

BRIEF COMMUNICATION

Supplemental Security Income and Social Security Disability Insurance Coverage Among Long-term Childhood Cancer Survivors

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Abstract

Supplemental security income (SSI) and social security disability insurance (DI) are federal programs that provide disability benefits. We report on SSI/DI enrollment in a random sample of adult, long-term survivors of childhood cancer ($n = 698$) vs a comparison group without cancer ($n = 210$) from the Childhood Cancer Survivor Study who completed a health insurance survey. A total of 13.5% and 10.0% of survivors had ever been enrolled on SSI or DI, respectively, compared with 2.6% and 5.4% of the comparison group. Cranial radiation doses of 25 Gy or more were associated with a higher risk of current SSI (relative risk [RR] = 3.93, 95% confidence interval [CI] = 2.05 to 7.56) and DI (RR = 3.65, 95% CI = 1.65 to 8.06) enrollment. Survivors with severe/life-threatening conditions were more often enrolled on SSI (RR = 3.77, 95% CI = 2.04 to 6.96) and DI (RR = 2.73, 95% CI = 1.45 to 5.14) compared with those with mild/moderate or no health conditions. Further research is needed on disability-related financial challenges after childhood cancer.

Five-year survival from a diagnosis of childhood cancer is over 80% (1). Treatments including surgery, radiotherapy, and/or chemotherapy place some patients at risk for medical late-effects (2,3), which include severe and life-threatening complications (eg, second cancers, cardiac failure) (2,4,5). These health problems can affect adult survivors' ability to work (6). With more than 420 000 US childhood cancer survivors (5), understanding their health and financial needs is critical, given their need for continued medical care.

In the United States, two federal disability programs, supplemental security income (SSI) and social security disability insurance (DI), provide income and insurance support for disabled adults. SSI is a "means-tested" program for those with limited income who are disabled, blind, or age 65 years and older and is

not based on prior work history. DI pays benefits to adults ages 18 years and older who have worked and paid social security taxes. To qualify for either program, an individual must be unable to engage in "substantial gainful activity," meaning they have an impairment lasting for a continuous period of 12 months or more or that is expected to result in death. Enrollment in either of these programs indicates substantial long-term health problems. We examine SSI and DI enrollment in a sample of adult, long-term survivors of childhood cancer and a comparison group from the Childhood Cancer Survivor Study (CCSS).

The CCSS is a multi-institutional, retrospective cohort developed to investigate health outcomes in childhood cancer survivors diagnosed younger than 21 years of age between 1970 and 1986 (7,8). All study participants provided informed consent. We

Table 1. Demographic and insurance characteristics for adult, long-term survivors of childhood cancer and comparison group weighted to reflect the age distribution of the full CCSS cohort

Characteristics	Survivors (n = 698)			Comparison group (n = 210)			P†
	No.	Unweighted %	Weighted %	No.	Unweighted %	Weighted %	
Age at survey, y							
22–29	214	30.7	11.3	61	29.1	13.5	.06
30–39	228	32.7	42.3	68	32.4	33.6	
40–62	256	36.7	46.4	81	38.6	53.0	
Sex							
Male	314	45.0	45.5	82	39.1	38.9	.11
Female	384	55.0	54.5	128	60.9	61.1	
Race*							
White	646	92.8	93.6	185	92.5	93.5	.96
Black	14	2.0	1.7	4	2.0	1.9	
Hispanic/Latino	24	3.5	3.0	6	3.0	2.4	
Other	12	1.7	1.8	5	2.5	2.2	
Household income*							
Less than \$20 000	91	13.5	12.0	12	6.0	5.2	.02
\$20 000 - \$39 999	106	15.8	14.9	24	11.9	10.7	
\$40 000 - \$59 999	104	15.5	15.8	35	17.4	16.9	
\$60 000 - \$79 999	95	14.1	14.8	32	15.9	16.1	
Over \$80 000	240	35.7	38.4	90	44.8	48.7	
Don't know	36	5.4	4.2	8	4.0	2.4	
Insurance*							
Employer-sponsored health insurance	464	67.1	70.1	161	78.2	81.8	.001
Individual	46	6.7	6.4	17	8.3	7.2	
Medicare	20	2.9	2.5	0	0	0	
Medicaid/state	81	11.7	10.2	7	3.4	3.0	
Uninsured or don't know	80	11.6	10.4	21	10.2	8.0	
Chronic condition‡							
None	111	15.9	15.1	68	32.4	32.3	<.001
Mild-moderate	319	45.7	45.2	114	54.3	52.0	
Severe-life threatening	268	38.4	39.7	28	13.3	15.7	
Cancer diagnosis							
Leukemia	255	36.5	35.0				
Central nervous system	104	14.9	14.9				
Wilms (kidney) tumor	66	9.5	8.1				
Non-Hodgkin's Lymphoma	39	5.6	6.7				
Bone	45	6.5	8.1				
Hodgkin's Lymphoma	71	10.2	12.9				
Neuroblastoma	67	9.6	6.1				
Soft tissue sarcoma	51	7.3	8.3				
Age at diagnosis, y							
0–4	365	52.3	39.2				
5–10	143	20.5	26.3				
11–15	109	15.6	19.8				
16–20	81	11.6	14.7				
Second cancer							
No	668	95.7	94.9				
Yes	30	4.3	5.1				
Recurrence of primary malignancy							
No	611	87.5	88.1				
Yes	87	12.5	11.9				
Cranial radiation*							
None (ref.)	269	41.6	36.6				
Scatter low/high§	172	26.6	29.8				
≤18 Gy	71	11.0	11.1				
19–24 Gy	50	7.7	8.8				
≥25 Gy	85	13.1	13.8				
Supplemental security income*							
Ever enrolled	100	14.9	13.5	5	2.5	2.6	<.001
Currently enrolled	59	8.8	7.3	2	1.5	1.2	.003¶
Never enrolled	570	85.1	86.2	199	97.6	97.4	

Table 1. Continued

Characteristics	Survivors (n = 698)			Comparison group (n = 210)			P†
	No.	Unweighted %	Weighted %	No.	Unweighted %	Weighted %	
Social security disability insurance*							
Ever enrolled	68	10.3	10.0	10	4.8	5.4	.05
Currently enrolled	47	7.1	6.4	7	3.4	4.3	.32¶
Never enrolled	595	89.7	89.6	197	95.2	94.6	

* Totals do not include participants who did not report on the indicated characteristic. CCSS = Childhood Cancer Survivor Study.

† P values are two-sided and compare weighted percentages using Pearson chi square test.

‡ Classified using the Common Terminology Criteria for Adverse Events v4.0.

§ Scatter low (no treatment to head/brain, but patient received radiation to some part of the body [>0 to <1 Gy])/scatter high (no direct treatment to head/brain segment, but treatment was nearby [dose range ≥ 1 to ≤ 5 Gy]).

|| Ever enrolled includes report of current or former social security income (SSI) and disability insurance (DI) enrollment; P value compares percentage ever enrolled between survivors and the comparison group.

¶ Compares percentage current SSI and DI between survivors and the comparison group.

utilized survey data gathered from 698 survivors and 210 comparison group participants (participation rate: survivors = 70%, comparison group = 65%). Clinical characteristics were abstracted from medical records while acute/chronic health conditions were self-reported from the 2007 to 2010 CCSS follow-up survey (2,3,8). Participants reported whether they were currently or formerly enrolled on SSI/DI. We used 2012 Social Security Administration annual report data to estimate current SSI/DI enrollment for the US population ages 18 to 64 years (9,10).

As the sample was randomly selected from age strata based on the 2007 to 2010 survey (22–29 years, 30–39 years, ≥ 40 years), analyses were weighted based on the distribution of age in the CCSS cohort. We compared survivors' SSI/DI enrollment to current national US estimates and calculated proportions of survivors and the comparison group who were currently/formerly enrolled in SSI/DI. Multivariable generalized linear models assessed differences between survivors and the comparison group, and by survivors' socio-demographic and clinical characteristics. We ran separate models evaluating severe/life-threatening health conditions compared with mild/moderate or no health conditions among survivors. P values are two-sided and statistically significant at $\alpha = 0.05$. Procedures were institutional review board approved.

Survivors were currently enrolled on SSI (7.3% vs US = 2.5%, $P < .001$) and DI (6.4% vs US = 4.8%, $P = .04$) more frequently than the US population. Differences between weighted percentages were analyzed using Pearson chi square test. In Table 1, 7.3% of survivors were currently enrolled on SSI vs 1.2% of the comparison group ($P = .003$); 13.5% of survivors vs 2.6% of the comparison group were ever enrolled on SSI ($P < .001$). Current enrollment on DI was reported by 6.4% of survivors and 4.3% of the comparison group ($P = .32$); ever enrolled on DI was reported by 10.0% of survivors and 5.4% of the comparison group ($P = .05$). Multivariable models adjusting for age, sex, and race demonstrated a higher risk of ever enrolled on SSI for survivors vs the comparison group (relative risk [RR] = 5.05, 95% confidence interval [CI] = 1.98 to 12.80, $P = .001$), but not for DI (RR = 1.76, 95% CI = 0.90 to 3.44, $P = .10$; data not shown).

Among survivors (Table 2), SSI was associated with female sex (RR = 1.74, 95% CI = 1.00 to 3.06, $P = .05$), age four years or younger at diagnosis (RR = 7.56, 95% CI = 1.02 to 56.16, $P = .05$), and cranial radiation doses of 25 Gy or more (RR = 3.93, 95% CI = 2.05 to 7.56, $P < .001$). P values in Table 2 were calculated using the Wald test. For DI coverage, second malignancy (RR = 3.35, 95% CI = 1.53 to 7.33, $P = .003$) and cranial radiation

doses of more than 18 Gy (19–24 Gy RR = 2.82, 95% CI = 1.08 to 7.33, $P = .03$; ≥ 25 Gy RR = 3.65, 95% CI = 1.65 to 8.06, $P < .001$) were statistically significant. In a separate analysis (data not shown), survivors with severe or life-threatening conditions were currently enrolled on SSI more often (RR = 3.77, 95% CI = 2.04 to 6.96, $P < .001$) and DI more often (RR = 2.73, 95% CI = 1.45 to 5.14, $P = .02$) compared with survivors with mild/moderate or no health conditions.

Our findings demonstrate that adult, long-term survivors of childhood cancer receive SSI/DI benefits more than the comparison group and the US population. Although these benefit programs alleviate some financial burden for disabled adults, the maximum SSI benefit pay-out is \$733.00 per month (ie, \$8796/year) in 2015, which is lower than the Federal Poverty Level for a single adult (\$11 770) (11). We found that survivors with greater cranial radiation doses, who were younger at diagnosis and had severe or life-threatening chronic conditions, were at a higher risk. Identifying or managing conditions among high-risk survivors before they impact employment can be challenging as neurocognitive or other health problems may not emerge before survivors are old enough to enter the workforce (12–15). Previous studies have indicated cognitive decline may increase as survivors age, meaning that employment problems could develop well after follow-up care ends (16).

Our study has limitations. The comparison group had few participants reporting SSI or DI enrollment, meaning that our conclusions are based on small numbers. Also, the comparison group was selected from siblings enrolled in the CCSS. Because of our study design, there were only 18 family pairs; thus, we were unable to account for childhood and genetic factors that may impact SSI/DI enrollment. Also, because marital status and income are intermediaries between survivor status and SSI/DI coverage, we did not adjust for these factors to show the direct relationship between cancer and SSI/DI. Thus, demographic factors that affect SSI/DI eligibility need further exploration. In addition, future studies should evaluate DI enrollment related to work history, as paying social security taxes is a requirement for eligibility. As social security applications increase during economic recessions, our assessment in 2011 and 2012 may be inflated.

Our findings add to the growing evidence that young cancer survivors not only bear a disproportionate burden of chronic health problems, but require a greater level of assistance to manage health complications (17–19). Adult, long-term survivors of childhood cancer are enrolled on SSI more

Table 2. Multivariable clinical factors associated with current SSI and DI coverage among adult, long-term survivors of childhood cancer

Clinical factors	Current supplemental security income*		Current social security disability insurance*	
	Relative risk (95% CI)	P	Relative risk (95% CI)	P
Sex				
Male (ref)	1		1	
Female	1.74 (1.00 to 3.06)	.05	1.16 (0.64 to 2.08)	.63
Years since diagnosis				
22–29 (ref)	1		1	
30–35	0.66 (0.26 to 1.71)	.40	1.21 (0.48 to 3.04)	.69
≥35	0.95 (0.39 to 2.30)	.91	1.32 (0.50 to 3.51)	.60
Age at diagnosis, y				
16–20 (ref)	1		1	
11–15	4.89 (0.66 to 36.51)	.12	1.55 (0.32 to 7.56)	.59
5–10	4.88 (0.63 to 37.89)	.13	1.78 (0.35 to 9.01)	.48
0–4	7.56 (1.02 to 56.16)	.05	2.20 (0.42 to 11.43)	.35
Recurrence				
No (ref)	1		1	
Yes	0.99 (0.45 to 2.18)	.97	1.48 (0.71 to 3.06)	.29
Second cancer				
No (ref)	1		1	
Yes	1.66 (0.59 to 4.65)	.33	3.35 (1.53 to 7.33)	.003
Cranial Radiation				
None (ref)	1		1	
Scatter low/high†	0.63 (0.25 to 1.59)	.33	0.78 (0.27 to 2.30)	.66
≤18 Gy	0.84 (0.27 to 2.62)	.76	1.24 (0.39 to 4.00)	.71
19–24 Gy	1.29 (0.41 to 4.07)	.67	2.82 (1.08 to 7.33)	.03
≥25 Gy	3.93 (2.05 to 7.56)	<.001	3.65 (1.65 to 8.06)	.001

* Models adjusted for current age. Race not included because of small sample size for certain groups. P values are two-sided and were estimated using a Wald test.

† Scatter low (no treatment to head/brain, but patient received radiation to some part of the body [>0 to <1 Gy])/scatter high (no direct treatment to head/brain segment, but treatment was nearby [dose range ≥ 1 to ≤ 5 Gy]).

often than US and noncancer comparisons. Further research is required to evaluate the effect of these benefits on the employment, financial status, and quality of life of childhood cancer survivors.

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