity and mortality effects of disease and its treatment *(11)*.

Prior studies of indirect and intangible costs of care for cancer survivors in the United States have typically been conducted in small samples from specific institutions or in specific regions of the country *(14–17)*, or in samples defined by tumor sites or specific treatments *(14,18–23)*. In addition, most studies have been conducted only among cancer patients, without comparison with similar individuals without cancer *(14,15,22,24)*. As a result, few population-based estimates of productivity and intangible costs of cancer and its treatment in the United States are available. We used data from a large national survey to estimate utility, lost productivity due to morbidity, and other measures of burden for cancer survivors compared with those of similar individuals never diagnosed with cancer. We also compared utility, lost productivity due to morbidity, and other burden measures for cancer survivors by tumor site and time since diagnosis.

SUBJECTS AND METHODS

Study Population

The study population was selected from the 2000 National Health Interview Survey (NHIS), an annual multistage survey conducted in the civilian noninstitutionalized population of the United States. The NHIS, a publicly available resource, is conducted by the National Center for Health Statistics (Hyattsville, MD) and administered by the U.S. Bureau of the Census *(25)*.

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The entire survey is submitted for approval by the U.S. Office of Management and Budget, as required by the Privacy Act, and prospective respondents are provided information appropriate to informed-consent requirements. The Cancer Control Module of the survey, which contains information on cancer diagnoses, had 32 374 respondents and a final response rate of 72.1%. More information on survey design and content is available from http://www.cdc.gov/nchs/nhis.htm (last accessed: July 8, 2004).

The survey contained the question, “Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?” Individuals who responded in the affirmative were then asked about the type of cancer and the age at each cancer diagnosis. We identified 2151 men and women aged 18 and older who reported that they had been diagnosed with cancer at some point in their lives as cancer survivors. The remaining 30 195 respondents who reported never being diagnosed with cancer were potential noncancer control subjects (28 respondents had missing data for this question and were excluded).

Because some of the lasting treatment effects reported among samples of cancer survivors, such as arthritis or rheumatism, cataracts, hearing loss, and memory loss *(26),* also increase with age *(27),* and because age is strongly associated with most measures of health limitations *(28),* we controlled carefully for age. In addition, age distributions of cancer survivors and potential noncancer control subjects were dramatically different (i.e., 24% of cancer survivors and 66% of noncancer control subjects were younger than 50). We matched control subjects to cancer survivors on the basis of age at the time of the survey in 5-year intervals (<20, 20–24, 25–29, 30–34, 35–39, 40–44, 45–49, 50–54, 55–59, 60–64, 65–69, and ≥70 years). Also, because sex and educational attainment are related to employment, type of employment *(29),* and self-reported health status *(30),* we also matched control subjects to cancer survivors by sex and educational attainment (less than high school graduate, high school graduate or greater). Noncancer control subjects were randomly selected and matched to cancer survivors in a 3 : 1 ratio based on age interval, sex, and educational attainment. Fourteen cancer survivors and 348 potential control subjects were excluded from this study sample because of missing data on educational attainment.

We considered including individuals ever diagnosed with nonmelanoma skin cancer in our study sample as cancer survivors but ultimately decided to exclude this group (n = 314) because diagnosis and treatment are generally considered to be minor *(31)* and because nonmelanoma skin cancer cases are routinely excluded from other studies of cancer survivors *(16,32).* In addition, most estimates of cancer incidence and lifetime risk of cancer exclude cases of nonmelanoma skin cancer *(1,33).* Our final sample consisted of 1823 cancer survivors and 5469 age-, sex- and educational attainment–matched noncancer control subjects.

Measures

Sample characteristics that were used for matching cancer survivors and control subjects were categorized as reported age at the time of the survey (<50, 50–64, ≥65 years), educational attainment (less than high school graduate, high school graduate or greater), and sex. Other descriptive characteristics included race/ethnicity (white, non-Hispanic; black, non-Hispanic; and Hispanic/other), marital status (married or living as married, other), health insurance (private/military, public only, no insurance) smoking status (current, former, never) and body mass index (underweight, normal weight, overweight, obese).

Comorbid conditions were measured with a series of questions related to functional limitations. Individuals who identified any functional limitations were asked about a series of conditions or health problems underlying the limitation. Individuals could identify multiple conditions. Comorbid conditions with prevalence of 5% or more in the population are listed separately (i.e., arthritis/rheumatism, back/neck problem, fracture/bone/joint injury, heart problem, stroke, hypertension, diabetes, lung/breath problem, depression/anxiety/emotional problems, weight problems, and musculoskeletal problems). Comorbid conditions were also categorized by absolute number of conditions individuals identified as causing limitations (0, 1, 2, ≥3).

Health utility is a summary measure of overall preference or desirability of a state of health across multiple domains of health-related quality of life *(34–36).* For example, the health of an individual with congestive heart failure, which may have its primary impact on physical functioning, could be compared with the health of an individual with depression, in which emotional but not physical functioning might be affected. Typically, health utilities are anchored by the values of 1, representing perfect health, and 0, representing death *(35).*

In this study, utility was estimated for each respondent by applying Health Activities and Limitations Index (HALex) utility weights to their self-reported health (excellent, very good, good, fair, or poor) and reported limitations in usual activities *(37).* The HALex was designed for use in large national surveys, specifically the NHIS *(37).* HALex utility weights were obtained from the 2000 Medical Expenditure Panel Survey by mapping responses to self-reported health and limitations in usual activities questions to independently obtained utility measures from EuroQol EQ-5D index *(38),* a well-validated utility index *(39,40).* The 2000 MEPS contained both the underlying HALex questions and the EuroQol EQ-5D questions.

Lost productivity due to morbidity was measured by whether the individual had a job within the past 12 months (yes, no), limitations in ability to work due to health problems (yes, no), limitations in amount or kind of work because of health problems (yes, no), and number of days lost from work in the past year among individuals with jobs. To include lost productivity among the 364 individuals in our study who were of working age but without jobs in the past year and unable to work or limited in amount or type of work because of health, we created a modified days-lost-from-work variable with assigned values. For individuals with jobs within the past 12 months who completed the question about days lost from work, this modified variable had the same value as originally reported. For individuals of working age but without jobs and unable to work because of health and without data on the number of days lost from work, the modified variable was assigned a value of 260 days to represent a 2000-hour work year. For individuals of working age but without jobs and limited in the amount or kind of work because of health and without data for the number of days lost from work, we assumed a 25% loss of productivity, equivalent to 65 days lost from work.

Health and functional limitation measures included self-rated health status (excellent, very good, good, fair, poor) and problems with any of the activities of daily living, including eating, bathing, dressing, getting in or out of bed or chairs, using the toilet, or getting around inside the home (yes, no). Other health limitations were measured with problems with any of the instrumental activities of daily living—needing help with routine needs, such as everyday household chores, doing necessary business or shopping, or getting around for other purposes (yes, no); any limitation in any way (yes, no); and the number of days spent in bed in the past 12 months (0, 1–10, >10).

Type of cancer and age at cancer diagnosis were also abstracted for cancer survivors. Cancer survivors were grouped by the most prevalent tumor sites—breast, colorectal, and prostate *(1,33)*. Although lung cancer is the leading cause of cancer mortality in men and women and one of the most common new cancers *(1,33)*, survival following diagnosis is usually short *(33)* and, as a result, the prevalence of lung cancer is low. We identified fewer than 50 lung cancer survivors. Because this was too small a number to group separately, we used data from the Surveillance, Epidemiology, and End Results (SEER[1]) Program to identify other short-survival cancers with 5-year relative survival of less than 25%. In addition to lung cancer, other cancers with short survival included those of the esophagus, liver, pancreas, and stomach *(33)*. Individuals who indicated that they had been diagnosed with more than one cancer were categorized separately from the other cancer survivors. Survivors diagnosed with cancer at all other sites (tumors other than breast, colorectal, prostate, lung, esophagus, liver, pancreas, and stomach) were combined in a single category.

Time since cancer diagnosis was calculated by subtracting age at diagnosis from age at the time of the survey. Because other studies of the direct medical costs of cancer care have reported that the first 6 months to 1 year following diagnosis are distinctly different from other periods in terms of treatment patterns *(6,8)*, we grouped survivors diagnosed within the year of the survey separately. To examine patterns by time since diagnosis, we created additional categories for diagnosis 2–5 years, 6–10 years, and 11 or more years prior to the survey. For survivors with more than one cancer diagnosis, time since diagnosis was defined using the age at most recent cancer diagnosis because this would be most relevant for measuring current cancer burden.

Some survey respondents appeared to have misinterpreted the question about age at diagnosis and may have reported the number of years since their cancer diagnosis. For example, several respondents reported that they had been diagnosed with lung cancer before they were 10 years old, but lung cancer incidence in children is exceedingly rare, and SEER reports indicate that incidence in this young age category is too small to calculate a rate *(33)*. As a result, we reviewed age at diagnosis by tumor site for all 29 tumor sites collected in the NHIS in relation to SEER age-specific incidence rates by tumor site. Cancer survivors with responses to age at cancer diagnosis in age ranges where site-specific incidence rates were too small to estimate rates from SEER were recoded to missing an age at diagnosis along with other cases with missing data for this value (n = 181) and were excluded from time-since-diagnosis analyses only.

Statistical Analyses

Descriptive statistics were calculated for cancer survivors and noncancer control subjects and were calculated separately for cancer survivors stratified by cancer site (breast, prostate, colorectal, and all other sites/multiple sites) and time since diagnosis (within the past year, 2–5 years, 6–10 years, ≥11 years). Frequencies of categoric variables were compared using chi-square statistics. Means for continuous variables (i.e., HALex utility values, days lost from work) were compared using linear regression. We did not adjust for the effects of age or educational attainment or stratify by sex because control subjects were matched on these factors, and comparisons between cancer survivors and control subjects already incorporated the influence of these characteristics. All tests of statistical significance were two-sided. We used SUDAAN *(41)* to incorporate the complex NHIS survey design and weighting for nonresponses.

RESULTS

Distributions of age, sex, and educational attainment—which were the matching variables for cancer survivors and control subjects—were similar in the two groups, as expected (Table 1). A larger proportion of cancer survivors than control subjects were non-Hispanic/white and current or former smokers. Cancer survivors were also more likely than control subjects to report limitations with arthritis or rheumatism, back or neck problems, fractures or bone or joint injuries, hypertension, or lung or breath problems than control subjects. In no case was the difference in prevalence of limitations between cancer survivors and matched control subjects greater than five percentage points, however. The proportions of cancer survivors and noncancer control subjects reporting heart problems, stroke, diabetes, depression, anxiety, emotional problems, weight problems, or musculoskeletal problems leading to limitations were similar. Cancer survivors were more likely to have multiple comorbid conditions than were control subjects.

Of the cancer survivors, 339 had a prior breast cancer diagnosis, 157 had a prior colorectal cancer diagnosis, 171 had a prior prostate cancer diagnosis, 69 had a prior lung cancer or other short-survival cancer diagnosis, 153 had multiple prior cancer diagnoses, and 930 had a prior diagnosis with another tumor site. Notable differences in characteristics by tumor site were observed. The highest percentage of cancer survivors aged 65 and older were among those with a prior diagnosis of prostate cancer (87.0%), followed by survivors of colorectal cancer (68.9%), lung and other short-survival cancers (63.6%), multiple cancers (58.9%), breast cancer (53.9%), and all other cancers (36.8%). Frequencies of specific conditions causing limitations were too small to make comparisons across tumor site, although for every tumor site the proportion of cancer survivors with one or more comorbid conditions was higher than that of control subjects ($P<.001$). The percentage of survivors with one or more comorbid condition was highest among individuals with multiple cancers (74.5%), followed by lung and other short-survival cancers (69.9%), colorectal cancer (67.0%), breast cancer (56.3%), other cancers (54.4%), and prostate cancer (51.4%).

Cancer survivors reported statistically significantly poorer health across every measure of utility, productivity, and general health compared with age-, sex-, and educational attainment–matched control subjects (Table 2). Mean HALex values of cancer survivors were lower than those of control subjects (0.74 versus 0.80; $P<.001$). Cancer survivors were also less likely than control subjects to have had a job in the past month, more likely to be unable to work because of health, more limited in the

Table 1. Characteristics of cancer survivors and age-, gender-, and educational attainment–matched control subjects

Characteristic	Cancer survivors (N = 1823)	Noncancer control subjects (N = 5469)	P*
Age (y), %			.79
<50	24.5	25.3	
50–64	24.7	24.9	
≥65	50.8	49.8	
Gender, %			.93
Male	37.8	37.9	
Female	62.2	62.1	
Educational attainment, %			.07
Less than high school graduate	22.5	20.1	
High school graduate or more	77.5	79.9	
Race/ethnicity, %			<.001
Non-Hispanic white	88.2	79.2	
Non-Hispanic black	5.9	10.1	
Hispanic	3.9	7.5	
Other (non-Hispanic)	2.0	3.3	
Marital status, %			.80
Currently married/living together	63.5	63.8	
Not currently married	36.5	36.2	
Health insurance, %			.20
Private/military (could have public)	74.1	73.9	
Public only (no private/military)	20.1	19.0	
No insurance	5.9	7.2	
Conditions causing limitations, %			
Arthritis/rheumatism	21.9	18.4	.005
Back/neck problem	12.0	9.5	.01
Fracture/bone/joint injury	7.0	5.3	.03
Heart problem	5.8	4.8	.17
Stroke	2.1	1.8	.50
Hypertension	3.6	2.6	.02
Diabetes	2.6	2.3	.57
Lung/breath problem	4.8	3.6	.03
Depression/anxiety/emotional problems	2.5	1.9	.21
Weight problem	1.9	1.5	.34
Musculoskeletal problems	4.3	3.5	.18
No. of comorbid conditions, %			<.001
0	42.4	54.7	
1	36.0	30.8	
2	13.3	9.3	
≥3	8.4	5.1	
Smoking status, %			<.001
Current	19.6	16.8	
Former	37.1	31.4	
Never	43.4	51.9	
Body mass (kg/m^2), %			.10
Underweight (<19)	4.9	3.1	
Normal weight (19–24.9)	37.2	38.6	
Overweight (25–29.9)	36.6	37.2	
Obese (≥30)	21.3	21.1	

*Categoric variables were compared with chi-square statistics. *P* values are two-sided.

amount or kind of work because of a health problem, and have more days lost from work in the past 12 months (all $P<.001$). Survivors were also more likely than control subjects to report fair or poor health (31.0% versus 17.9%; $P<.001$) and needing help with activities of daily living ($P = .003$) and with instrumental activities of daily living ($P<.001$). Survivors were more likely to have spent 10 or more days in bed in the past 12 months than control subjects (14.0% versus 7.7%; $P<.001$).

To assess whether the observed differences between cancer survivors and control subjects were attributable to differences in smoking status or race, we also compared utility, lost productivity, and general health measures for cancer survivors and matched control subjects while controlling for these characteristics with logistic or linear regression (data not shown). Cancer survivors had poorer health across all utility, lost productivity, and general health measures than matched control subjects, controlling for the effect of smoking and race ($P<.01$)

Burden Estimates by Type of Cancer

Across the vast majority of burden measures, cancer survivors originally diagnosed with breast, prostate, colorectal, lung and other short survival sites, multiple sites, and all other tumor sites had lower utility values, greater lost productivity, and worse general health than did control subjects ($P \leq .05$) (Table 3). HALex values ranged from 0.60 for individuals with lung and other short-survival cancers to 0.75 for breast, prostate, and all other tumor sites. Individuals with lung and other short-survival cancers or multiple cancers had the most limitations in amount or kind of work or ability to work at all because of health problems. These two groups of survivors were also more likely to report fair or poor health, to have limitations of any type, and to have spent 10 or more days in bed than survivors with other tumors sites or control subjects.

Burden Estimates by Time Since Diagnosis

A total of 16.5% of cancer survivors in our sample were diagnosed in the past year, 27.2% within 2–5 years, 19.4% within 6–10 years, and 27.0% were diagnosed 11 or more years from the time of the survey. For almost every measure of burden, cancer survivors within each time-since-diagnosis category had poorer health outcomes than did control subjects (Table 4); most of these differences were statistically significant. Values among cancer survivors with the longest interval since diagnosis (diagnosis ≥11 years) were similar to values in survivors closer to the time at diagnosis.

To address whether cancer survivors with a diagnosis 11 or more years prior to the survey are more likely to be older than survivors with more recent diagnoses, and therefore more likely to have age-related health or productivity limitations, we stratified all measures for cancer survivors and their matched control subjects by time since diagnosis. HALex measures were lower for survivors than their matched control subjects in every time-since-diagnosis interval ($P<.001$). Among survivors, patterns in lost productivity by time since diagnosis were complicated. A higher percentage of survivors diagnosed in the past year also had jobs in the past 12 months than survivors in any of the other time-since-diagnosis intervals. However, this group of survivors also had the most reported work loss days. Work loss days for survivors diagnosed 6–10 years and 11 or more years prior to the survey were similar to those of matched control subjects. Findings with the modified days-lost-from-work variable with assigned values for individuals of working age but without jobs and unable to work because of health were quite different from findings with the days-lost-from-work variable, as reported. Values for the modified days-lost-from-work variable were higher for cancer survivors than their matched control subjects in every time-since-diagnosis category, although there was some variability due, in part, to small sample sizes.

Table 2. Burden in cancer survivors and age-, gender-, and educational attainment–matched controls

Burden measure*	Cancer survivors (N = 1817)	Noncancer control subjects (N = 5465)	*P*†
Utility			
HALex utility value, mean (95% CI)	0.74 (0.72 to 0.75)	0.80 (0.80 to 0.81)	<.001
Lost productivity			
Job in past 12 months, % (95% CI)	41.0 (38.5 to 43.4)	45.9 (44.3 to 47.5)	.001
Unable to work due to health problems, % (95% CI)	18.0 (16.1 to 19.9)	10.3 (9.3 to 11.3)	<.001
Limited in amount/kind of work because of health problems, % (95% CI)	27.4 (25.1 to 29.8)	17.6 (16.3 to 18.8)	<.001
Days lost from work, past 12 mo (as reported), mean (95% CI)	13.2 (9.9 to 16.5)	5.7 (4.5 to 7.0)	<.001
Days lost from work, past 12 mo (modified variable with assigned data), mean (95% CI)	50.6 (43.6 to 57.6)	23.6 (20.3 to 26.8)	<.001
General health			
Health status, % (95% CI)			<.001
Excellent	13.5 (11.8 to 15.1)	21.9 (20.5 to 23.3)	
Very good	22.7 (20.3 to 25.1)	31.2 (29.8 to 32.7)	
Good	32.8 (30.4 to 35.3)	29.0 (27.5 to 30.5)	
Fair	20.6 (18.4 to 22.7)	13.4 (12.4 to 14.5)	
Poor	10.4 (8.8 to 12.1)	4.5 (3.8 to 5.2)	
Needs help with activities of daily living, % (95% CI)	4.9 (3.8 to 5.9)	3.0 (2.5 to 3.6)	.003
Needs help with instrumental activities of daily living, % (95% CI)	11.4 (9.9 to 13.0)	6.5 (5.7 to 7.2)	<.001
Any limitation in any way, % (95% CI)	36.2 (33.6 to 38.8)	23.8 (22.5 to 25.2)	<.001
No. of bed days in past 12 mo, % (95% CI)			<.001
0	57.1 (54.6 to 59.6)	66.2 (64.7 to 67.6)	
1–10	28.9 (26.6 to 31.2)	26.1 (24.7 to 27.5)	
>10	14.0 (12.2 to 15.7)	7.7 (6.9 to 8.6)	

*CI = confidence interval. Activities of daily living include eating, bathing, dressing, getting in or out of bed or chairs, using the toilet, and getting around inside the home. Instrumental activities of daily living are routine needs such as everyday household chores, doing necessary business or shopping, or getting around for other purposes.

†Categoric variables were compared with chi-square statistics, and continuous variables were compared with linear regression. *P* values are two-sided.

DISCUSSION

In this study, we used a population-based, national sample of prevalent cancer survivors and age-, sex-, and educational attainment–matched control subjects to assess the indirect and intangible components of the burden of cancer. We found statistically significantly lower utility values, more lost productivity, and more health limitations in cancer survivors compared with matched control subjects. These findings were consistent across tumor site and time since diagnosis. Our findings suggest that the productivity costs due to morbidity and intangible burden of illness associated with cancer are substantial, even among those who have survived well beyond 5 years following diagnosis. Our estimates of lost productivity and utility in cancer survivors can be combined with estimates of other components of productivity costs—namely, mortality costs *(10,13,42)*, lost productivity among caregivers *(10,14,15,43)*, and direct costs of cancer care *(5–10)*—to help delineate the overall cancer burden in the United States.

The high levels of burden among cancer survivors diagnosed within the past year are consistent with receipt of initial cancer treatment and additional use of health services, which have been reported to be high in this period *(6)*. Contrary to our expectations, however, long-term cancer survivors, even 11 or more years after diagnosis, had statistically significantly higher burden than their matched control subjects, across multiple measures. These findings did not appear to be due to an older age distribution in long-term cancer survivors than in control subjects. Moreover, similar findings have been reported in a study assessing general health and disability *(32)*. The findings may be due, in part, to inclusion of some individuals with recurrences and individuals without recurrences in these groups. Some studies have reported few differences in health limitations between long-term disease-free cancer survivors and control subjects *(44,45)*, but even survivors without recurrences may experience lasting effects of initial treatment. For example, several studies have reported that men undergoing surgery for localized prostate cancer may continue to experience incontinence and impotence well beyond the initial treatment period *(46,47)*. We were not able to identify survivors with recurrences or metastatic disease at diagnosis and short life expectancies from the 2000 NHIS; future studies might focus on methods for identifying such individuals. Exploration of lasting effects of treatment might be conducted in prospective studies with detailed treatment information and population-based control subjects.

Our work with the HALex utility measure builds on previous work developing utility measures with large nationally representative data sources *(24,37,48–51)* by using weights for the HALex developed from a national sample in which respondents answered the component questions of the HALex and completed an established utility measure, the EuroQol EQ-5D *(38)*. These HALex estimates were developed independent of cancer status, allowing comparison of cancer survivors with control subjects. A number of studies have examined utilities for cancer patients in clinical settings *(17,52–59);* national estimates have been reported in Canada *(60)* and in the United States for specific tumor sites *(24)*, but to our knowledge this is the first study to compare HALex estimates for cancer survivors and similar control subjects in a population setting in the United States. The HALex has a limited number of response levels used to generate scores and is subject to both ceiling and floor effects. For example, 13.4% of cancer survivors had the highest possible score (ceiling effect), and 2.3% had the lowest possible score (floor effect). However, as demonstrated in this study and elsewhere *(48)*, the HALex can discriminate between individuals

Table 3. Burden in cancer survivors by tumor site* and age-, gender-, and educational attainment–matched controls

Burden measure†	Cancer survivors: Breast cancer (n = 339)	Colorectal cancer (n = 157)	Prostate cancer (n = 171)	Short-survival cancers§ (n = 69)	Multiple cancers (n = 153)	All other tumor sites (n = 930)	Noncancer control subjects (N = 5468)	*P*‡
Utility								
HALex utility value, mean (95% CI)	0.75 (0.73 to 0.78)	0.73 (0.70 to 0.76)	0.75 (0.71 to 0.78)	0.60 (0.52 to 0.68)	0.68 (0.64 to 0.72)	0.75 (0.73 to 0.76)	0.80 (0.80 to 0.81)	<.001
Lost productivity								
Job in past 12 mo, % (95% CI)	36.9 (31.0 to 42.8)	22.4 (15.6 to 29.3)	21.6 (15.6 to 27.5)	24.1 (12.9 to 35.4)	31.8 (21.8 to 41.8)	52.3 (48.6 to 56.0)	45.9 (44.3 to 47.5)	<.001
Unable to work due to health problems, % (95% CI)	14.3 (10.0 to 18.5)	22.3 (14.8 to 29.8)	12.1 (7.7 to 16.6)	27.3 (16.1 to 38.6)	25.8 (17.6 to 34.0)	18.0 (15.2 to 20.8)	10.3 (9.3 to 11.3)	<.001
Limited in amount/kind of work because of health problems, % (95% CI)	22.5 (17.4 to 27.6)	32.4 (24.2 to 40.6)	18.9 (13.2 to 24.6)	49.0 (35.2 to 62.8)	41.4 (32.2 to 50.6)	26.4 (23.2 to 29.7)	17.6 (16.3 to 18.8)	<.001
Days lost from work, past 12 mo (as reported), mean (95% CI)	21.0 (10.8 to 31.3)	10.0 (3.4 to 16.7)	9.0 (0.0 to 19.8)	53.4 (0.0 to 107.2)	31.4 (5.1 to 57.7)	8.9 (6.0 to 11.7)	5.7 (4.5 to 7.0)	.002
Days lost from work, past 12 mo (modified variable with assigned data), mean (95% CI)	43.4 (28.4 to 58.3)	62.3 (22.3 to 102.3)	28.8 (8.8 to 48.8)	117.6 (66.8 to 168.4)	91.7 (56.6 to 126.8)	45.5 (37.3 to 53.7)	23.6 (20.3 to 26.8)	<.001
General health								
Health status, % (95% CI)								<.001
Excellent/very good	37.4 (31.3 to 43.6)	26.2 (18.1 to 34.4)	36.6 (28.2 to 44.9)	19.7 (8.6 to 30.8)	21.2 (13.5 to 28.9)	40.8 (37.3 to 44.3)	53.1 (51.5 to 54.7)	
Good	35.1 (28.9 to 41.4)	43.0 (33.7 to 52.3)	33.6 (25.8 to 41.4)	26.1 (14.8 to 37.5)	35.8 (26.7 to 44.8)	30.2 (26.8 to 33.5)	29.0 (27.5 to 30.5)	
Fair/poor	27.5 (21.8 to 33.1)	30.8 (22.4 to 39.2)	29.9 (22.6 to 37.2)	54.2 (40.5 to 68.0)	43.1 (33.6 to 52.5)	29.0 (26.0 to 32.1)	17.9 (16.7 to 19.1)	
Needs help with activities of daily living, % (95% CI)	3.9 (1.8 to 6.1)	3.9 (0.3 to 7.6)	4.5 (1.1 to 7.9)	14.0 (4.4 to 23.7)	5.7 (1.5 to 9.8)	4.6 (3.3 to 6.0)	3.0 (2.5 to 3.6)	.105
Needs help with instrumental activities of daily living, % (95% CI)	10.5 (6.9 to 14.1)	14.6 (8.8 to 20.5)	9.4 (4.5 to 14.4)	15.5 (6.3 to 24.8)	16.1 (10.0 to 22.3)	10.6 (8.5 to 12.6)	6.5 (5.7 to 7.2)	<.001
Any limitation in any way, % (95% CI)	30.6 (24.7 to 36.5)	39.9 (31.0 to 48.7)	33.7 (26.5 to 40.9)	61.0 (47.4 to 74.5)	53.0 (44.2 to 61.9)	33.6 (30.4 to 36.9)	23.8 (22.5 to 25.2)	<.001
No. of bed days in past 12 mo, % (95% CI)								
0	54.1 (48.0 to 60.2)	70.1 (61.8 to 78.4)	72.0 (64.7 to 79.3)	49.7 (36.7 to 62.6)	55.0 (46.0 to 64.0)	53.9 (50.5 to 57.3)	66.2 (64.7 to 67.6)	<.001
1–10	31.5 (25.8 to 37.3)	19.2 (11.5 to 26.8)	19.7 (13.0 to 26.4)	32.0 (19.6 to 44.4)	21.5 (14.0 to 29.0)	32.4 (29.2 to 35.6)	26.1 (24.7 to 27.5)	
>10	14.4 (10.3 to 18.5)	10.8 (5.0 to 16.5)	8.3 (3.4 to 13.2)	18.4 (8.8 to 28.0)	23.5 (16.5 to 30.5)	13.7 (11.3 to 16.2)	7.7 (6.9 to 8.6)	

*Four cancer survivors had missing data on tumor site and were excluded from these analyses.

†CI = confidence interval. Activities of daily living include eating, bathing, dressing, getting in or out of bed or chairs, using the toilet, and getting around inside the home. Instrumental activities of daily living are routine needs such as everyday household chores, doing necessary business or shopping, or getting around for other purposes.

‡Categorical variables were compared with chi-square statistics, and continuous variables were compared with linear regression. *P* values are two-sided.

§Short-survival cancers are tumor sites with less than a 25% 5-year relative survival rate and include esophagus, liver, lung, pancreas, and stomach.

with chronic conditions in large, nationally representative data, such as that in the NHIS. Notably, the mean HALex value for control subjects was 0.80 and was not equivalent to perfect health (i.e., a utility value of 1.00). Analysts using these HALex utility data for cancer survivors could potentially bias the results of a decision or cost-effectiveness analysis by using a utility value of 1.0 to represent the health state of a prevented or cured cancer.

Days lost from work is a common measure of morbidity among the employed used to estimate morbidity costs in burden-of-illness studies *(12,13)*. Cancer survivors lost more days from work than their matched control subjects, although the patterns of employment and lost productivity among survivors appeared complicated. Work loss days among the employed (as reported) varied dramatically by the time since diagnosis, with the highest levels occurring among the newly diagnosed. The newly diagnosed are also the group most likely to have jobs, whereas the groups diagnosed 2–5, 6–10, and 11 or more years before the survey are more likely to be unable to work because of health problems. Distributions of the modified variable we created to incorporate lost productivity among individuals of working age but without jobs and who were unable to work due to health were more similar by time since diagnosis and were higher than their matched control subjects in every category. Our findings suggest that using reported days lost from work among employed individuals to estimate cancer burden may underestimate the impact of disease on productivity among individuals of working age. In addition, because many cancer survivors are older than 65 when originally diagnosed *(1)* and may be retired, days-lost-from-work measures among the employed may also

Table 4. Health limitations among cancer survivors and age-, gender-, and educational attainment–matched controls by time since diagnosis∗

	≤1 y		2–5 y		6–10 y		≥11 y	
Burden measure†	Cancer survivors (n = 301)	Matched control subjects (n = 903)	Cancer survivor subjects (n = 495)	Matched control subjects (n = 1485)	Cancer survivor subjects (n = 353)	Matched control subjects (n = 1059)	Cancer survivor subjects (n = 493)	Matched control subjects (n = 1479)
Utility								
HALex utility value, mean (95% CI)	0.73 (0.70 to 0.76)	0.82 (0.80 to 0.83)‡	0.75 (0.73 to 0.77)	0.81 (0.80 to 0.82)‡	0.74 (0.72 to 0.77)	0.81 (0.79 to 0.82)‡	0.73 (0.71 to 0.76)	0.80 (0.79 to 0.81)‡
Lost productivity								
Job in past 12 mo, % (95% CI)	48.5 (42.1 to 55.0)	55.3 (51.9 to 58.8)	42.4 (37.3 to 47.6)	46.3 (43.6 to 49.0)	39.1 (33.4 to 44.7)	44.1 (40.4 to 47.8)	41.5 (36.7 to 46.2)	46.2 (43.1 to 49.3)
Unable to work due to health problems, % (95% CI)	15.3 (10.8 to 19.9)	7.5 (5.7 to 9.3)‡	17.4 (13.5 to 21.2)	9.8 (8.1 to 11.5)‡	17.9 (13.6 to 22.1)	10.8 (8.6 to 13.1)§	19.1 (15.6 to 22.6)	11.3 (9.5 to 13.1)‡
Limited in amount/kind of work because of health problems, % (95% CI)	26.3 (20.9 to 31.7)	14.5 (12.1 to 16.9)‡	26.0 (21.6 to 30.4)	16.6 (14.4 to 18.8)‡	27.4 (21.9 to 32.9)	18.5 (15.7 to 21.4)§	27.7 (23.6 to 31.7)	18.3 (16.0 to 20.6)‡
Days lost from work, past 12 mo (as reported), mean (95% CI)	30.5 (20.3 to 40.7)	5.7 (3.4 to 8.1)‡	14.7 (7.3 to 22.2)	5.9 (3.8 to 8.0)§	3.7 (2.3 to 5.0)	5.0 (3.0 to 7.0)	6.5 (2.3 to 10.8)	5.9 (2.9 to 9.0)
Days lost from work, past 12 mo (modified variable with assigned data), mean (95% CI)	55.5 (40.8 to 70.1)	17.5 (12.0 to 23.0)‡	54.7 (39.6 to 69.7)	22.4 (16.5 to 28.2)‡	35.8 (22.9 to 48.7)	25.9 (17.6 to 34.1)	53.8 (40.4 to 67.2)	27.5 (21.5 to 33.5)‡
General health								
Health status, % (95% CI)								
Excellent/very good	36.8 (30.7 to 42.9)	57.0 (53.3 to 60.7)‡	34.1 (29.4 to 38.7)	53.4 (50.4 to 56.3)‡	35.8 (30.4 to 41.2)	50.8 (47.4 to 54.3)‡	39.9 (35.2 to 44.6)	53.8 (50.7 to 56.8)‡
Good	28.0 (22.4 to 33.7)	26.2 (22.8 to 29.6)	37.4 (32.5 to 42.3)	29.4 (26.7 to 32.1)	35.3 (29.9 to 40.6)	32.1 (28.8 to 35.4)	28.0 (23.7 to 32.4)	27.7 (25.1 to 30.3)
Fair/poor	35.2 (29.6 to 40.7)	16.8 (13.9 to 19.7)	28.5 (24.2 to 32.9)	17.2 (15.1 to 19.4)	29.0 (24.1 to 33.8)	17.1 (14.6 to 19.7)	32.1 (27.4 to 36.7)	18.6 (16.2 to 21.0)
Needs help with activities of daily living, % (95% CI)	3.9 (1.6 to 6.2)	2.4 (1.2 to 3.6)	3.9 (1.9 to 5.9)	3.0 (2.1 to 3.9)	3.7 (1.5 to 5.9)	3.0 (1.6 to 4.5)	5.7 (3.5 to 7.9)	3.0 (2.0 to 3.9)§
Needs help with instrumental activities of daily living, % (95% CI)	9.6 (5.9 to 13.2)	4.8 (3.4 to 6.2)§	8.4 (5.7 to 11.2)	5.9 (4.6 to 7.1)	10.1 (6.5 to 13.6)	6.3 (4.5 to 8.1)	11.8 (8.8 to 14.7)	7.0 (5.4 to 8.5)§
Any limitation in any way, % (95% CI)	35.4 (29.3 to 41.6)	20.5 (17.6 to 23.4)‡	33.5 (28.8 to 38.2)	22.8 (20.3 to 25.3)‡	33.3 (27.7 to 38.9)	24.9 (22.0 to 27.9)§	36.3 (31.4 to 41.1)	23.5 (21.0 to 26.0)‡
Bed days in past 12 mo, % (95% CI)								
0	44.1 (37.6 to 50.6)	64.7 (61.2 to 68.3)‡	63.1 (58.2 to 68.0)	68.3 (65.8 to 70.8)	59.2 (53.1 to 65.2)	65.6 (62.6 to 68.7)	58.0 (53.5 to 62.5)	64.8 (61.9 to 67.7)§
1–10	31.9 (25.4 to 38.4)	28.2 (24.9 to 31.5)	27.0 (22.5 to 31.5)	25.0 (22.7 to 27.3)	28.6 (23.1 to 34.2)	25.7 (22.7 to 28.7)	28.6 (24.2 to 32.9)	26.6 (23.8 to 29.3)
>10	24.0 (18.8 to 29.2)	7.1 (5.1 to 9.0)	9.9 (7.2 to 12.6)	6.7 (5.3 to 8.1)	12.2 (8.1 to 16.3)	8.7 (6.5 to 10.8)	13.4 (10.2 to 16.7)	8.7 (7.0 to 10.3)

∗A total of 181 cancer survivors had missing data on age at diagnosis and were excluded from these analyses. Categoric variables were compared with chi-square statistics, and continuous variables were compared with linear regression.

†CI = confidence interval. Activities of daily living include eating, bathing, dressing, getting in or out of bed or chairs, using the toilet, and getting around inside the home. Instrumental activities of daily living are routine needs such as everyday household chores, doing necessary business or shopping, or getting around for other purposes.

‡Value(s) for matched control different from case at $P<.005$.

§Value(s) for matched control different from case at $P<.05$.

underestimate the lost productivity and burden of illness among this group. Development of additional measures of lost productivity with application to retired populations for use in prospective studies will be an important component of future research.

We identified a clear pattern in burden by tumor site: Survivors of lung and other short-survival cancers or of cancer at multiple sites reported greater burden than did survivors of breast, colorectal, prostate, and all other cancers. This likely reflects a greater proportion of survivors with metastatic, or at least active, disease. Our sample was not sufficient to simultaneously assess tumor site and time since diagnosis. In addition, differences in most common stage at diagnosis, initial and current types of treatment, treatment duration, and underlying distribution of age at diagnosis—factors likely to influence health limitations, utility values, and lost productivity—also vary by tumor site. For example, in a study of disease-free women 5 years after an early-stage breast cancer diagnosis, initial systemic treatment was associated with decrements in physical functioning, bodily pain, social functioning, and general health compared with similar women without systemic treatment *(61)*. We did not have information on treatment type or duration; further exploration of differences in health limitations by tumor site and treatment and by tumor site and time since diagnosis among cancer survivors compared with similar control subjects will be an important area for additional research.

Finally, we did not measure two components of the indirect or productivity costs of cancer—mortality costs and caregiver burden. Mortality costs have been reported to be between 50% and 68% of the total cost of specific cancers in a single state *(13,58)*. The caregiver burden has also been reported to be substantial *(62–65)*. Developing estimates of these components of the burden of illness will be important; some of this research is currently being supported by the Office of Cancer Survivorship at the National Cancer Institute *(66)*.

Despite the strengths of a large, population-based national sample, this study has several limitations. Although the NHIS had a high response rate, 72.1%, it is possible that individuals who responded to the survey are different from individuals who did not respond. Other limitations include lack of clinical details of the cancer diagnosis and use of self-report data to identify cancer survivors and control subjects. The questions in the NHIS did not ask about original stage of disease at diagnosis, treatments, or recurrences. Cancer survivors were identified as individuals who reported having a previous diagnosis of cancer in response to a survey question. Similarly, potential control subjects were individuals who reported not having a cancer diagnosis. Cancer patients have been found to under-report a history of cancer compared with medical records or tumor registries *(67)*, which could lead to inaccurate estimates of cancer prevalence. In this study, however, individuals not reporting a prior cancer diagnosis could have been randomly selected as control subjects. Possible inclusion of survivors as control subjects may understate the differences between cancer survivors and control subjects, however.

There are also some limitations associated with the use of the NHIS, a cross-sectional survey, to assess burden of illness. Although a cross-sectional design is useful to estimate burden prevalence, because cancer history and burden are assessed at the same time, burden cannot be definitively attributed to cancer diagnosis and treatment. We matched control subjects to cancer survivors on age, sex, and educational attainment, however, to help control for the influence of these characteristics on these health outcome measures. In addition, our findings were consistent for multiple measures and across tumor site and time since diagnosis.

In this study, we found that cancer survivors had poorer health outcomes than did similar individuals without cancer, across burden measures. These decrements were consistent in individuals with different tumors and in individuals across multiple periods following diagnosis. Improved measurement of long-term burden of illness and particularly lost productivity will be important for future prospective research for cancer and other chronic diseases. Our findings support additional research in indirect and intangible components of cancer burden, in a prospective study.

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NOTES

[1] *Editor's note:* SEER is a set of geographically defined, population-based, central cancer registries in the United States, operated by local nonprofit organizations under contract to the National Cancer Institute (NCI). Registry data are submitted electronically without personal identifiers to the NCI on a biannual basis, and the NCI makes the data available to the public for scientific research.

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