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## Employer-Sponsored Health Insurance Coverage Limitations: Results from the Childhood Cancer Survivor Study

Anne C. Kirchhoff<sup>1,2,3</sup>, Karen Kuhlthau<sup>4</sup>, Hannah Pajolek<sup>4</sup>, Wendy Leisenring<sup>5,6</sup>, Greg T. Armstrong<sup>7</sup>, Leslie L. Robison<sup>7</sup>, and Elyse R. Park<sup>4</sup>

<sup>1</sup>Center for Children's Cancer Research, Huntsman Cancer Institute, Salt Lake City, UT

<sup>2</sup>Cancer Control and Population Sciences Research Program, Huntsman Cancer Institute, Salt Lake City, UT

<sup>3</sup>University of Utah, Salt Lake City, UT

<sup>4</sup>Massachusetts General Hospital, 100 Cambridge Street, Boston, MA 02114

<sup>5</sup>Fred Hutchinson Cancer Research Center, 1100 Fairview Ave N Seattle, WA 98109

<sup>6</sup>University of Washington, Seattle, WA

<sup>7</sup>St. Jude Children's Research Hospital, 262 Danny Thomas Place, Memphis, TN 38105-3678

### Abstract

**Purpose**—The Affordable Care Act (ACA) will expand health insurance options for cancer survivors in the United States. It is unclear how this legislation will affect their access to employer-sponsored health insurance (ESI). We describe the health insurance experiences for survivors of childhood cancer with and without ESI.

**Methods**—We conducted a series of qualitative interviews with 32 adult survivors from the Childhood Cancer Survivor Study to assess their employment-related concerns and decisions regarding health insurance coverage. Interviews were performed from August to December 2009 and were recorded, transcribed, and content analyzed using NVivo 8.

**Results**—Uninsured survivors described ongoing employment limitations, such as being employed at part-time capacity, which affected their access to ESI coverage. These survivors acknowledged they could not afford insurance without employer support. Survivors on ESI had previously been denied health insurance due to their pre-existing health conditions until they obtained coverage through an employer. Survivors feared losing their ESI coverage, which created a disincentive to making career transitions. Others reported worries about insurance rescission if their cancer history was discovered. Survivors on ESI reported financial barriers in their ability to pay for health care.

**Conclusions**—Childhood cancer survivors face barriers to obtaining employer-sponsored health insurance. While Affordable Care Act provisions may mitigate insurance barriers for cancer survivors, many will still face cost barriers to affording health care without employer support.

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Corresponding Author/Reprints: Anne C. Kirchhoff, Huntsman Cancer Institute, Assistant Professor, Department of Pediatrics, University of Utah, 2000 Circle of Hope, Salt Lake City, UT 84112, Phone: 801-587-4084, Fax: 801-585-0900, anne.kirchhoff@hci.utah.edu.

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## Keywords

Employer-sponsored health insurance; childhood cancer survivors; Affordable Care Act; Insurance reform

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## Introduction

Employer-sponsored health insurance (ESI), the predominant source of health insurance coverage for working-age adults in the United States, has been declining over the past decade. From 2000 to 2010, the percent of adults under age 65 covered by an ESI plan dropped from 69.2% to 58.6% [10]. During the same years, cost sharing increased substantially for employees with premium costs rising 114% [2, 9]. With the recession, the unemployment rate jumped from 5.8% to 9.3% during 2008 to 2009, along with a concomitant drop in ESI coverage [8]. Since 2010, the number of businesses offering insurance dropped from 69% to 60% in 2011, placing more adults at risk for losing coverage [10].

These trends are of particular concern for medically vulnerable adults, who are at higher risk for job loss during economic downturns, affecting their access to health insurance coverage [1]. Adult survivors of childhood cancer often have a lifetime of long-term health complications that impact their ability to work [4] and, subsequently, their access to jobs offering ESI [24]. Over 330,000 long-term survivors of childhood cancer live in the US and 65% of survivors are 20 to 59 years [18], which are the prime years of labor force participation. Many childhood cancer survivors develop chronic conditions as they age, including secondary cancers [22], and therefore, need continual medical surveillance and treatment. Due to limitations in educational attainment and health-related problems with employment [5, 15, 20] survivors may face substantial barriers to obtaining ESI coverage. Employed survivors are often in lower skill occupations, which typically offer fewer insurance benefits [14].

The 2010 Patient Protection and Affordable Care Act (ACA) has several provisions to expand insurance coverage and to improve primary care for adults with chronic health problems [16, 21]. Individuals with health-related exclusions or high costs in buying individual health insurance now have access to pre-existing conditions insurance plans. Young adults can now stay on their parents' insurance plans up to age 26. By 2014, state-run insurance exchanges and Medicaid expansion could benefit many individuals with chronic health limitations and provide support for smaller employers to expand their benefits [21, 31]. There is mixed opinion on the effect these exchanges will have on ESI plans, with some studies suggesting a drop in employer plans [17] and others anticipating gains in covered employees [6]. However, ESI coverage will continue to be the primary insurance option for most working-age adults in the United States; thus, efforts to establish how cancer survivors will fare as insurance options change are necessary to ensure no decreases in their insurance quality.

Exploring childhood cancer survivors' attitudes and experiences with ESI coverage can provide context for the impact of the ACA on medically vulnerable populations in the United States. Uninsured survivors may have specific employment-related barriers, such as being unable to find jobs offering insurance or having physical limitations in their ability to work that prohibit certain occupations that are more likely to provide coverage. Concerns such as job lock – i.e., staying in a job due to fear of losing insurance coverage – have been identified as potentially influencing the employment decisions of chronically ill workers [27, 29], but job lock has not been explored among employed childhood cancer survivors.

The current qualitative study describes the experiences of survivors with and without employer-sponsored health insurance. We first discuss the difficulties survivors face in obtaining ESI coverage. We then describe the experiences and concerns reported by survivors on ESI regarding insurance rescission fears, job lock and financial worries.

## Methods

This study was conducted as part of a larger qualitative study to assess the quality of insurance coverage among childhood cancer survivors. The findings pertaining to insurance quality and health care access are published elsewhere [23]. For the current analyses, we focused on themes pertaining to employment and insurance coverage, because of the considerable role employment plays in insurance access in the United States. All study procedures were approved by the Institutional Review Boards of St. Jude Children's Research Hospital and the Massachusetts General Hospital/Partners HealthCare. In accordance with Consolidated Criteria for Reporting Qualitative Research guidelines, we describe our research team, study design, data analysis and findings.

### Study participants

Childhood Cancer Survivor Study (CCSS) participants who had completed the 2007 survey (approximately 9600 participants) were eligible for this study. CCSS is a multi-institutional retrospective cohort with longitudinal follow-up, funded by the National Cancer Institute [25]. CCSS participants were diagnosed between 1970 and 1986, before 21 years of age, with leukemia, CNS malignancies, Hodgkin's and non-Hodgkin lymphoma, Wilms tumor, neuroblastoma, soft tissue sarcoma, and bone cancer. Eligible survivors had survived at least 5 years from diagnosis and were identified at 26 centers in the United States and Canada. For our current study, we limited eligibility to survivors 18 years or older as of 2009. Using random selection, stratifying by age (<30 years, >30 years) and health insurance status (uninsured, insured) on the 2007 follow-up survey, we sent recruitment letters to 95 participants and were able to contact 48 (51%). Of those contacted and eligible, 88% participated.

We recruited participants until thematic saturation (the point at which no new themes emerged) was achieved [12]. From September 2009 through February 2010, in-depth interviews were conducted via telephone with 39 participants. Interviews lasted approximately 30 minutes. Demographic characteristics were obtained from the follow-up survey. Participants received a \$20 gift card. Because our study aim was to elicit themes related to employer-sponsored health insurance, and why uninsured survivors may face employment-related barriers to ESI, we limited our analyses to the 18 survivors with ESI coverage and the 14 survivors who were uninsured. The 7 remaining survivors on public insurance or individual health insurance were not included in these analyses.

### Data Collection and Analysis

We developed a semi-structured interview guide. The interview guide included questions regarding concerns and difficulties with health insurance coverage. We asked both insured and uninsured survivors if concerns about having health insurance affected their work decisions or career choices and to describe how these choices influenced their employment. We queried insured survivors about their concerns regarding the services, costs or access with their current ESI plans. Uninsured survivors were asked questions about their experiences with employment, previous insurance coverage and concerns about being uninsured. The guide was pilot tested on eight adult childhood cancer survivors who had received treatment at Massachusetts General Hospital in Boston, MA, and was modified based on feedback. One trained CCSS interviewer conducted the telephone interviews.

Interviews were recorded and transcribed; content analyses were conducted [19]. Two members of the research team coded all data independently using NVivo 8. At each analysis phase, the two coders compared their results to confirm intercoder reliability (final Kappa=0.88), resolving discrepancies through discussion with the PI and comparison of the raw data. The study was funded by the Lance Armstrong Foundation and National Cancer Institute (U24-CA55727).

## Results

Demographics for the 32 eligible participants are presented in Table 1 by insurance status at time of interview. Age at interview was comparable (insured ESI 32.3[*sd*=5.1] years and uninsured 33.5[*sd*=6.8] years). Uninsured/insured were similarly male and the most frequent cancer diagnosis for both groups was leukemia. The sample was generally low to mid-income, with 8 of 18 (44%) on employer insurance having household incomes below \$40,000 and 8 of 14 (57%) uninsured below \$40,000.

Of the 18 survivors on ESI, 3 reported receiving their insurance through their spouse's employer; the rest were on their own employer plan. The 14 uninsured survivors reported having health insurance coverage in the past; six previously had ESI through previous employment, while four had aged out of their parents' employer-sponsored insurance, and another four had a history of both public and private. The uninsured survivors were unemployed (*N*=7), employed in low-wage or part-time jobs with no insurance (*N*=5) or self-employed (*N*=2). Approximately two-thirds of the uninsured reported last having insurance within the last one to four years, while the remaining had been uninsured for much longer (range 9–20 years).

### Employment limitations drive being uninsured

Many survivors reported that they were unable to afford insurance without an employer contribution. They tended to value ESI plans as their only avenue to insurance coverage. Three uninsured survivors reported that they did not have health insurance due to losing their employer-sponsored insurance upon becoming unemployed. These survivors reported substantial difficulties in finding new jobs that offered insurance. One woman described her situation as *"I've been looking for a job since October. I've been looking for a job trying to find an employer and get insurance back."* Although we did not specifically ask survivors about the effect of the recession on their employment, most survivors reported having inconsistent employment over several years, rather than issues that arose due to the current economic situation.

Other survivors were only able to find part-time employment. Younger survivors (ages 26–30) who had more recently transitioned into the labor force particularly ascribed their lack of insurance to being unable to secure employment that offered coverage. Lower-income survivors acknowledged that they faced a trade-off between having a job and having insurance. They were unable to find jobs that offered ESI coverage and needed the income, but they could not afford to purchase an individual insurance plan. However, these survivors believed this meant that they did not qualify for public insurance programs because they made too much money.

A few uninsured survivors stated they needed additional vocational training to qualify for occupations that provided ESI. One woman had public insurance in the past, but had lost coverage after moving to a new state and was going back to school. She stated *"I'm going back to school so that I can actually get a job, where I can feel like I can take care of my kids and have insurance for myself."*

### **Losing eligibility for parents' ESI**

Several younger survivors (ages 26–30) lost their parents' insurance as they transitioned to adulthood, but were unable to find jobs that offered ESI coverage and could not afford to buy individual insurance. For four of these survivors, their coverage ended as they finished school or when they moved away from home. One part-time employed man stated *“(I had ESI coverage from my parents until) I was graduating college, until I was no longer a full-time student.”* This survivor had been unable to find a job that was full-time and provided benefits, which was a problem reported by many younger survivors.

### **Health limitations make survivors dependent on obtaining ESI or spouse's ESI**

Several survivors with current ESI coverage reported previous health insurance denials due to their cancer history. These survivors remained uninsured until they were able to obtain ESI coverage from their employer. This was a source of frustration because they considered their cancer to be in the past. One male survivor reported previously trying to buy individual coverage but being denied as *“I actually tried to get individual coverage myself through the same [insurance] company...and I ran into some fun issues. [But since I'm now insured through my employer] they suddenly had no problem with it.”*

Two survivors who had health limitations relied on their spouses to provide ESI coverage. One woman described having a gap in her past insurance coverage due to having brain surgery that limited her ability to work. However, because her husband had a job that offered ESI, she was currently insured. The other survivor obtained insurance coverage from his wife's employer, because he was disabled and unable to work.

### **Stable employment is the key to insurance for survivors**

A few survivors reported that they never had issues with having ESI coverage because they “always had worked.” However, ten survivors who were currently insured via an ESI plan had previous experience with being uninsured due to being unable to find work or from job loss. This group had been more consistently employed over time than the uninsured survivors, but stated finding employment was not always easy. One woman who currently had ESI described *“I've had problems obtaining a job...due to my side effects of the radiation, chemotherapy, surgery stuff like that,”* but had subsequently found a job with insurance.

The survivors with ESI reported making strategic decisions about their occupational choices. One man spoke about choosing a specific employment pathway so that he would be insured as *“I joined the union because they had the insurance...I made decisions throughout my pipeline career about where I would work, who I would work for so I could continue to have health care.”* Other ESI insured survivors described limiting their job search to positions that offered insurance coverage. Because they prioritized jobs that offered insurance, many survivors reported lengthy job searches before they were able to secure work that provided ESI.

### **ESI limits job mobility for survivors and spouses**

Job lock was an issue for several survivors. One woman had recently gone back to school, but learned she could not get insurance in her new career. She said *“I went through school to become a certified medical assistant and [when] I graduated school there wasn't any jobs that were with guaranteed insurance benefits. I ended up going back to a previous job that was not in the field that I'd been in school for because I knew that job had insurance benefits...I'm in here today a year and a half later after school I'm still at a job that's not in my career field all because insurance plays a very big key in my life.”*

Survivors' spouses also faced mobility problems. One woman described "*[My husband] would rather be a preacher and that doesn't come with typically health insurance and I haven't been able to find a job that provides affordable health insurance so that I can take that responsibility and so he stays with the job he has.*"

### **Job changes, unemployment and rescission cause worry for survivors on ESI**

For the ten survivors with ESI coverage who had been uninsured in the past, some reported ongoing worries about losing their ESI. One fear was losing their ESI eligibility from a reduction in work hours. One male survivor stated "*I'm on the insurance right now that my job provides but next year I have to have so many hours to have insurance and I may not have enough hours that are worked so that's what I'm concerned about.*" Other survivors had previous experience with ESI loss due to being laid off from their jobs and were acutely worried about job loss affecting their current coverage.

Survivors also worried that their insurer would retroactively cancel their policy due to their health status even though they were insured under an employer group plan – that is, they feared insurance rescission. This was described by one woman as: "*My fear of [losing my coverage] is just that if something really bad were to happen, they were to really look back on my medical record and say oh you had cancer when you were a kid.*"

Others were concerned their insurer would deny coverage of certain treatments due to their cancer history. One woman, who had taken FMLA leave from her employer, was waiting for a kidney transplant. She stated "*I'm afraid that they are going to start calling what I'm going through now a pre-existing condition. I'm getting ready to have a kidney transplant which is a pre-existing condition from my childhood cancer... I'm afraid that there's going to be a problem when it comes to the insurance side of things.*"

### **ESI coverage does not mitigate medical cost burdens for survivors**

Survivors mentioned financial issues with affording health care even with ESI coverage. Several reported that their ESI coverage did not adequately cover their health care needs and that they faced large financial barriers in their ability to pay for health care. One woman stated that the amount her family paid out of pocket, despite her husband's ESI, was substantial. She said "*I have had to leave a couple doctors because the plan dropped them and we couldn't afford to pay the whole bill.*" She later added, "*I usually put off paying off medical things, I pay my [other] bills first. I pay medical things but then we wind up with collection for medical bills.*"

## **Discussion**

Employer-sponsored insurance is typically less expensive for subscribers than individual coverage, and will remain the primary avenue for insurance coverage in the United States even under the Affordable Care Act [3]. However, the potential impact of this legislation on medically vulnerable populations is unclear. We found that adult childhood cancer survivors face many of the same employment barriers as the general population in obtaining ESI coverage, such as losing insurance due to changes in employment or having limited job choices that offered insurance coverage [26]. Yet, survivors' health status barriers led to ongoing limitations in their ability to work in jobs offering insurance beyond those of the general population. Many reported fears about insurance rescission due to their health history despite being insured on a group ESI plan. Others described not making career changes because they feared losing their insurance coverage.

The ACA provisions, while increasing insurance access in the general population and eliminating barriers to insurance for those with pre-existing conditions, may provide insufficient insurance protections for high-risk populations without access to ESI. Younger survivors (ages 26–30) were underemployed, had lost ESI after aging off their parents' plans and subsequently remained unable to afford individual health insurance or secure employment that offered it, similar to other populations of young adults with health limitations [30]. Unfortunately, these survivors are too old to qualify for the expanded parental insurance provision in the ACA, which only allows coverage up to age 26. Although the ACA's high risk insurance plans and state-run exchanges will provide subsidized access to coverage for those uninsured with pre-existing conditions [21], the cost sharing required by these plans may be burdensome for those who are underemployed [11].

Although the ACA provisions will ensure insurance coverage for many uninsured adults, the key to creating stable and affordable insurance opportunities for medically-vulnerable adults may be improving their employment outcomes [1]. Uninsured survivors reported needing additional training to qualify for jobs that offered insurance coverage, or if they were working, many were underemployed. The situations described by the survivors in our study mimic other analyses that find employees with limitations may not be employed to their fullest potential, and are often in jobs that pay less, have higher unemployment and have fewer insurance benefits than individuals without limitations [13].

Since 2000, the greatest drop in ESI coverage in the U.S. has been among lower-income, working-age adults ages 25–54 years old [8]. Lower-income individuals with ESI are more likely to be underinsured and often spend a higher proportion of their income on health care than those of higher income [7]. This is of concern because survivors in our study with ESI coverage described feeling financially stressed by their medical costs and some could not pay their medical bills. Insufficient insurance coverage may particularly affect access to important survivor-specific follow-up care and screening for late effects. In our earlier report, uninsured survivors avoided accessing health care due to cost, while many insured survivors had high out-of-pocket health care costs. Both insured and uninsured survivors had worries about future health care costs [23]. Survivors who restrict their use of survivor-specific health care services may face increased health problems over time, leading to future employment and insurance barriers. With the employee share of ESI premiums growing 9% in 2011 [2], cost barriers to health care will continue to increase for those on employee plans and will particularly burden those of low income.

There are certain limitations in our analysis. First, these data were collected just prior to the passing of the ACA in March 2010; therefore, we did not ask survivors about whether the provisions might influence their decisions about employment and ESI. Second, these data are drawn from a cohort of survivors who were treated at tertiary cancer centers, so our results may not be generalizable to more diverse cohorts of survivors. The income of the survivors in our qualitative interview sample was somewhat lower than the general Childhood Cancer Survivor Study, because we oversampled uninsured survivors. This suggests that the cost-related issues may be less salient for the overall participant cohort. However, in general, unemployment is higher for survivors [4], suggesting that ESI barriers most likely affect the larger population of childhood cancer survivors. Finally, we did not interview individuals without a history of cancer, which limits our ability to compare our findings to the general population.

Adults in the United States with chronic health problems face increased employment risks during times of economic downturn, and their access to ESI coverage may be particularly vulnerable. Many childhood cancer survivors have few viable avenues to insurance coverage because of poor employment. The Affordable Care Act provisions provide many

opportunities to expand health insurance options for survivors without access to ESI plans, and to protect those who are insured through their employer. Moving forward, the United States must ensure that medical vulnerable populations fare well with ACA by evaluating how their access to employer-sponsored health insurance is affected.

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**Table 1**

## Participant demographics by insurance status

N=32	Employer-Sponsored Insurance N=18	Uninsured N=14
Age, years (SD) (range 25–46)	32.3(5.1)	33.5(6.8)
Gender		
Male, N	9	7
Female, N	9	7
Cancer diagnosis		
Leukemia, N	8	5
Central Nervous System, N	3	0
Wilms (Kidney) Tumor, N	3	4
Lymphoma, N	1	2
Other, N	3	3
Race/ethnicity		
Non-Hispanic White, N	14	9
Other, N	4	5
Current employment status		
Employed, N*	14	7
Unemployed, N	4	7
Household income <sup>†</sup>		
<\$20,000	5	5
\$20,000–39,000	3	3
>\$40,000	10	6

\* Includes self-employed survivors (2 uninsured) and full-time students (1 uninsured)

<sup>†</sup> Missing income for 1 insured and 1 uninsured