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Job Lock among Long-Term Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study

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Abstract

Importance: Job lock occurs when an employee stays at a job in order to keep work-related health insurance, which may affect earning power.

Objective: Examine prevalence of job lock in a sample of full-time employed childhood cancer survivors from an established multi-institutional cohort compared to their siblings and explore factors associated with job lock among survivors.

Design: Cross-sectional survey

Setting: Cohort from 25 pediatric oncology centers

Participants: Full-time employed adult survivors of childhood cancer (N=394) and a random sample of siblings (N=128).

Exposures: Demographic, insurance, and chronic conditions

Main Outcome/Measures: Self-report of job lock.

Results: Job lock was reported by 23.2% (95% CI 18.9–28.1) of survivors, compared to 16.9% (95% CI 11.1–25.0) of siblings (p=0.16). Job lock was more common among survivors reporting previous health insurance denial (Relative Risk (RR)=1.60, 95% CI 1.03–2.52) and problems

paying medical bills (RR=2.43, 95% CI 1.56–3.80). Among survivors, being female vs. male (RR=1.70, 95% CI 1.11–2.59) and having a severe or life-threatening health condition vs. none-mild/moderate health condition (RR=1.72, 95% CI 1.09–2.69) were associated with job lock.

Conclusions/Relevance: Job lock is common among long-term childhood cancer survivors who are employed full-time. A survivor's decision to remain in a job due to worries about insurance may affect their career trajectory, diminish their potential earning power, and ultimately impact their quality of life.

Introduction

Among the almost 400,000 survivors of childhood cancer in the United States (US), 55% are between the ages 20 to 59, the prime years for labor force participation.¹ As they age, many childhood cancer survivors develop chronic health conditions resulting from their cancer and treatment,² which may affect their ability to work. Childhood cancer survivors are less likely to be employed compared with their siblings and the general population.^{3,4} In addition, employed survivors are more likely to work in lower-income occupations with less access to employee benefits (including health insurance) compared with their siblings.^{5,6}

Survivors who are employed may be at increased risk for real or perceived job lock. 'Job lock' is a term used to describe the self-reported inability of an employee to freely leave their job because of the limited portability of health insurance. In the US, where the majority of insurance is provided via an employer, job lock may be particularly problematic for individuals with chronic health conditions.⁷ In the past 20 years, legislation has sought to mitigate the occurrence of job lock. The 1997 Health Insurance Portability and Accountability Act (HIPAA) limited health insurers' ability to enforce preexisting condition exclusions for insured individuals. HIPAA guaranteed continued employer-sponsored insurance (ESI) coverage for workers and their family during job transitions.⁸ In 2010, the Patient Protection and Affordable Care Act (ACA) increased insurance options outside of employment.⁹ However, workers may still face insurance limitations given the lack of Medicaid expansion in 19 states and anticipated federal modifications to health insurance protections in the coming years.¹⁰

In a prior qualitative study, we found that many childhood cancer survivors feared losing their ESI coverage, which led them to avoid or forgo job changes.¹¹ In the current study, we sought to quantify the prevalence of self-reported job lock in a sample of full-time employed childhood cancer survivors and their siblings in the Childhood Cancer Survivor Study (CCSS). Among survivors, we examined the association of job lock with a history of health insurance denial and difficulties paying medical bills, as these concerns may affect survivors' experiences with job lock. We also examined sociodemographic factors associated with job lock for survivors.

Methods

The CCSS is a multi-institutional, retrospective cohort study with ongoing longitudinal follow-up that was initiated in 1994 to track the health outcomes of survivors of childhood cancer.¹² Eligible survivors included those diagnosed with cancer between 1970 and 1986,

younger than 21 years old at diagnosis, and alive five years from diagnosis. The CCSS includes survivors of leukemia, lymphoma, CNS malignancy, Wilms tumor, neuroblastoma, soft tissue sarcoma, and bone cancers. The original cohort had 14,357 survivors from 26 participating centers and a cohort of randomly selected nearest-age siblings (n=4,023).

For the current study, 1101 survivors and 360 siblings were randomly selected by age strata groups from the 25 US institutions. Surveys were completed via paper or Internet from May 2011-April 2012.^{13,14} The final sample included 698 survivor (response rate=70%) and 210 sibling (response rate=65%) surveys. Because part-time employees are often not eligible for ESI, and thus may not experience job lock, we focused on participants with full-time employment (≥ 35 hours/week at their primary job).

To assess job lock, participants were asked to respond yes or no to “Have you ever decided to stay in a job rather than take a new job in order to keep health insurance coverage?” Also, participants reported their current insurance status (e.g., ESI, individual, uninsured), marital status, and household income, and whether they had problems paying their medical bills in the past year or had previously been denied health insurance coverage. Data on other sociodemographic, medical, and cancer-related factors were determined from CCSS baseline and follow-up surveys (<https://ccss.stjude.org>).

Analyses were weighted based on the distribution of age in the CCSS cohort. We used descriptive statistics to compare demographic characteristics between survivors and siblings. We examined the associations between job lock and reports of health insurance denial and problems paying medical bills using a multivariable generalized linear model (GLM). We fit a separate GLM to assess the associations between sex, age, household income, marital status and presence of severe/life-threatening chronic disease with job lock among survivors, while adjusting for treatment. P-values are two-sided and statistically significant at $\alpha=0.05$. The CCSS protocol is Institutional Review Board approved.

Results

Characteristics of full-time employed survivors and siblings were similar, although survivors had greater levels of severe/life-threatening chronic conditions (33.9% vs. 17.7%, $p<0.001$; Table 1).

Survivors reported job lock (23.2%, 95% CI 18.9–28.1 vs. 16.9%, 95% CI 11.1–25.0, $p=0.16$) and problems paying medical bills (20.1%, 95% CI 16.1–24.7 vs. 12.9%, 95% CI 7.9–20.6, $p=0.09$) more than siblings (Table 2). Health insurance denial (13.4%, 95% CI 10.2–17.5 vs. 1.8%, 95% CI 0.47–6.23, $p<0.001$) was significantly more prevalent among survivors. When examined in multivariable GLMs adjusted for demographic factors and severe/life-threatening chronic disease (data not shown), insurance denial remained significantly more common among survivors compared to siblings (RR=7.38, 95% CI 2.01–27.08).

Among survivors, we examined associations between job lock, health insurance denial, and problems paying medical bills together in a multivariable regression adjusted for demographic factors, chronic disease, and treatment. We found that 38% of survivors with a

previous insurance denial reported job lock compared to 20% of those who never experienced denial (RR=1.60, 95% CI 1.03–2.52). Similarly, job lock occurred among 44% of survivors who reported problems paying their medical bills compared to 16% reporting no problems paying medical bills (RR=2.43, 95% CI 1.56–3.80) (data not shown).

We then identified sociodemographic characteristics associated with job lock (Table 3). In a multivariable model adjusted for demographics, chronic disease, and treatment, female survivors (RR=1.70, 95% CI 1.11–2.59 vs. males) and survivors with a severe or life-threatening chronic condition (RR=1.72, 95% CI 1.09–2.69 vs. unaffected) were more likely to report job lock.

Discussion

We found that nearly one in four full-time employed survivors of childhood cancer self-report job lock. Survivors who report a history of health insurance denial and those who have problems paying their medical bills are more likely to report job lock. Also, job lock is more common for female survivors and/or those with severe or life-threatening chronic conditions.

National data from Kaiser indicate that 20% of participants ages 18–64 with at least one household member with a pre-existing condition reported staying in a current job instead of taking a new job due to worries about losing health benefits compared to 9% without pre-existing conditions. Our findings demonstrate that full-time employed survivors face worries about their insurance coverage at similar levels to the general population with pre-existing conditions, which may subsequently limit their job mobility.

The potential repeal and replacement of the ACA means that survivors who wish to change jobs, reduce their work hours, or launch their own businesses may face fewer and more costly options to purchase insurance.¹⁵ In addition, replacement proposals for the ACA include waiting periods for pre-existing conditions for those with a lapse in coverage, which may further impede job mobility for survivors.

With the proposed ACA changes, worries about denial of coverage, insurance costs, and lack of comprehensive insurance will likely increase among survivors. A survivor's decision to remain in a job due to worries about insurance may affect their career trajectory, diminish their potential earning power, and ultimately impact their quality of life. Future research should investigate how modifications to the ACA affect the relationship between childhood cancer survivors' health status, employment decisions, access to insurance, and income, and how these factors influence the quality of survivorship care.

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Key Points:

Question: What is the association between job lock and having a history of childhood cancer?

Findings: Almost one in four full-time employed survivors of childhood cancer reported a history of job lock; being female, and having a history of insurance denial, problems paying medical bills, and a severe chronic health condition were associated with job lock.

Meaning: The need for insurance coverage may limit childhood cancer survivors' employment trajectory.

Table 1:

Sociodemographic and treatment characteristics for full-time employed survivors and siblings

| | Survivors N=394 | | Siblings N=128 | | P value ^b |
|-------------------------------------|--------------------|------------|-------------------|------------|----------------------|
| | N | Weighted % | N | Weighted % | |
| Age at survey (years) | | | | | |
| 22–29 | 114 | 10.5 | 31 | 10.8 | |
| 30–39 | 137 | 44.3 | 44 | 34.4 | 0.09 |
| 40–62 | 143 | 45.2 | 53 | 55.8 | |
| Sex | | | | | |
| Male | 209 | 54.5 | 64 | 51.5 | |
| Female | 185 | 45.5 | 64 | 48.5 | 0.58 |
| Race/Ethnicity^a | | | | | |
| White non-Hispanic | 363 | 92.7 | 116 | 95.1 | |
| Black non-Hispanic | 8 | 1.4 | 1 | 1.1 | |
| Hispanic/Latino | 14 | 3.6 | 3 | 2.3 | 0.85 |
| Other | 8 | 2.3 | 2 | 1.5 | |
| Education^a | | | | | |
| <High school - High School Graduate | 29 | 8.1 | 12 | 11.7 | |
| Some post-graduate college | 92 | 23.8 | 25 | 20.6 | 0.47 |
| Completed college and above | 240 | 68.1 | 81 | 67.7 | |
| Marital Status^a | | | | | |
| Married, living as married | 259 | 70.5 | 87 | 71.9 | |
| Single, never married | 102 | 19.8 | 26 | 15.0 | 0.36 |
| Divorced or separated | 32 | 9.8 | 15 | 13.1 | |
| Household Income^a | | | | | |
| Less than \$20,000 | 16 | 2.4 | 3 | 2.5 | |
| \$20,000 - \$39,999 | 64 | 14.6 | 15 | 10.7 | |
| \$40,000 - \$59,999 | 55 | 15.0 | 19 | 14.2 | |
| \$60,000 - \$79,999 | 66 | 17.3 | 22 | 17.9 | 0.92 |
| Over \$80,000 | 180 | 49.5 | 64 | 53.7 | |
| Don't know | 7 | 1.1 | 2 | 1.2 | |
| Chronic conditions | | | | | |
| None/mild/moderate | 270 | 66.1 | 109 | 82.3 | |
| Severe/disabling/life-threatening | 124 | 33.9 | 19 | 17.7 | 0.001 |
| Cancer diagnosis | | | | | |
| Leukemia | 146 | 35.4 | -- | -- | |
| Hodgkin lymphoma | 47 | 14.9 | -- | -- | |
| Central Nervous System | 36 | 9.5 | -- | -- | |
| Wilms (Kidney) Tumor | 44 | 9.4 | -- | -- | |
| Soft tissue sarcoma | 27 | 7.9 | -- | -- | |

| | Survivors N=394 | | Siblings N=128 | | P value ^b |
|---------------------------------|--------------------|------------|-------------------|------------|----------------------|
| | N | Weighted % | N | Weighted % | |
| Bone | 28 | 8.7 | -- | -- | |
| Non-Hodgkin lymphoma | 23 | 7.1 | -- | -- | |
| Neuroblastoma | 43 | 7.2 | -- | -- | |
| Age at diagnosis (years) | | | | | |
| 0–5 | 228 | 47.2 | -- | -- | |
| 6–10 | 62 | 19.8 | -- | -- | |
| 11–15 | 61 | 19.4 | -- | -- | |
| 16–20 | 43 | 13.6 | -- | -- | |
| Chemotherapy | | | | | |
| Yes | 287 | 77.2 | -- | -- | |
| No | 79 | 22.8 | -- | -- | |
| Radiation | | | | | |
| Yes | 214 | 63.9 | -- | -- | |
| No | 151 | 36.1 | -- | -- | |
| Surgery | | | | | |
| Yes | 285 | 81.1 | -- | -- | |
| No | 80 | 18.9 | -- | -- | |

^aTotals limited to survivors who reported on the indicated demographic characteristic. Missing data: race N=1, education N=44, marital status N=3, household income N=12.

^bPercentages and P-values from chi-square statistics calculated incorporating survey weights to reflect the distribution of the full CCSS cohort.

Table 2:

Prevalence of job lock, health insurance and problems paying medical bills among full-time employed survivors and siblings

| | Survivors N=394 | | | Siblings N=128 | | | P value ¹ |
|---|--------------------|-------------------------------------|--|-------------------|-------------------------------------|--|----------------------|
| | N | Weighted % ^a (95% CI) | | N | Weighted % ^a (95% CI) | | |
| Ever Experienced Job Lock | | | | | | | |
| Yes | 84 | 23.2 (18.9–28.1) | | 22 | 16.9 (11.1–25.0) | | 0.16 |
| No or don't know | 307 | 76.8 (71.9–81.1) | | 105 | 83.1 (75.0–88.9) | | |
| Health Insurance | | | | | | | |
| Employer Sponsored Insurance | 339 | 88.0 (84.1–90.9) | | 110 | 88.5 (81.9–92.9) | | 0.50 |
| Individual | 23 | 5.3 (3.4–8.3) | | 6 | 3.0 (1.2–6.9) | | |
| Public | 10 | 2.3 (1.6–4.5) | | 3 | 1.9 (0.5–6.1) | | |
| Uninsured | 20 | 4.4 (2.7–7.1) | | 9 | 6.7 (3.4–7.1) | | |
| Problems Paying Medical Bills in Past Year | | | | | | | |
| Yes | 75 | 20.1 (16.1–24.7) | | 15 | 12.9 (7.9–20.6) | | 0.09 |
| No | 315 | 79.9 (75.2–83.9) | | 112 | 87.1 (79.4–92.1) | | |
| History of Health Insurance Denial | | | | | | | |
| Yes | 52 | 13.4 (10.2–17.5) | | 3 | 1.8 (0.47–6.23) | | <0.001 |
| No or don't know | 340 | 86.6 (82.5–89.8) | | 123 | 98.2 (93.7–99.5) | | |

^aPercentages and P-values from chi-square statistics calculated incorporating survey weights to reflect the distribution of the full CCSS cohort.

Table 3:

Relative Risks and 95% Confidence Intervals of demographic and clinical characteristics related to job lock among full-time employed survivors^{a,b}

| N=394 | Relative Risk | 95% CI | p-value |
|---|----------------------|------------------|----------------|
| Sex | | | |
| Male (ref) | 1 | | |
| Female | 1.70 | 1.11–2.59 | 0.01 |
| Age | | | |
| 22–29 (ref) | 1 | | |
| 30–39 | 1.41 | 0.79–2.52 | 0.24 |
| 40–62 | 1.10 | 0.59–2.06 | 0.76 |
| Household Income^c | | | |
| Income >\$40,000 (ref) | 1 | | |
| Income <\$39,999 | 0.77 | 0.38–1.53 | 0.45 |
| Marital Status^d | | | |
| Single, widowed, divorce (ref) | 1 | | |
| Married | 1.51 | 0.84–2.70 | 0.17 |
| Severe or life-threatening chronic condition | | | |
| No (ref) | 1 | | |
| Yes | 1.72 | 1.09–2.69 | 0.02 |

^aModel adjusted for receipt of chemotherapy, surgery, and radiation, as well as the other variables listed in the table.

^bSurvivors who did not report on the indicated demographic characteristic were not included.

^cHousehold income missing for N=11

^dMarital status missing for N=1