



Published in final edited form as:

Pediatrics. 2016 November ; 138(Suppl 1): S15–S21. doi:10.1542/peds.2015-4268D.

Annual Economic Burden of Productivity Losses Among Adult Survivors of Childhood Cancers

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Abstract

BACKGROUND AND OBJECTIVES: Although adult survivors of childhood cancers have poorer health and greater health limitations than other adults, substantial gaps remain in understanding the economic consequences of surviving childhood cancer. Therefore, we estimated the economic burden of productivity losses among adult survivors of childhood cancers.

METHODS: We examined health status, functional limitations, and productivity loss among adult survivors of childhood cancers ($n = 239$) diagnosed at 14 years of age compared with adults without a history of cancer ($n = 304\ 265$) by using the 2004–2014 National Health Interview Survey. We estimated economic burden using the productivity loss from health-related unemployment, missed work days, missed household productivity, and multivariable regression models controlling for age, sex, race/ethnicity, education, comorbidities, and survey year.

RESULTS: Childhood cancer survivorship is associated with a substantial economic burden. Adult survivors of childhood cancers are more likely to be in poorer health, need assistance with personal care and routine needs, have work limitations, be unable to work because of health, miss more days of work, and have greater household productivity loss compared with adults without a history of cancer (all $P < .05$). The annual productivity loss for adult survivors of childhood cancer is \$8169 per person compared with \$3083 per person for individuals without a history of cancer.

CONCLUSIONS: These findings underscore the importance of efforts to reduce the health and economic burden among adult survivors of childhood cancer. In addition, this study highlights the

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Dr Guy conceptualized and designed the study, carried out the data analysis and interpretation, and drafted the original manuscript; Ms Berkowitz conceptualized and designed the study, carried out the data analysis and interpretation, and critically reviewed the manuscript; Drs Ekwueme and Yabroff and Ms Rim conceptualized and designed the study and critically reviewed the manuscript; and all authors approved the final manuscript as submitted.

FINANCIAL DISCLOSURE: The authors have indicated they have no financial relationships relevant to this article to disclose.

POTENTIAL CONFLICT OF INTEREST: The authors have indicated they have no potential conflicts of interest to disclose.

potential productivity losses that could be avoided during adulthood from the prevention of childhood cancer in the United States.

Each year, ~10 000 children between the ages of 0 and 14 years receive a cancer diagnosis in the United States.¹ As a result of treatment advances, the overall 5-year survival rate for childhood cancer has improved from 57.9% for patients diagnosed between 1975 and 1979 to 83.1% for patients diagnosed between 2003 and 2009.² Although these increases in survival rates represent some of the most impressive accomplishments in oncology, children diagnosed with cancer may experience treatment-related side effects not only during treatment, but also many years after diagnosis. Aggressive treatments used for childhood cancers have resulted historically in a number of late effects, including an increased risk of subsequent cancers and toxicity-related consequences.² Even newer, less toxic therapies increase the risk of serious health conditions among long-term childhood cancer survivors.³ Thus, success in preventing deaths from childhood cancer has not eliminated the tremendous burden of childhood cancer.⁴ Many studies have documented the late effects of treatment, including subsequent cancers, chronic health conditions, cognitive impairments, and functional limitations.^{5–7} Adult survivors of childhood cancers are more likely to be limited in work activities, have difficulties obtaining and maintaining employment, and have higher rates of unemployment.^{6,8,9}

A cancer diagnosis itself, cancer treatment, and other lasting effects associated with having had cancer are associated with substantial productivity loss among cancer survivors.^{6,10–13} However, there are gaps in understanding the lasting economic consequences of surviving childhood cancer. Previous studies have quantified the economic burden of productivity loss among adult cancer survivors diagnosed at all ages¹⁰ and those diagnosed as adolescents and young adults (15–39 years).¹² However, no study, to our knowledge, quantifies the economic burden of productivity loss nationally among adult survivors of childhood cancers diagnosed between ages 0 to 14 years. In this study, we used nationally representative data to estimate the annual indirect morbidity costs among adult survivors of childhood cancers compared with adults without a history of cancer. Examining the long-term economic consequences of surviving cancer among adult survivors of childhood cancers may help guide the development of comprehensive, systems-level intervention programs and highlight the potential productivity losses that could be avoided in adulthood from the prevention of childhood cancer.

METHODS

Data

We examined the health and economic burden of childhood cancer survivorship using data from the 2004–2014 National Health Interview Survey (NHIS) Sample Adult component. NHIS data are collected annually from a nationally representative sample of the civilian, noninstitutionalized population aged ≥18 years in the United States, primarily through in-person household interviews. Data about sociodemographic characteristics, health information, functional limitations, and employment characteristics were collected from adults aged ≥18 years for analysis. During the study period, the final response rate for the Sample Adult component ranged from 58.9% to 72.5%.

Sample weights were applied to account for the complex study design and to reflect probability of selection, adjustments for nonresponse, and poststratification to provide nationally representative estimates. Analyses were conducted by using SAS version 9.3 (SAS Institute, Inc, Cary, NC), SUDAAN version 10.0.1 (RTI International, Research Triangle Park, NC), and Stata version 14 (Stata Corp, College Station, TX).

Study Population

We defined adult survivors of childhood cancers as individuals who were first diagnosed with cancer between the ages of 0 and 14 years. Respondents were asked, “Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?” Respondents who replied yes to that question were then asked about the type of cancer and their age when they were first diagnosed. We identified 239 adult survivors of childhood cancer. When survivors reported an implausible age of diagnosis based on site-specific incidence rates, we assumed that they had misinterpreted the question, and we excluded them.¹³ Adults with no reported history of cancer were placed in the comparison group ($n = 304\ 265$). Individuals with missing data about cancer history were excluded from the analysis. Individuals who were diagnosed solely with nonmelanoma skin cancer were not classified as cancer survivors and were included in the comparison group.^{10,13} Sample characteristics of cancer survivors and adults without a history of cancer at the time of the survey included the following: age, sex, race/ethnicity, educational attainment, marital status, health insurance status, and number of comorbid conditions.

Health Status and Functional Limitations

We examined health status, functional limitations, and productivity loss to assess the health burden among adult survivors of childhood cancers. We assessed self-reported health status (excellent/very good, good, and fair/poor) and 4 measures of functional limitations as a result of physical, mental, or emotional problems: (1) needing the help of others with personal care needs, such as bathing, dressing, or getting around inside the home; (2) needing the help of others in handling routine needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes; (3) being limited in the kind or amount of work that can be done; and (4) being limited in any way. We used multivariable logistic regression modeling to estimate the adjusted percentage of individuals reporting each health status and functional limitation controlling for age, sex, race/ethnicity, education, and number of comorbid conditions. Adjusted estimates are presented as predictive margins, which standardize expenditures to the covariate distribution of the overall population.¹⁴

Annual Productivity Losses

We estimated productivity losses among adult survivors of childhood cancers by examining excess annual indirect morbidity costs, measured by employment disability, missed work days because of health, and days spent in bed because of health during the past year. Employment disability was defined as being unable to work at a job or business because of a physical, mental, or emotional problem. Multivariable logistic regression modeling was used to estimate the adjusted percentage of individuals reporting employment disability controlling for age, sex, race/ethnicity, education, and number of comorbid conditions.

Annual productivity loss from employment disability was estimated by multiplying the adjusted percentage reporting employment disability by the median annual wage in 2014 (\$35 540) from the US Bureau of Labor Statistics.¹⁵

Missed work days were determined by assessing the number of work days missed at a job or business because of illness or injury (not including maternity leave) during the past year. Household productivity loss was assessed by determining the number of days (more than half a day) spent in bed because of illness or injury. Negative binomial regression models were used to estimate the adjusted number of missed work days and days spent in bed controlling for age, sex, race/ethnicity, education, and number of comorbid conditions. Productivity loss from missed work days was calculated as the product of the adjusted average number of missed days and cost per day by using the 2014 median hourly wage (\$17.05) from the US Bureau of Labor Statistics.¹⁵ Because we are not able to differentiate between missed full and partial days, we assumed each missed work day to be 6 hours. Household productivity loss was calculated by multiplying the average number of days spent in bed by the value of daily household productivity (\$44.07),¹⁶ adjusted to 2014 dollars by using the US Consumer Price Index.¹⁷

RESULTS

Characteristics of Adult Survivors of Childhood Cancers

A higher proportion of adult survivors of childhood cancers were aged 18 to 34 years (42%), female (57%), non-Hispanic white (89.1%), not married (56%), and had 1 comorbid conditions (29%) compared with individuals without a history of cancer (Table 1). Survivors of childhood cancers were less likely to be uninsured or have private health insurance and were more likely to have public health insurance (27%). Most survivors (72%) were long-term survivors, diagnosed 20 years before the survey. The most common cancer sites among survivors were leukemia/blood (21%), brain (14%), and lymphoma (9%) (data not shown).

Functional Limitations

Adult survivors of childhood cancers were more likely to be in fair or poor health compared with individuals without a history of cancer (27.5% vs 11.8%; $P < .001$) (Table 2). Survivors of childhood cancers were also more likely than those without a history of cancer to need help with personal care needs (7.6% vs 1.8%; $P < .001$), routine needs (14.5% vs 3.7%; $P < .001$), be limited in the amount or kind of work they can perform because of health (12.8% vs 4.4%; $P < .001$), and be limited in any way (34.4% vs 14.2%; $P < .001$).

Productivity Losses

Adult survivors of childhood cancers were less likely to be employed (54.3% vs 69.6%; $P < .001$) and more likely to report being unable to work because of health (18.7% vs 7.1%; $P < .001$) during the past year (Table 2). Survivors of childhood cancers also reported more missed work days because of health (8.6 days vs 3.7 days; $P = .07$) and more additional days spent in bed because of health (14.6 days vs 4.1 days; $P = .004$) than individuals without a history of cancer.

Among adult survivors of childhood cancers, total annual per capita productivity loss was \$8169 (95% confidence interval [CI]: \$4789–\$11 575) compared with \$3083 (95% CI: \$3032–\$3133) among individuals without a history of cancer ($P < .001$) (Table 3). Annual productivity loss resulting from employment disability accounted for the largest portion of total productivity loss for cancer survivors (\$6646), followed by missed work days (\$880) and household productivity loss (\$643).

DISCUSSION

This study used a nationally representative sample of adult survivors of childhood cancer to assess the lasting economic consequences of surviving childhood cancer. The health and economic burdens among adult survivors of childhood cancers were substantial, resulting in excess annual productivity losses compared with adults without a history of cancer. Adult survivors of childhood cancers were more likely to be in poor health, have functional limitations, including needing help with personal care and routine needs, and have work limitations. Adult survivors of childhood cancers were also less likely to be employed, more likely to be unable to work because of health, and missed more days of work and household productivity during the past year compared with adults without a history of cancer. During 2004 to 2014, the excess annual per capita productivity loss was \$5086 for adult survivors of childhood cancer. Employment disability made up the largest share, accounting for 81.4% of the total productivity loss. These results add to the growing body of literature examining the lasting effects of a childhood cancer diagnosis.^{6,8,18}

Increased productivity losses among cancer survivors can result from the direct health effects of the cancer and its treatment as well as other factors associated with having had cancer. Our findings about poorer health outcomes and greater health limitations among adult survivors of childhood cancers are consistent with the late and lasting effects of cancer and with previous findings in the literature.^{7,19,20} The increased risk of chronic health conditions, including secondary cancers, underscores the importance of continued surveillance among adult survivors of childhood cancer. Despite risk-based guidelines about medical care and cancer screening practices among childhood cancer survivors,^{21,22} research shows that survivors of childhood cancer receive suboptimal levels of regular, risk-based care and recommended cancer screenings.^{23,24} Primary care providers, including pediatricians, can play an important role in the ongoing care of childhood cancer survivors.^{25,26} Ongoing communication among oncology specialists and primary care providers is integral to providing high-quality, risk-based follow-up care among adult survivors of childhood cancers.^{25,26} Childhood cancer survivors have also been shown to engage in risky health behaviors, such as tobacco and alcohol use, and physical inactivity, all of which can further contribute to their health risks as they age.²⁴ Thus, health counseling and the promotion of healthy behaviors are important aspects of long-term follow-up care to promote risk reduction for health problems that may arise during adulthood and mitigate potential productivity losses.^{7,26}

We found substantial limitations in employment and productivity loss among survivors of childhood cancers compared with individuals without a history of cancer. These findings are consistent with previous research indicating higher rates of unemployment and work

limitations among survivors of childhood cancers.^{6,8} A cancer diagnosis during childhood and the late and lasting effects of treatment may interrupt developmental transitions and have a significant influence on educational attainment, potential earnings, and future career development.^{27,28}

In addition to affecting employment outcomes directly, a childhood cancer diagnosis may limit access to employer-sponsored insurance. Survivors of childhood cancers have difficulty obtaining and maintaining health insurance,²⁹ an important component in ensuring access to lifelong, risk-based medical care among this population. Accessing needed medical care is critical for cancer survivors to minimize the adverse sequelae of cancer and any potential productivity losses. The Affordable Care Act (ACA) contains several general provisions, such as the elimination of annual or lifetime coverage limits on essential health benefits and prohibition of coverage exclusions for previous health conditions by insurers, which broaden health insurance coverage to help meet the continuing medical needs of childhood cancer survivors.^{30,31} Although childhood cancer survivors have indicated a preference for many features of the ACA, many, particularly uninsured survivors, are not familiar with the ACA provisions that make insurance more available through the Health Insurance Marketplace or through the expansion of Medicaid eligibility.³² For childhood cancer survivors to benefit from ACA provisions, it is crucial that clinicians, hospitals, and community-based organizations encourage and help survivors to use these benefits.³² Evaluation of continued access to comprehensive health insurance and risk-based care will be important for future research in longitudinal cohorts of childhood cancer survivors.

Although our study uses a population-based, nationally representative sample, several limitations must be acknowledged. First, this study relied on household-reported data, including the identification of cancer survivors, which introduces potential reporting biases. Although the degree of misreporting cannot be determined, studies have shown agreement between household reports and physician-reported conditions.^{33,34} Additionally, our results were robust when including cancer survivors reporting an implausible age of diagnosis. Second, because the cancer diagnosis question refers to cancer or malignancy of any kind, it may include individuals with preinvasive disease, likely resulting in an underestimate of differences between adult survivors of childhood cancers and those without a cancer history. Third, we were unable to examine productivity losses by cancer site given inadequate sample sizes, and we were unable to examine differences by stage of disease at diagnosis, treatments, or recurrence because of the absence of such data in the NHIS. Lastly, our estimates underestimate the total economic burden among adult survivors of childhood cancer because we did not include additional costs, such as those associated with medical care, patient transportation, caregivers' productivity losses, and intangible costs associated with pain and suffering.

CONCLUSIONS

Our study found that the economic burden of cancer survivorship among adult survivors of childhood cancers is substantial, resulting in excess productivity costs compared with individuals without a history of cancer. Our findings underscore the importance of efforts to reduce the health and economic burden among adult survivors of childhood cancers and

highlight the potential productivity losses that could be avoided in adulthood from the prevention of cancer in childhood.

Acknowledgments

FUNDING: All authors are federal government employees, and the preparation of the manuscript was entirely funded by the US Government.

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention or the National Cancer Institute.

ABBREVIATIONS

ACA	Affordable Care Act
CI	confidence interval
NHIS	National Health Interview Survey

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TABLE 1

Characteristics of Adult Survivors of Childhood Cancers and Adults Without a History of Cancer, NHIS, 2004–2014

	Adult Survivors of Childhood Cancers ^a (n = 239)			Adults Without a History of Cancer (n = 304 265)			<i>P</i> ^b
	<i>n</i>	%	95% CI	<i>n</i>	%	95% CI	
Age, y							.001
18–34	92	42	34.1–49.7	90 267	32.3	31.9–32.7	
35–50	72	33	26.0–41.5	90 474	30.6	30.3–30.9	
51–64	32	12	7.7–17.1	67 692	22.2	22.0–22.5	
65	43	13	9.6–18.3	55 832	14.9	14.6–15.1	
Sex							.18
Male	105	43	35.5–51.4	136 428	48.8	48.5–49.0	
Female	134	57	48.6–64.5	167 837	51.2	51.0–51.5	
Race/ethnicity							<.001
Non-Hispanic white	200	89.1	84.4–92.5	182 064	67.8	67.3–68.4	
Other	38	11	7.3–15.4	121 025	31.8	31.3–32.4	
Education							.90
Less than high school graduate	31	13	8.1–20.3	51 789	14.9	14.6–15.2	
High school graduate	66	28	21.0–35.4	81 084	27.3	27.0–27.6	
Some college	82	32	25.0–40.0	89 729	29.9	29.6–30.2	
College degree or higher	59	26	19.6–34.2	79 448	27.2	26.7–27.6	
Marital status							<.001
Married/living together	92	44	36.3–52.2	154 278	61.4	61.0–61.8	
Not married/separated	147	56	47.8–63.7	148 974	38.4	38.0–38.8	
Health insurance							.011
Any private	138	58	49.1–66.2	193 089	67.5	67.1–68.0	
Public only	68	27	20.2–36.0	54 969	14.6	14.3–14.9	
Uninsured	32	15	9.8–21.2	54 701	17.3	17.0–17.6	
No. of comorbid conditions ^c							.002
0	93	42	34.0–50.9	166 886	57.2	56.9–57.6	
1	71	29	22.0–37.3	70 674	23.0	22.8–23.2	
2	75	29	22.0–36.5	66 703	19.8	19.5–20.0	

^a Childhood cancer survivors are those whose first diagnosis of cancer occurred at ages 0–14 y.

^b Calculations of statistical differences were performed with the Wald *F* test. Missing values were excluded from these calculations.

^c Comorbid conditions include: arthritis, chronic bronchitis, diabetes, emphysema, heart disease, hypertension, and stroke.

TABLE 2

Health Status, Functional Limitations, and Productivity Loss Among Adult Survivors of Childhood Cancers and Adults Without a History of Cancer, NHIS, 2004–2014

	Adult Survivors of Childhood Cancers ^a		Adults Without a History of Cancer		
	Adjusted % ^b	95% CI	Adjusted % ^b	95% CI	P
Health status					
Excellent/very good/good	72.5	66.1–78.8	88.2	88.0–88.4	<.001
Fair/poor	27.5	21.2–33.9	11.8	11.6–11.9	<.001
Functional limitations					
Needs help with personal care needs	7.6	3.7–11.5	1.8	1.7–1.9	<.001
Needs help with routine needs	14.5	8.9–20.1	3.7	3.6–3.8	<.001
Limited in amount/kind of work because of health	12.8	6.8–18.9	4.4	4.3–4.5	<.001
Limited in any way	34.4	27.4–41.5	14.2	14.0–14.4	<.001
Productivity loss					
Employed during the past 12 mo	54.3	47.5–61.1	69.6	69.4–69.9	<.001
Unable to work because of health	18.7	13.0–24.5	7.1	7.0–7.2	<.001
Days lost from work because of health, past 12 mo	8.6	0.7–16.4	3.7	3.6–3.8	.07
Days spent in bed because of health, past 12 mo	14.6	2.2–27.0	4.1	4.0–4.2	.004

^a Childhood cancer survivors are those whose first diagnosis of cancer occurred between ages 0–14 y.

^b Regressions controlled for age, sex, race/ethnicity, education, number of comorbid conditions, and survey year.

TABLE 3

Annual Productivity Loss Among Adult Survivors of Childhood Cancers and Adults Without a History of Cancer, NHIS, 2004–2014

	Adult Survivors of Childhood Cancers ^a		Adults Without a History of Cancer		P
	Adjusted Productivity Loss, \$ ^{b,c}	95% CI	Adjusted Productivity Loss, \$ ^{b,c}	95% CI	
Total per capita productivity loss ^b	8169	4789–11 575	3083	3032–3133	<.001
Type of productivity loss ^c					
Employment disability ^d	6646	4620–8707	2523	2488–2559	<.001
Missed work days ^e	880	72–1678	379	368–389	.07
Household productivity ^f	643	97–1190	181	176–185	.004

^a Childhood cancer survivors are those whose first diagnosis of cancer occurred between ages 0–14 y.

^b All monetary units are in 2014 US dollars.

^c Regressions controlled for age, sex, race/ethnicity, education, and number of comorbid conditions.

^d Median annual wage in 2014 (\$35 540) multiplied by the adjusted percentage unable to work because of health.

^e Median daily wage in 2014 (\$17.05) multiplied by 6 h and the adjusted average number of days lost from work.

^f Value of daily lost household productivity (\$44.07) multiplied by the adjusted number of days spent in bed.