Unemployment among Adult Survivors of Childhood Cancer: A report from the Childhood Cancer Survivors Study

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Abstract

Background—Adult childhood cancer survivors report high levels of unemployment although it is unknown whether this is due to health or employability limitations.

Objectives—We examined two employment outcomes from 2002–2005 in the Childhood Cancer Survivor Study (CCSS): 1. health-related unemployment and 2. unemployed but seeking work. We compared survivors to a nearest-age CCSS sibling cohort and examined demographic and treatment-related risk groups for each outcome.

Methods—We studied 6339 survivors and 2280 siblings aged ≥ 25 years excluding those unemployed by choice. Multivariable generalized linear models evaluated whether survivors were more likely to be unemployed than siblings and whether certain survivors were at a higher risk for unemployment.

Results—Survivors (10.4%) reported health-related unemployment more often than siblings (1.8%; Relative Risk [RR] 6.07, 95% Confidence Interval [CI] 4.32–8.53). Survivors (5.0%) were more likely to report being unemployed but seeking work than siblings (2.7%; RR 1.90, 95% CI 1.43–2.54). Health-related unemployment was more common in female survivors than males (Odds Ratio [OR] 1.73, 95% CI 1.43–2.08). Cranial radiotherapy doses ≥ 25 Gy were associated with higher odds of unemployment (health-related: OR 3.47, 95% CI 2.54–4.74; seeking work: OR 1.77, 95% CI 1.15–2.71). Unemployed survivors reported higher levels of poor physical functioning than employed survivors, and had lower education and income and were more likely to be publicly insured than unemployed siblings.

Conclusions—Childhood cancer survivors have higher levels of unemployment due to health or being between jobs. High-risk survivors may need vocational assistance.

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Introduction

Since the mid-1960s, childhood cancer mortality has decreased substantially due to new and improved treatments and advancements in supportive care.[1, 2] In the United States, there are an estimated 328,652 cancer survivors who were diagnosed with cancer when younger than 21 years of age.[3] Childhood cancer survivors are almost two times more likely to be unemployed as adults when compared to siblings or healthy comparisons.[4] Earlier analyses of data from the Childhood Cancer Survivor Study (CCSS) cohort indicated that 15% of survivors compared to 8% of siblings were unemployed in the previous 12 months.[5] Evaluating reasons for unemployment among childhood cancer survivors is a growing priority because the majority of survivors in the United States are of working age or approaching working age.[6] Only 4% are 60 years of age or older, while 65% of survivors are 20 to 59 years, and 31% are 0 to 19 years.[3]

Childhood cancer may impact adult employment status through many pathways. Survivors often have chronic diseases, mental and physical limitations, and cancer recurrence or secondary cancers[7–10] that adversely affect their educational opportunities and employment.[11, 12] These late effects may influence the ability for some survivors to work consistently or to hold certain jobs during adulthood. Cancer may also alter survivors' educational and work-related intentions, while concerns for the future may impact their ability to transition into education and employment.[13, 14] Central nervous system tumor (CNS) survivors are most likely to have long-term complications from treatments[15–17] and elevated rates of being unemployed as adults.[4, 5] Earlier age of diagnosis and history of radiotherapy – especially to the brain – are also associated with lower levels of employment.[4, 5]

We developed the current analysis to identify the demographic, treatment and cancer-related factors that may be driving higher unemployment among childhood cancer survivors. We also wanted to understand the specific contributions of health problems, disability, job loss or lifestyle choices to unemployment in this population. Our analysis looked at two unemployment outcomes that have not been previously described among childhood cancer survivors[4, 5]: 1) unemployed because of health or disability (described here as "health-related unemployment"), and 2) unemployed but actively seeking employment. Information gained from this analysis will both guide researchers as they design employment interventions specific to the needs of childhood cancer survivors, and will inform policy makers and clinicians about the resource needs of these survivors as they seek employment.

In these analyses, we compare unemployment outcomes among childhood cancer survivors to a similarly aged cohort of siblings. We hypothesized that survivors would be more likely to report health-related unemployment and to be unemployed but seeking work than siblings. We hypothesized that survivors of CNS tumors and survivors treated with cranial radiation would more often report the two unemployment outcomes. We also evaluated the associations between employment status and other socioeconomic indicators, including income, health insurance coverage, educational attainment, physical health and mental health.

Methods

Participants and Procedures

The CCSS is a multi-institutional research initiative started in 1994 to investigate health outcomes in childhood and adolescent cancer survivors. The original cohort includes 14,357 participants diagnosed with cancer when younger than age 21 years and a randomly selected group of siblings (N=3,418).[18] Participants were diagnosed between January 1, 1970 and

December 31, 1986 and had survived at least five years from the time of diagnosis.[19, 20] Eligible diagnoses included leukemia, CNS malignancies (all histologies), Hodgkin's lymphoma (HL), non-Hodgkin lymphoma (NHL), kidney cancer, neuroblastoma, soft tissue sarcoma, or malignant bone tumor. The Human Subjects Committees at the 26 participating institutions approved the CCSS protocol and participants provided formal consent for data collection.

CCSS survivors and siblings have completed a baseline survey (1994–96) and four follow-up surveys. The current analyses were based on data from the second follow-up survey (referred to as Follow-up 2003, although completed from 2002–2005) that contained the most detailed unemployment information. We obtained information on cancer type, treatments received, and clinical characteristics of the survivors from medical records.

There were 9289 survivors and 2792 siblings who completed the 2003 CCSS assessment (Appendix 1). Because the oldest eligible survivors were 54 years and siblings 58 years, we used no upper age limit. We excluded the 2060 survivors and 502 siblings ages 25 years or younger at the time of the 2003 survey because of potential differences in employment status for participants still in school. We eliminated the 85 survivors and 10 siblings with missing employment information, leaving 7144 survivors and 2280 siblings. We limited our sample based on the Bureau of Labor Statistics (BLS) definition of the labor force as the sum of employed and unemployed persons, excluding those "unemployed by choice" (retired persons, students, those taking care of children or other family members and others who are neither working or seeking work),[21] for analysis sample size of 6339 survivors and 1967 siblings.

Measures

We created two mutually-exclusive outcomes: 1) health-related unemployment (being unable to work due to illness or disability) or 2) unemployed but seeking work. The CCSS survey asked participants to select all categories that applied to their current employment status. Other choices included full-time (30 hours per week) or part-time (<30 hours per week) employment; caring for home or family and not seeking work; retired; student; and other. Because participants were asked to choose all employment categories that applied, we assumed that health status was the primary cause of unemployment for those who selected being unable to work due to illness or disability, unless they also reported being unemployed but seeking work. If this choice was selected, seeking work was considered the primary unemployment outcome. We considered participants unemployed by choice if they reported being a student, retired, caring for home or family, or otherwise unemployed but not seeking work.

Other measures included demographic and cancer-related variables as listed in Table 2. For the survivor-specific analyses, we included both cancer recurrence and secondary cancers (not including nonmelanoma skin cancers) to account for subsequent malignancies. Age at diagnosis was categorized at 4 years of age or younger based on the earlier CCSS employment analyses.[5] We documented chemotherapy and specific types of chemotherapeutic agents (alkylating agents, anthracyclines, bleomycin, and cisplatin), and radiation and the location of radiation by specific body regions.

For cranial doses, we created a 7 level categorical variable: 1. no radiation; 2. scatter low (no treatment to head/brain, but patient received radiation to some part of the body [dose range >0 to <1 Gy]); 3. scatter high (no direct treatment to head/brain segment, but treatment was nearby [dose range 1 to 5 Gy]); 4. Less than 18 Gy; 5. 18–24 Gy; 6. 25–34 Gy; 7. Greater than or equal to 35 Gy. Surgeries included amputations, limb-sparing procedures, and central nervous system tumor resections. Using the Short Form 36 Health Survey (SF-36)

physical (PCS) and mental (MCS) function component scores, we created binary variables (>40=normal; 40=low) to indicate low physical or mental functioning (T-scores 1 SD below the US population norm of 50).[22, 23] Because only a random sample of 500 siblings were given the SF-36, we lacked enough responses for sibling comparison by employment.

Statistical analyses

We compared overall demographic characteristics of survivors and siblings. Proportions were calculated for the demographic, and where relevant, cancer and treatment characteristics, of survivors and siblings by employment status.

To compare survivors and siblings, we used multivariable relative risk regression for the two primary outcomes of interest. We calculated the relative risk [RR] and 95% confidence intervals [95% CI] with clustering by family to account for survivors with a sibling.[24] Relative risk regression was used to directly estimate relative risks rather than an odds ratio approximation because of the high proportion of unemployment for certain cancers. Our main analyses adjusted only for age, sex, and race because other variables related to employment, such as income, may mediate the relationship of these variables. As a secondary analysis, we further adjusted for demographic differences by including a propensity score comprised of the demographic variables in Table 1. Models were fit to examine the eight cancer diagnoses in reference to siblings. Because we were interested in the categories of health-related unemployment and unemployed but seeking work in relationship to the potential labor force, we assessed the two outcomes in reference to a combined category of full- and part-time employment plus the other outcome.

In analyses limited to cancer survivors, we used multivariable logistic regression[24] to generate odds ratios (OR) and 95% CI to examine the associations between demographic, cancer and treatment-related factors and the two outcomes. Our survivor-specific analyses did not include cancer diagnosis because treatment is highly correlated with cancer type (e.g., CNS tumor resection in CNS tumor patients) and because we hypothesized that employment status would be more sensitive to treatment effects. Our final models were developed based on the literature and the influence of highly related treatment variables on the regression estimates. The highest doses of cranial radiation (25–34 Gy and 35 Gy) were grouped after examination in the multivariable models. Because employment differs by sex,[5] we fit separate models for males and females.

We also examined bivariate associations between education, health insurance coverage, household income, and physical and mental health functioning (as determined by SF-36 PCS and MCS scores) by employment status. Analyses were performed using Stata version 11.0 (Stata Corp, College Station, TX). All reported p-values are two-sided and considered significant at α=0.05.

Results

Characteristics of the study population

Eleven percent of survivors and 14% of siblings (P=0.005) were unemployed by choice and were excluded from subsequent analyses. Excluding those unemployed by choice, health-related unemployment was reported by 10.4% of survivors and 1.8% of siblings (P<0.001). Survivors were the most likely to be unemployed but seeking work (5.0% vs. 2.7% of siblings, P<0.001).

Table 1 presents the demographic characteristics for the survivor and sibling samples. Mean (standard deviation) age in years was 34.2(6.2) and 36.1(7.2), respectively. Survivors were younger (56% age 25–34 vs. 45% for siblings; P<0.001), more often male (55% vs. 50%

P<0.001), and less likely to report their race as White than siblings (87% vs. 92%; P<0.001). In Table 2, female survivors were more likely to report health-related unemployment than males (13% vs. 8%; P<0.001). CNS tumor patients reported the highest proportion of health-related unemployment (25% compared to 6%–13% for other cancers; P<0.001) and were also most likely to report being unemployed but seeking work (10% compared to 3%–6% for other cancers; P<0.001). Associations between radiation sites (besides cranial radiation) and chemotherapeutic agents and employment status were not statistically significant in regression analyses and are not reported.

Employment status of survivors and siblings

In multivariable comparisons adjusted for age, sex and race, survivors were 6 times more likely to report health-related unemployment than siblings (RR 6.07, 95% CI 4.32–8.53) (Figure 1). The likelihood of health-related unemployment was significantly increased for all cancer types when compared to siblings, but was highest for CNS tumors (RR 14.84, 95% CI 10.42–21.14). Survivors were also at a higher risk of being unemployed but seeking work compared to siblings (RR 1.90, 95% CI 1.43–2.54). The risk of seeking work was increased for all cancers when compared to siblings except for Hodgkin's lymphoma, neuroblastoma and soft tissue sarcoma. When we included all demographics in the propensity score (results not shown in figure), survivors continued to be at higher risk (health-related unemployment RR 4.02 (95% CI 2.73, 5.94); seeking work RR 1.57 (95% CI 1.13, 2.20)).

Survivor-specific analyses

In multivariable analyses, female survivors were 73% more likely to report health-related unemployment than male survivors (Table 3). Black, Hispanic and Other/mixed race survivors were all significantly more likely to report health-related unemployment than White survivors (Odds Ratios 1.89, 1.66, and 1.43, respectively). Longer time since diagnosis conferred an increased risk of health-related unemployment (test of trend P<0.001). Higher doses of cranial radiation were associated with health-related unemployment (18–24 Gy: OR 1.45, 95% CI 1.06–1.98 and   25 Gy: OR 3.47 95% CI 2.54–4.74; test of trend P<0.001) when compared to survivors who had no cranial radiation. CNS tumor resection (OR 2.01, 95% CI 1.53–2.66), amputations (OR 2.18, 95% CI 1.54–3.10) and limb-sparing surgeries (OR 4.23, 95% CI 2.33–7.69) all conferred higher odds of health-related unemployment.

For the unemployed but seeking work outcome (Table 3), the highest dose of cranial radiation (25 Gy) was significant (OR 1.77, 95% CI 1.15–2.71) when compared to patients without radiation. No other treatment variables were significant. In sex-stratified models (results not shown in tables), Black (OR 3.09, 95% CI 1.45–6.57), Hispanic (OR 2.32, 95% CI 1.22–4.44) and Mixed/Other (OR 2.21, 95% CI 1.23–3.68) female survivors were all significantly more likely than White females to be unemployed but seeking work, whereas no differences existed for males or for siblings.

Socioeconomic characteristics and SF-36 PCS and MCS

Survivors reporting health-related unemployment and who were unemployed but seeking work (Figure 2) were more likely to have a high school education or less compared to their sibling counterparts (49% vs. 26% and 27% vs. 17%, respectively; overall P<0.001). Although survivors reporting health-related unemployment had any health insurance coverage at a similar proportion to siblings (83% vs. 84%, not shown), over 70% of these survivors compared to 54% of siblings had public health insurance. Public insurance also differed for those unemployed but seeking work (survivors 29% vs. siblings 7%; overall P<0.001). For the SF-36, 70% of survivors reporting health-related unemployment also

reported low physical functioning (PCS 40) compared to 19% of those seeking work and 11% of those working (overall P<0.001). For mental health, 36% of survivors of both unemployment groups had MCS scores 40 compared to 15% of employed (P<0.001).

Discussion

This study adds to the growing literature on unemployment among survivors of childhood cancer by examining specific reasons for unemployment. We found that survivors are more often unemployed because of health problems and disabilities than are siblings. Survivors were more likely to be unemployed but seeking work than siblings and these differences were significant even after adjusting for demographic characteristics.

The highest risk of health-related unemployment was seen in survivors treated with higher doses of cranial radiation and certain surgeries, exposures with known associations to risks of long-term neurocognitive dysfunction or physical disability. Survivors with a longer duration since treatment, with more time to develop secondary cancers or chronic conditions, were also at an increased risk. Although not presented in our results because of the high correlation with duration since treatment, we found that survivors treated during 1978–1986 were between 25%–45% less likely to report health-related unemployment than those treated before 1978.

Female survivors may be at particular risk for poor employment outcomes. Women in the general US population, especially those of racial or ethnic minority populations, are more likely to be in poor health and unemployed.[25] We found no differences in employment by sex for siblings but higher levels of health-related unemployment among female survivors and higher levels of being unemployed but seeking work among minority female survivors. Female survivors report poorer health outcomes and have a higher risk of neurocognitive impairment than males.[26, 27] As a result, there may be many female survivors who want to work but face health- or employability-related barriers. Future research should also assess whether female survivors face differential barriers to returning to work after having children than female siblings.

Unemployed survivors may be the most vulnerable of the adult population of childhood cancer survivors. Those unable to work or who are intermittently employed may face both economic hardship and problems obtaining or keeping health insurance coverage.[28, 29] We found that both groups of unemployed survivors were more likely than unemployed siblings to have a high school education or less and public health insurance. Survivors in both unemployment groups also reported higher levels of poor physical functioning than currently employed survivors, which may be driven by chronic health conditions.[9, 16] Mental health status did not differ as strikingly between unemployed and employed, suggesting that physical limitations may be one of the biggest factors determining whether or not a survivor is able to work.

Our results suggest that employment interventions for this population should be tailored to address the specific needs of individual survivors. Survivors reporting health or disability-related unemployment may need intensive job training programs and screening for sensory, physical or mental health problems to provide them with strategies to address their limitations in the workplace. Some of these survivors, such as those with a history of high-dose cranial radiation, may have neurocognitive impairments that make working impossible. These individuals could benefit from assistance in obtaining disability benefits. Survivors who are unemployed but seeking work due to their cancer or treatment history may need job placement assistance, career counseling or training in communicating with prospective employers about necessary job-related accommodations. Many childhood cancer survivors

do not receive cancer-focused follow-up care,[30] suggesting that interventions to improve employment outcomes should be coupled with innovative strategies to reach childhood cancer survivors through web- or telephone-based programs.

This study has limitations that should be considered in the interpretation of its findings. We had no information on childhood socioeconomic status, which is correlated with adult employment, but we provide control for a shared environment during childhood by comparing the survivors to a sibling cohort. Because the CCSS is drawn from major US cancer centers, the survivors and siblings are of higher socioeconomic status than the general population, which may limit the generalizability of the findings to other populations of childhood cancer survivors.

Beyond the medical and physical consequences of cancer treatment, childhood cancer survivors are at risk for long-term social and economic limitations. A pediatric cancer patient who is cured of their disease might expect to have a life expectancy of 70–80 years. While survivors are protected under the Americans with Disabilities Act (ADA) and other state and federal laws from employment discrimination,[31] many may not know their employment rights or realize that workplace accommodations for health problems are possible. Additionally, assessing the specific health and employability reasons related to obtaining and maintaining employment for survivors warrants exploration in longitudinal studies. The employment needs of survivors may change over time depending on their current health status and should be continually evaluated. The long-term follow-up guidelines from the Children's Oncology Group (http://www.survivorshipguidelines.org) recommend periodic monitoring of survivors for educational or vocational delays and should be expanded to include recommendations for evaluating survivors at high risk for poor employment outcomes. Because employment conveys health and social benefits, apart from other benefits such as access to health insurance coverage, improving employment opportunities for survivors of childhood cancer should be given a higher priority in cancer follow-up.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

APPENDIX

The Childhood Cancer Survivor Study (CCSS) is a collaborative, multi-institutional project, funded as a resource by the National Cancer Institute, of individuals who survived five or more years after diagnosis of childhood cancer. CCSS is a retrospectively ascertained cohort of 20,346 childhood cancer survivors diagnosed before age 21 between 1970 and 1986 and approximately 4,000 siblings of survivors, who serve as a control group. The cohort was assembled through the efforts of 26 participating clinical research centers in the United States and Canada. The study is currently funded by a U24 resource grant (NCI grant # U24 CA55727) awarded to St. Jude Children's Research Hospital. Currently, we are in the process of expanding the cohort to include an additional 14,000 childhood cancer survivors diagnosed before age 21 between 1987 and 1999. For information on how to access and utilize the CCSS resource, visit www.stjude.org/ccss

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References

1. American Cancer Society. Cancer Facts and Figures, 2009. Atlanta, GA: American Cancer Society; 2009.

2. Ries, LAG.; Smith, MA.; Gurney, JG., editors. Cancer incidence and survival among children and adolescents: United States SEER Program 1975–1995. Bethesda, MD: National Institutes of Health; 1999.

3. Mariotto AB, Rowland JH, Yabroff KR, et al. Long-Term Survivors of Childhood Cancers in the United States. Cancer Epidemiol Biomarkers Prev. 2009; 18:1033–1040. [PubMed: 19336557]

4. de Boer AG, Verbeek JH, van Dijk FJ. Adult survivors of childhood cancer and unemployment: A metaanalysis. Cancer. 2006; 107:1–11. [PubMed: 16718655]

5. Pang JW, Friedman DL, Whitton JA, et al. Employment status among adult survivors in the Childhood Cancer Survivor Study. Pediatr Blood Cancer. 2008; 50:104–110. [PubMed: 17554791]

6. Institute of Medicine. Childhood Cancer Survivorship: Improving Care and Quality of Life. Washington, D.C.: National Academies Press; 2003.

7. Diller L, Chow EJ, Gurney JG, et al. Chronic disease in the Childhood Cancer Survivor Study cohort: a review of published findings. J Clin Oncol. 2009; 27:2339–2355. [PubMed: 19364955]

8. Ness KK, Mertens AC, Hudson MM, et al. Limitations on physical performance and daily activities among long-term survivors of childhood cancer. Ann Intern Med. 2005; 143:639–647. [PubMed: 16263886]

9. Oeffinger KC, Mertens AC, Sklar CA, et al. Chronic health conditions in adult survivors of childhood cancer. N Engl J Med. 2006; 355:1572–1582. [PubMed: 17035650]

10. Meadows AT, Friedman DL, Neglia JP, et al. Second neoplasms in survivors of childhood cancer: findings from the Childhood Cancer Survivor Study cohort. J Clin Oncol. 2009; 27:2356–2362. [PubMed: 19255307]

11. Mitby PA, Robison LL, Whitton JA, et al. Utilization of special education services and educational attainment among long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Cancer. 2003; 97:1115–1126. [PubMed: 12569614]

12. Gurney JG, Krull KR, Kadan-Lottick N, et al. Social Outcomes in the Childhood Cancer Survivor Study Cohort. J Clin Oncol. 2009

13. Zebrack BJ, Chesler M. Health-related worries, self-image, and life outlooks of long-term survivors of childhood cancer. Health Soc Work. 2001; 26:245–256. [PubMed: 11758866]

14. Zeltzer LK. Cancer in adolescents and young adults psychosocial aspects. Long-term survivors. Cancer. 1993; 71:3463–3468. [PubMed: 8490896]

15. Pogany L, Barr RD, Shaw A, Speechley KN, Barrera M, Maunsell E. Health status in survivors of cancer in childhood and adolescence. Qual Life Res. 2006; 15:143–157. [PubMed: 16411038]

16. Hudson MM, Mertens AC, Yasui Y, et al. Health status of adult long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. Jama. 2003; 290:1583–1592. [PubMed: 14506117]

17. Reulen RC, Winter DL, Lancashire ER, et al. Health-status of adult survivors of childhood cancer: a large-scale population-based study from the British Childhood Cancer Survivor Study. Int J Cancer. 2007; 121:633–640. [PubMed: 17405119]

18. Leisenring WM, Mertens AC, Armstrong GT, et al. Pediatric Cancer Survivorship Research: Experience of the Childhood Cancer Survivor Study. J Clin Oncol. 2009

19. Robison LL, Mertens AC, Boice JD, et al. Study design and cohort characteristics of the Childhood Cancer Survivor Study: a multi-institutional collaborative project. Med Pediatr Oncol. 2002; 38:229–239. [PubMed: 11920786]

20. Robison LL, Armstrong GT, Boice JD, et al. The Childhood Cancer Survivor Study: A National Cancer Institute-Supported Resource for Outcome and Intervention Research. J Clin Oncol. 2009

21. [Accessed September 1, 2009] U.S. Department of Labor, Labor Force Characteristics. 2009. at http://www.bls.gov/cps/lfcharacteristics.htm#laborforce

22. Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. Med Care. 1992; 30:473–483. [PubMed: 1593914]

23. Ware, JE., Jr; Kosinski, M.; Keller, SD. SF-36 Physical and Mental Health Summary Scales: A User's Manual. Boston: The Health Institute; 1994.

24. Hosmer, DW.; Lemeshow, L. Applied logistic regression. 2nd ed. John Wiley and Sons; 2000.

25. Wagener DK, Walstedt J, Jenkins L, Burnett C, Lalich N, Fingerhut M. Women: work and health. Vital Health Stat. 1997; 3:1–91.

26. Ellenberg L, Liu Q, Gioia G, et al. Neurocognitive status in long-term survivors of childhood CNS malignancies: a report from the Childhood Cancer Survivor Study. Neuropsychology. 2009; 23:705–717. [PubMed: 19899829]

27. Duffner PK. Long-term effects of radiation therapy on cognitive and endocrine function in children with leukemia and brain tumors. Neurologist. 2004; 10:293–310. [PubMed: 15518596]

28. Crom DB, Lensing SY, Rai SN, Snider MA, Cash DK, Hudson MM. Marriage, employment, and health insurance in adult survivors of childhood cancer. J Cancer Surviv. 2007; 1:237–245. [PubMed: 18648974]

29. Park ER, Li FP, Liu Y, et al. Health insurance coverage in survivors of childhood cancer: the Childhood Cancer Survivor Study. J Clin Oncol. 2005; 23:9187–9197. [PubMed: 16361621]

30. Nathan PC, Greenberg ML, Ness KK, et al. Medical care in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. J Clin Oncol. 2008; 26:4401–4409. [PubMed: 18802152]

31. Short PF, Vargo MM. Responding to employment concerns of cancer survivors. J Clin Oncol. 2006; 24:5138–5141. [PubMed: 17093276]
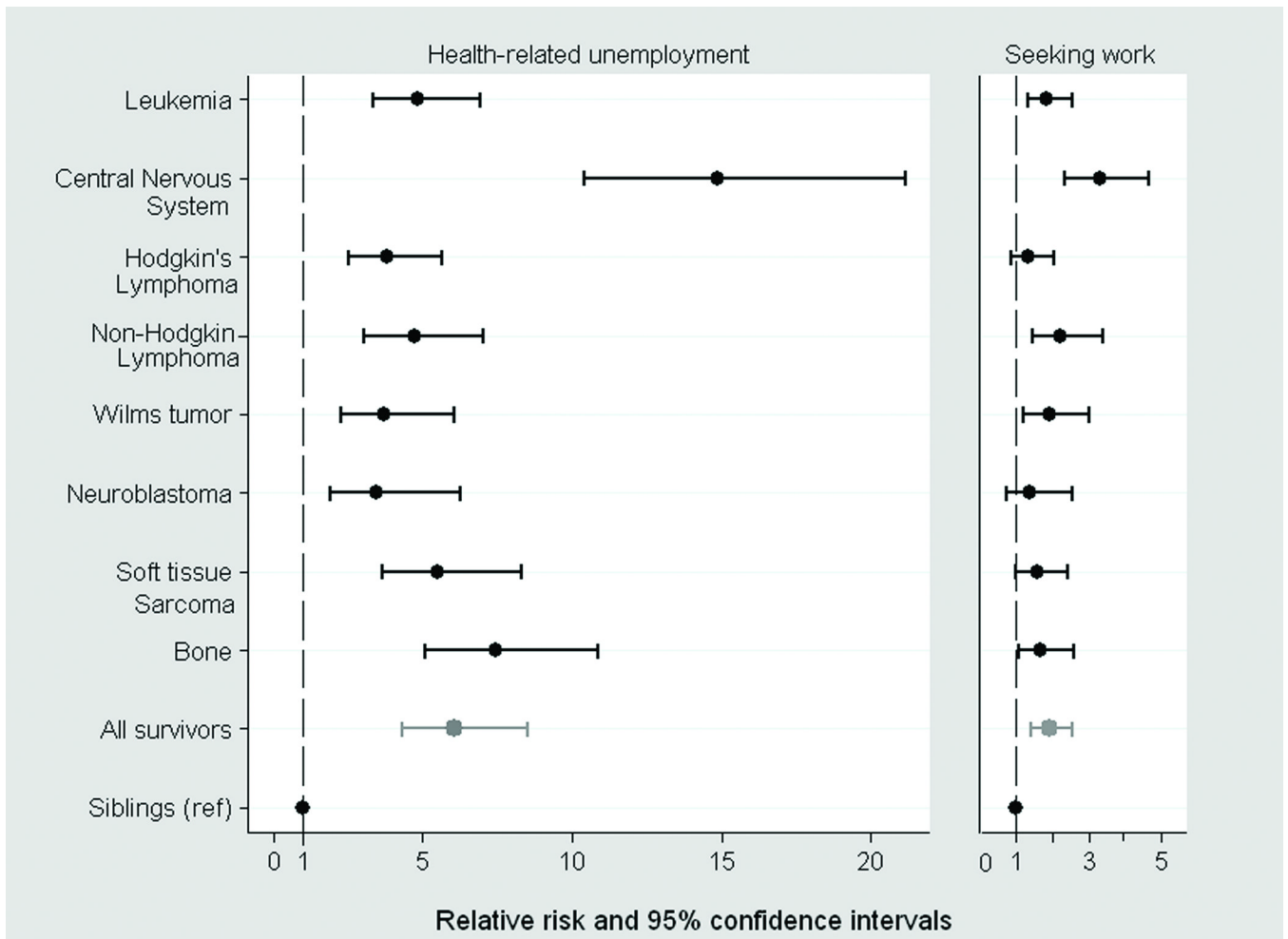
Figure 1. Relative Risk and 95% Confidence Interval (CI) of health-related unemployment and unemployed but seeking work for survivors of specific cancers type compared to siblings*
*Adjusted for current age, sex and race. Regressions for all survivors vs. siblings and for specific cancer diagnoses were performed using generalized linear models clustered by the survivor-siblings pairs to generate relative risk estimates because of the high proportion of central nervous system tumor patients and bone tumor patients reporting health-related unemployment (25% and 13%, respectively).
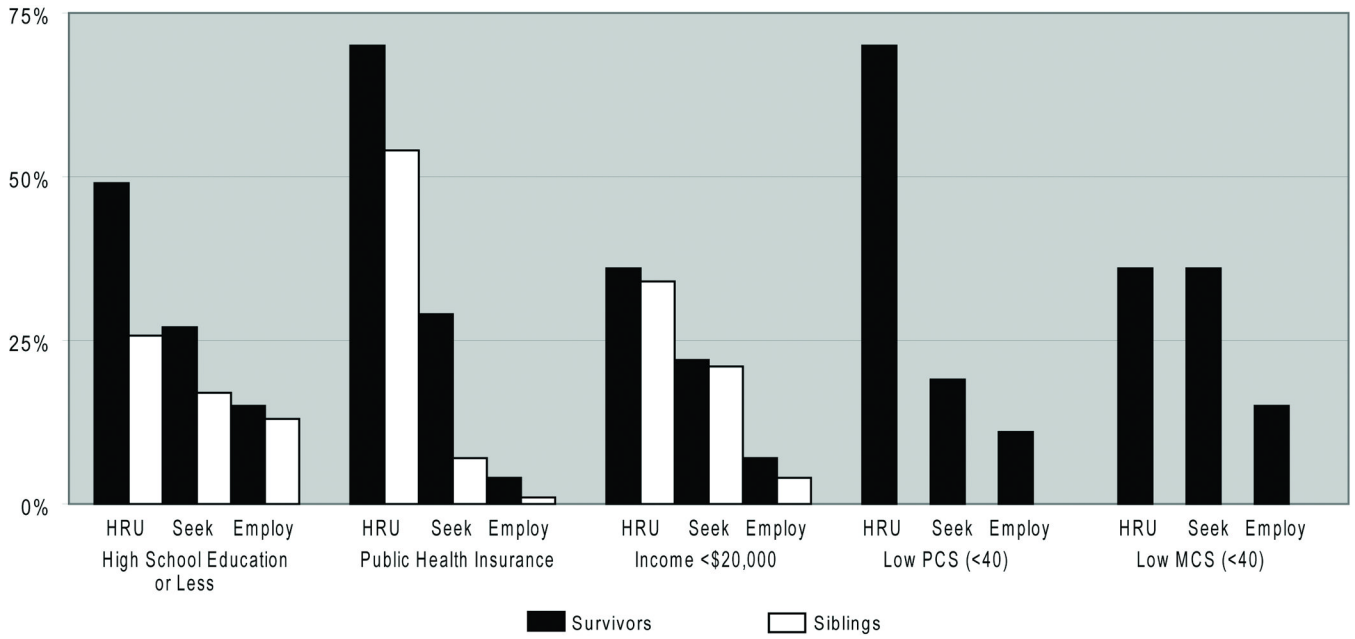
Figure 2. Percent reporting selected socioeconomic characteristics by survivors and siblings and percent with low SF-36 physical (PCS) and mental (MCS) component scores for survivors by employment*
*Because a random sample of siblings was given the SF-36 questions, we lacked enough responses for SF-36 calculation for siblings.

Table 1

Demographic characteristics of adult survivors of childhood cancer and siblings

Demographics	Survivors N=6339		Siblings N=1967	
	N	%	N	%
Current age (years)				
25–34	3584	56	883	45
35–44	2196	35	757	38
45+	559	9	327	17
Sex				
Male	3499	55	992	50
Female	2840	45	975	50
Race[†]				
White, non-Hispanic	5485	87	1763	92
Black, non-Hispanic	205	3	37	2
Hispanic	219	3	50	3
Other/mixed	413	7	50	3
Education[‡]				
High school education or less	1181	19	254	13
Some college or more	5109	81	1707	87
Marital status[§]				
Married	3053	48	1236	63
Not married	3264	52	721	37
Household Income[‖]				
<$20,000	658	11	94	5
$20,000	5150	89	1797	95
Children				
Yes	2250	35	1143	58
No	4089	65	824	42
Health Insurance[¶]				
Yes	5232	83	1640	84
Canadian	403	6	174	9
No	655	11	149	8

[*] All survivor-sibling comparisons significant at P<0.001.

[†] Race/ethnicity reported by 6,322 survivors and 1,900 siblings.

[‡] Highest achieved education reported by 6,290 survivors and 1,961 siblings.

[§] Marital status reported by N=6,317 survivors and N=1,957 siblings.

[‖] Income reported by N=5,808 survivors and N=1,891 siblings.

[¶] Health insurance reported by N=6,290 survivors and N=1,963 siblings.

Table 2

Demographic characteristics of survivors and siblings and treatment characteristics for survivors by employment status

| | Survivors N=6339 Percents calculated across variable category rows* | | | | | | | Siblings N=1967 Percents calculated across variable category rows* | | | | | | |
| | N | Health-related unemployment N=660 (10%) | | Unemployed seeking work N=361 (6%) | | Employed full or part-time N=5318 (84%) | | N | Health-related unemployment N=35 (2%) | | Unemployed seeking work N=54 (3%) | | Employed full or part-time N=1878 (95%) | |
		N	%	N	%	N	%	N	N	%	N	%	N	%
Current age (years)														
25–34	3584	339	9	246	7	2999	84	883	15	2	21	2	847	96
35–44	2196	258	12	94	4	1844	84	757	13	2	26	3	718	95
45+	559	63	11	21	4	475	85	327	7	2	7	2	313	96
Sex														
Male	3499	297	8	184	5	3018	86	992	14	3	27	1	951	96
Female	2840	363	13	177	6	2300	81	975	21	2	27	3	927	95
Race														
White, non-Hispanic	5485	533	10	288	5	4664	85	1763	33	2	41	2	1689	96
Black, non-Hispanic	205	37	18	19	9	149	73	37	0	0	3	8	34	92
Hispanic	219	31	14	17	8	171	78	50	1	2	6	12	43	86
Other/mixed	413	56	14	35	8	322	78	50	0	0	2	4	48	96
Education														
High school	1181	305	26	98	8	778	66	254	9	4	9	4	236	93
>High school	5109	324	6	261	5	4524	89	1707	26	2	45	3	1636	96
Marital status														
Married	3053	153	5	103	3	2797	92	1236	14	1	22	2	1200	97
Not married	3264	505	15	257	8	2502	77	721	20	3	31	4	670	93
Household Income														
<$20,000	658	224	34	78	12	356	54	94	12	13	11	12	71	76
$20,000	5150	306	6	224	4	4620	90	1797	20	1	36	2	1741	97
Children														
Yes	2250	178	8	98	4	1974	88	1143	17	1	25	2	1101	96
No	4089	482	12	263	6	3344	82	824	18	2	29	4	777	94
Health Insurance														

	Survivors N=6339 Percents calculated across variable category rows[*]					Siblings N=1967 Percents calculated across variable category rows[*]					
	N	Health-related unemployment N=660 (10%)		Unemployed seeking work N=361 (6%)		Employed full or part-time N=5318 (84%)		N	Health-related unemployment N=35 (2%)		Unemployed seeking work N=54 (3%)		Employed full or part-time N=1878 (95%)
	N	N	%	N	%	N	%	N	N	%	N	%	N	%
Yes	5232	519	10	194	4	4519	86	1640	26	2	30	2	1584	97
Canadian	403	50	12	30	7	323	80	174	1	1	4	2	169	97
No	655	80	12	129	20	446	68	122	7	5	20	13	122	82
Diagnosis		N	%	N	%	N	%	NA						
Leukemia	1984	162	8	115	6	1707	86							
CNS	795	200	25	78	10	517	65							
HL	1013	70	7	35	3	908	90							
NHL	568	42	7	35	6	491	86							
Wilms tumor	434	27	6	27	6	380	88							
Neuroblastoma	262	15	6	12	5	235	90							
Soft tissue sarcoma	624	57	9	28	4	539	86							
Bone cancer	659	87	13	31	5	541	82							
Age at diagnosis								NA						
4 years	1703	186	11	108	6	1409	83							
>4 years	4636	474	10	253	5	3909	84							
Cancer recurrence								NA						
Yes	39	7	18	3	8	29	74							
No	6300	653	10	353	6	5289	84							
Secondary cancers								NA						
Yes	284	45	16	18	6	221	78							
No	6055	615	10	343	6	5097	84							
Years since diagnosis								NA						
20	1428	125	9	95	7	1208	85							
21–30	3979	409	10	230	6	3340	84							
>30	932	126	14	36	4	770	83							
Treatment era								NA						
1970–73	1042	138	13	42	4	862	83							

	Survivors N=6339 Percents calculated across variable category rows*							Siblings N=1967 Percents calculated across variable category rows*						
	N	Health-related unemployment N=660 (10%)		Unemployed seeking work N=361 (6%)		Employed full or part-time N=5318 (84%)		N	Health-related unemployment N=35 (2%)	Unemployed seeking work N=54 (3%)	Employed full or part-time N=1878 (95%)
		N	%	N	%	N	%				
1974–77	1643	186	11	89	5	1368	83				
1978–81	1903	193	10	118	6	1592	84				
1982–86	1751	143	8	112	6	1496	85				
Chemotherapy								NA			
No chemotherapy	1261	166	13	75	6	1020	81				
Any chemotherapy	4489	424	9	245	5	3820	85				
Missing†	589	70	11	41	7	478	81				
Radiation		**N**	**%**	**N**	**%**	**N**	**%**	NA			
No radiation	1636	141	9	88	5	1407	86				
Any	4018	440	11	228	6	3350	83				
Missing†	685	79	12	45	7	561	82				
Cranial radiation								NA			
None	1636	141	9	88	5	1407	86				
Cumulative dose‡											
Scatter low§	1732	121	7	69	4	1542	89				
Scatter high§	181	14	8	9	5	158	87				
<18 Gy	531	34	6	34	6	463	87				
18–24 Gy	854	82	10	53	6	719	84				
25 Gy	597	169	28	58	10	370	62				
Specific surgery sites								NA			
Amputation	413	64	16	22	5	327	79				
Limb-sparing	67	19	28	2	3	46	69				
CNS resection	900	208	23	71	8	621	69				
Treatment combinations								NA			
Surgery only	421	40	10	24	6	357	85				
Radiation only	16	1	6	1	6	14	88				

		Survivors N=6339 Percents calculated across variable category rows[*]				Siblings N=1967 Percents calculated across variable category rows[*]		
	N	Health-related unemployment N=660 (10%)	Unemployed seeking work N=361 (6%)	Employed full or part-time N=5318 (84%)	N	Health-related unemployment N=35 (2%)	Unemployed seeking work N=54 (3%)	Employed full or part-time N=1878 (95%)
Chemotherapy only	251	15 6	6 2	230 92				
Chemo + radiation	700	68 10	50 7	582 83				
Chemo + surgery	943	82 9	58 6	803 85				
Radiation + surgery	818	124 15	50 6	644 79				
Chemotherapy + radiation + surgery	2583	259 10	131 5	2193 85				
Missing[†]	607	71 12	41 7	495 82				

[*] Percentages for the full sample of survivors (N=6339) and siblings (N=1967) calculated by column. Work status percentages calculated across levels of the variables.

[†] Includes subjects who did not provide consent for release of medical information regarding detailed treatment exposures.

[‡] Denominator is number of patients receiving radiation exposure with cranial radiation information (N=3895).

[§] Scatter Low= no treatment to head or brain, but patient received radiation to some part of the body (dose range >0 to <10 Gy); Scatter high = no direct treatment to segment, but treatment was nearby (dose range 1 to 5 Gy)

Table 3

Odds Ratio (OR) and 95% Confidence Interval (CI) of health-related unemployment and unemployed but seeking work among survivors

N=6339	Health-related unemployment			Unemployed but seeking work		
	OR	95% CI	P-value	OR	95% CI	P-value
Current age (years)						
25–34 (referent)	1			1		
35–44	1.31	1.07, 1.61	0.01	0.62	0.46, 0.81	<0.001
45+	1.03	0.71, 1.49	0.87	0.68	0.39, 1.15	0.14
Sex						
Male (referent)	1			1		
Female	1.73	1.43, 2.08	<0.001	1.19	0.94, 1.51	0.15
Race						
White, non-Hispanic (referent)	1			1		
Black, non-Hispanic	1.89	1.16, 3.10	0.01	2.16	1.21, 3.84	0.001
Hispanic	1.66	1.05, 2.63	0.03	1.51	0.85, 2.67	0.15
Other/mixed	1.43	1.03, 1.99	0.03	1.57	1.06, 2.35	0.03
Years since diagnosis						
20 (referent)	1			1		
21–30	1.36	1.06, 1.75	0.02	0.90	0.68, 1.18	0.43
>30	1.89	1.35, 2.64	<0.001	0.64	0.40, 1.04	0.07
Cranial radiation						
None (referent)	1			1		
Scatter low	0.91	0.69, 1.20	0.51	0.78	0.55, 1.11	0.17
Scatter high	1.18	0.65, 2.13	0.59	0.90	0.42, 1.92	0.78
<18 Gy	0.97	0.63, 1.48	0.87	1.06	0.69, 1.64	0.78
18–24 Gy	1.45	1.06, 1.98	0.02	1.10	0.75, 1.63	0.62
25 Gy	3.47	2.54, 4.74	<0.001	1.77	1.15, 2.71	0.009
Recurrence						
No (referent)	1			1		
Yes	1.35	1.02, 1.78	0.03	1.01	0.69, 1.49	0.95
Secondary cancer						

N=6339	Health-related unemployment			Unemployed but seeking work		
	OR	95% CI	P-value	OR	95% CI	P-value
No (referent)	1			1		
Yes	1.50	1.04, 2.14	0.03	1.28	0.76, 2.15	0.38
CNS tumor resection						
No (referent)	1			1		
Yes	2.01	1.53, 2.66	<0.001	1.06	0.72, 1.56	0.75
Amputation						
No (referent)	1			1		
Yes	2.18	1.54, 3.10	<0.001	0.90	0.52, 1.58	0.72
Limb-saving						
No (referent)	1			1		
Yes	4.23	2.33, 7.69	<0.001	0.28	0.04, 2.00	0.21