Health insurance coverage and medical financial burden: Implications for childhood and adolescent cancer survivors

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University of Utah School of Medicine
Huntsman Cancer Institute
September is Childhood Cancer Awareness Month
A little about me

• MPH in Behavioral Science and Health Education
• PhD in Health Services Research
• Post-Doctoral Fellowship in Biobehavioral Cancer at the Fred Hutchinson Cancer Research Center
• Huntsman Cancer Institute’s Cancer Control and Population Sciences and Department of Pediatric Hematology/Oncology at the University of Utah
Research program goals

• Employ novel data resources to investigate public health and health services questions in cancer survivorship.
  • Healthcare access and utilization, insurance, and costs
  • Social and financial experiences
• Develop and test programs to support cancer patients & survivors.
Overview of talk

• Background and preliminary data
• Childhood Cancer Survivor Study (CCSS) – Insurance Study
  • Insurance coverage, medical costs, and ACA
  • Employment and insurance – job lock
  • Federal disability
• Utah data resources for cancer survivorship research
• Next steps
Childhood Cancer Survivors

- In the United States, there are approximately 400,000 childhood and adolescent cancer survivors.
- 5 year survival for children ages 0-14 years: <30% in 1960 increased to >80% today
- Risks of long-term complications from treatment:
  - 73%: ≥1 chronic health condition by 30 years after diagnosis
  - 54%: severe, life-threatening condition by age 50 years

Robison 2014 Nat Rev Cancer; Oeffinger 2006 NEJM; Armstrong 2014 JCO
Health insurance and survivors

• Quality health insurance is critical for childhood cancer survivors.
• Uninsured childhood survivors receive less recommended survivorship care.
• High copayments, high deductibles, and the recent declines in access and increased costs of employer-sponsored insurance have financial implications for survivors.

Park 2005 JCO; Casillas 2011 Cancer; Commonwealth Fund
Qualitative data on insurance

Insured survivors
• “We have a huge deductible because we’re paying, you know, like a thousand a month....But that’s all we could do, we both have pre-existing conditions.”
• “If I wouldn't have had that option [to stay on my parents' insurance]...I wouldn't be able to go to school because I'd [have] to work full-time to get insurance...and we would be in a lot of debt.”

Uninsured survivors
• “Yeah it does concern me that, if something happens....Nobody’s going to give me insurance. That’s a pre-existing condition and a million dollars worth of bills.”
Insurance and employment

• “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.”
Unemployment among CCSS survivors

Total not working/not in labor force:
- Survivors 25% & Siblings 18%

National Health Interview Survey: 21% not working due to health problems vs. 6% of controls (Dowling 2010, Cancer)
Patient Protection and Affordable Care Act

• The 2010 ACA established provisions intended to increase access to affordable health insurance.

• Specific provisions of the ACA benefit childhood cancer survivors and other high risk populations:
  ✓ Pre-existing conditions coverage
  ✓ Dependent coverage expansion to age 26
  ✓ Medicaid expansion
  ✓ Exchanges
  ✓ Prohibiting lifetime or annual limits
BRIEF COMMUNICATION

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


Research Letter | Health Care Reform

Assessing Health Insurance Coverage Characteristics and Impact on Health Care Cost, Worry, and Access: A Report From the Childhood Cancer Survivor Study

Elyse R. Park, PhD, MPH(2); Anne C. Kirchoff, PhD, MPH(2); Ryan D. Nipp, MD, MPH(2), et al

Childhood Cancer Survivor Study Participants’ Perceptions and Understanding of the Affordable Care Act


Financial Burden in Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study

Funded in 1994

Retrospective Cohort, diagnosed 1970-1986 with cancer ages 0-20 years

Expansion to diagnoses 1987-1999

26 Contributing Centers

5-Year Survivors & random sample of Siblings

Leukemia, lymphoma, central nervous system, Wilms, neuroblastoma, sarcoma, and bone cancers

Detailed Treatment Data, Wide Range of Outcomes

*20,720 Eligible

Lost (n=3017)

17,703 Contacted

Refusal (n=3189)

14,372 Participants

CURRENT STUDY (Park PI):

Used random selection, stratifying by age and health insurance status (uninsured, insured)
Study design

Phase 1: Qualitative exploration (survivors)
Phase 2: Survey (survivors & siblings)

To assess survivors’ & siblings’:
- Coverage difficulties and medical cost burden
- Familiarity with the ACA prior to its full implementation
- Employer-sponsored insurance and job lock
- Federal disability coverage
  - Priorities of insurance coverage
Data collection

- Surveys to N=1101 Survivors and N=360 Siblings
  - Mailed and internet completion options from June 2011-March 2012
  - Survivors: 64% response rate & 70% participation rate
  - Siblings: 59% response rate & 65% participation rate
- Final sample:
  - N=698 survivors & N=210 siblings
Currently **Insured** Persons

The following questions are for currently **insured** persons. If you currently do not have health insurance, please fill out the yellow survey.

You can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

Your generosity in participating is greatly appreciated.

Sincerely,

The LTFU study staff

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Currently **Uninsured** Persons

The following questions are for currently **uninsured** persons. If you currently have health insurance, please fill out the green survey.

You can be assured that we will respect your privacy at all times. Your name or other identifiers will not be used in any report of our findings, or released to any person or agency, except study investigators.

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Sincerely,

The LTFU study staff

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**Do you currently have health insurance that covers doctor and hospital care?**

- **Yes**  → *If Yes, please proceed to Question 1 on the next page.*
- **No**  → *If No, please stop and complete the Yellow survey.*

**Do you currently have health insurance that covers doctor and hospital care?**

- **Yes**  → *If Yes, please stop and complete the Green survey.*
- **No**  → *If No, please proceed to Question 1 on the next page.*
<table>
<thead>
<tr>
<th></th>
<th>Survivors N=698</th>
<th>Siblings N=210</th>
<th>p value</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
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<tr>
<td><strong>Age at survey (years)</strong></td>
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<td>22-29</td>
<td>30.7</td>
<td>29.1</td>
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<td>30-39</td>
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<tr>
<td>40-62</td>
<td>28.8</td>
<td>26.2</td>
<td></td>
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<tr>
<td><strong>Male</strong></td>
<td>45.0</td>
<td>39.1</td>
<td>0.13</td>
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<td><strong>Race/Ethnicity</strong></td>
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<td>White</td>
<td>92.8</td>
<td>92.5</td>
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<td>Black</td>
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<td><strong>Education (as of 2007 survey)</strong></td>
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<tr>
<td>≤High School</td>
<td>15.6</td>
<td>9.9</td>
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<td>Some college</td>
<td>28.5</td>
<td>26.6</td>
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<td>Completed college and above</td>
<td>56.0</td>
<td>63.5</td>
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<td><strong>Married, living as married</strong></td>
<td>56.8</td>
<td>67.5</td>
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<td><strong>Employed (full/part-time)</strong></td>
<td>74.0</td>
<td>78.7</td>
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<td>Diagnosis</td>
<td>%</td>
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<tr>
<td>---------------------------------</td>
<td>-------</td>
<td></td>
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<tr>
<td>Leukemia</td>
<td>35.0</td>
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<td>Central Nervous System Tumor</td>
<td>14.9</td>
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<td>Hodgkin lymphoma</td>
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<td>Other</td>
<td>37.3</td>
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<td>11-15</td>
<td>19.8</td>
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<td>16-20</td>
<td>14.7</td>
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<table>
<thead>
<tr>
<th>Years since diagnosis (mean, SD)</th>
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<td></td>
<td>30.3</td>
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<td>Second Cancer</td>
<td>5.1</td>
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# Insurance coverage, difficulties, & cost burden

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<th>Survivors N=698</th>
<th>Siblings N=210</th>
<th>P value</th>
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<tr>
<td><strong>Insured</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>%</td>
<td>89.8</td>
<td>92.2</td>
<td>0.31</td>
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<td><strong>Types of Insurance</strong></td>
<td></td>
<td></td>
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<tr>
<td>Employer</td>
<td>79.4</td>
<td>86.0</td>
<td>0.04</td>
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<tr>
<td>Individual</td>
<td>7.5</td>
<td>8.9</td>
<td>0.52</td>
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<td>Medicare</td>
<td>7.4</td>
<td>&lt;1.0</td>
<td>&lt;0.001</td>
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<td>Medicaid/State</td>
<td>12.3</td>
<td>4.4</td>
<td>&lt;0.01</td>
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<td><strong>History of health insurance denial</strong></td>
<td>15.4</td>
<td>1.6</td>
<td>&lt;0.001</td>
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<tr>
<td><strong>Difficulty getting coverage in past 2 years</strong></td>
<td>6.8</td>
<td>0.7</td>
<td>&lt;0.001</td>
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<tr>
<td><strong>&gt;10% of income on medical expenses</strong></td>
<td>16.7</td>
<td>9.5</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Park 2015 JAMA; Park 2017 JAMA IM
Out of pocket costs & healthcare utilization

- Skipped medical test, treatment, or follow-up
- Had a medical problem but did not go to a health care provider
- Did not see a specialist
- Put off/postponed Preventive Care
- Put off/postponed Dental Care
- Put off/postponed Vision Care
- Put off/postponed Mental Health
- Did not fill a prescription
- Had no primary care provider
- Took a smaller dose/fewer pills than prescribed

All P<0.01

Nipp 2017 J Clinic Oncol
Familiarity with ACA & other legislation

**Fig 2.** Familiarity of (A) survivors of childhood cancer and their siblings and of (B) insured and uninsured survivors with health insurance–related legislation. Multivariable logistic regressions adjusted for current age, sex, marital status, and chronic disease. Models comparing survivors and siblings were also adjusted for insurance status. ACA, Patient Protection and Affordable Care Act; ADA, Americans with Disabilities Act; COBRA, Consolidated Omnibus Budget Reconciliation Act; FMLA, Family Medical Leave Act; HIPAA, Health Insurance Portability and Accountability Act; OR, odds ratio.

Park 2015 J Clinic Oncol
Job lock

• Survivors report working in jobs that typically require a lower level of skill and education than their siblings.
  • Survivors have lower incomes compared to their siblings.
  • Survivors are less likely to be covered by an employer-sponsored insurance plan.

• Job lock – staying in a job due to fear of losing insurance coverage – may limit employment options among survivors.

# Job lock among full-time employed

**Survivors**

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
<th>N</th>
<th>%</th>
<th>P value</th>
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<tbody>
<tr>
<td>History of Job Lock</td>
<td>84</td>
<td>23.2</td>
<td>22</td>
<td>16.9</td>
<td>0.16</td>
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<tr>
<td>Health Insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Employer</td>
<td>339</td>
<td>88.0</td>
<td>110</td>
<td>88.5</td>
<td>0.50</td>
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<tr>
<td>Self</td>
<td>304</td>
<td>80.2</td>
<td>101</td>
<td>83.8</td>
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<tr>
<td>Other (family member)</td>
<td>70</td>
<td>19.3</td>
<td>17</td>
<td>16.2</td>
<td></td>
</tr>
<tr>
<td>Individual</td>
<td>23</td>
<td>5.4</td>
<td>6</td>
<td>3.0</td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>10</td>
<td>2.3</td>
<td>3</td>
<td>1.9</td>
<td></td>
</tr>
<tr>
<td>Uninsured</td>
<td>20</td>
<td>4.4</td>
<td>9</td>
<td>6.7</td>
<td></td>
</tr>
<tr>
<td>History of Health Insurance Denial</td>
<td>52</td>
<td>13.4</td>
<td>3</td>
<td>1.8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Problems Paying Medical Bills in Past Year</td>
<td>75</td>
<td>20.1</td>
<td>15</td>
<td>12.9</td>
<td>0.06</td>
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</table>
## Predictors of job lock among survivors

<table>
<thead>
<tr>
<th>N=394</th>
<th>Job lock</th>
<th>Relative Risk</th>
<th>95% CI</th>
<th>p-value</th>
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<tbody>
<tr>
<td></td>
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<td></td>
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<tr>
<td>Female vs. Male (ref)</td>
<td></td>
<td>1.65</td>
<td>1.10-2.47</td>
<td>0.02</td>
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<td>Age at survey</td>
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<tr>
<td>22-29 (ref)</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
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<tr>
<td>30-39</td>
<td></td>
<td>1.53</td>
<td>0.90-2.59</td>
<td>0.12</td>
</tr>
<tr>
<td>40-62</td>
<td></td>
<td>1.08</td>
<td>0.61-1.91</td>
<td>0.79</td>
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<tr>
<td>Household income &lt;$39K vs. &gt;$40K (ref)</td>
<td></td>
<td>0.81</td>
<td>0.41-1.60</td>
<td>0.55</td>
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<tr>
<td>Married vs. other (ref)</td>
<td></td>
<td>1.46</td>
<td>0.82-2.59</td>
<td>0.19</td>
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<tr>
<td>Severe conditions vs. Other (ref)</td>
<td></td>
<td>1.61</td>
<td>1.09-2.40</td>
<td>0.02</td>
</tr>
</tbody>
</table>

Kirchhoff 2017 JAMA Onc
Job lock, insurance denial, & problems paying medical bills

**HI denial history**

- Denial: RR=1.75, 95% CI 1.14-2.69
- No Denial

**Problems paying medical bills**

- Problem: RR=2.64, 95% CI 1.69-4.13
- No Problem

Adjusted for age at survey, sex, race, & years since diagnosis

Kirchhoff 2017 JAMA Onc
Supplemental Security Income (SSI) and Social Security Disability Insurance (DI)

• Survivors are 6 times more likely not to work due to health problems compared to their siblings.

• SSI and DI federal programs provide disability benefits.
  o SSI: limited income; not based on prior work history; most enrollees are on Medicaid and food stamps.
  o DI: pays benefits to those who worked and paid Social Security taxes; Medicare eligible after 2 years.

Kirchhoff 2015 JNCI
Steps to Enrolling Supplemental Security Income & Social Security Disability Insurance

1. Not working earning average less than $1,040/month
2. "Severe" condition (cancer, heart, diabetes, etc.) for at least 12 months
3. Condition found in list of disabling conditions (if not, SSA will decide if it is of equal severity)
4. Cannot do your prior work.
5. Cannot adjust to other type of work.
6. Individual may be eligible for SSI or DI

Supplemental Security Income: Pays benefits to disabled or blind adults, aged 65 and older, or children who have limited income and resources. Sometimes called "Income of Resource."  

Social Security Disability Insurance: Pays disability benefits to individuals aged 18 and older if they have worked long enough (paid SS taxes) and have a medical condition preventing them from working for 12 months or more.

Fill out the Online Disability Report
Individual can also fill out report with SI step in subsequent step.

Schedule an appointment with SSA representative
Information needed to apply:
- SS card/copies of SS card
- Birth certificateproof of age
- Residency information (address, household, landlord name)
- Payroll slips, bank books, insurance policies, burial fund records, other recorded income and resources.
- Contact information for doctors, hospitals, and clinics attended.
- Proof of U.S. Citizenship or non-citizenship eligible status.
- Checkbooks, paper showing back credit union, savings, and loan account information.
- Income tax, bank statements, and other financial or medical information.

Income Exclusions:
- Free MCI income limits
- Free SSA income limits
- Free SI income limits
- Income tax refunds, SSI
- Other, authorized expenses

State agency completes decision by contacting individual’s doctors and disability specialists for:
- "What is the medical condition?"
- "What medical tests have been done?"
- "What treatment has been received?"

SSA review application if it has been approved for disability benefits turned over

Select Terms
- SSI: Social Security Disability Insurance
- DI: Supplemental Security Income
- SSA: Social Security Administration
SSI & DI among survivors and siblings

SSI (p<0.001)

- Ever on SSI: RR 5.05, 95% CI 1.98-12.80*

- SSI 7.3% vs U.S. 2.5%, P<0.001

DI (p=0.016)

- Ever on DI: RR 1.76, 95% CI 0.90-3.44*

- DI 6.4% vs U.S. 4.8%, P=0.04

Survivors currently enrolled more than the U.S. population:

- SSI 7.3% vs U.S. 2.5%, P<0.001
- DI 6.4% vs U.S. 4.8%, P=0.04

*Adjusted for age, gender & race
# Current SSI & DI among survivors

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<tr>
<th></th>
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<th>DI</th>
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<tr>
<td></td>
<td>RR</td>
<td>95% CI</td>
<td>P value</td>
<td>RR</td>
<td>95% CI</td>
<td>P value</td>
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<tr>
<td><strong>Female vs. Male (ref)</strong></td>
<td>1.74</td>
<td>1.00-3.06</td>
<td>0.05</td>
<td>1.16</td>
<td>0.64-2.08</td>
<td>0.63</td>
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<td>16-20 (ref)</td>
<td>1</td>
<td>1</td>
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<td>1</td>
<td>1</td>
<td></td>
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<td>11-15</td>
<td>4.89</td>
<td>0.66-36.51</td>
<td>0.12</td>
<td>1.55</td>
<td>0.32-7.56</td>
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<td>5-10</td>
<td>4.88</td>
<td>0.63-37.89</td>
<td>0.13</td>
<td>1.78</td>
<td>0.35-9.01</td>
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<td>0-4</td>
<td>7.56</td>
<td>1.02-56.16</td>
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<td>0.59-4.65</td>
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<td>3.35</td>
<td>1.53-7.33</td>
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<td><strong>Cranial Radiation</strong></td>
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<tr>
<td>None (ref)</td>
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<td>Scatter Low/High†</td>
<td>0.63</td>
<td>0.25-1.59</td>
<td>0.33</td>
<td>0.78</td>
<td>0.27-2.30</td>
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<td>≤18 Gy</td>
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<td>0.27-2.62</td>
<td>0.76</td>
<td>1.24</td>
<td>0.39-4.00</td>
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<td>19-24 Gy</td>
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<td>0.41-4.07</td>
<td>0.67</td>
<td>2.82</td>
<td>1.08-7.33</td>
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<td>≥25 Gy</td>
<td>3.93</td>
<td>2.05-7.56</td>
<td>&lt;0.001</td>
<td>3.65</td>
<td>1.65-8.06</td>
<td>0.001</td>
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<td><strong>Severe conditions vs. Other (ref)</strong></td>
<td>3.77</td>
<td>2.04-6.96</td>
<td>&lt;0.001</td>
<td>2.73</td>
<td>1.45-5.14</td>
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Adjusted for age at survey, race, & years since diagnosis

Kirchhoff 2015 JNCI
Summary

• Growing literature on insurance, employment, and economic impact of cancer on young survivors.

• Medical costs and dependence on employment for insurance continue to affect survivors.

• Upcoming challenges to the ACA could leave cancer survivors particularly vulnerable from an insurance and access to care standpoint.
Challenges for cancer survivors

• States not participating in Medicaid expansion
• Forgo coverage
• Underinsured
  • Narrow plans limit where care is obtained
  • Limited access to specialists
  • No coverage for survivor-specific prevention guidelines
  • High out-of-pocket costs and skipping care
• ACA future unknown – pre-existing conditions; essential benefits; cost-sharing
Next steps

• New survey to CCSS participants on financial toxicity.
• Develop and pilot a psychoeducational navigation-based health insurance intervention to assist survivors with obtaining and utilizing coverage, and managing costs.
  • Pilot study to move program into the adolescent and young adult age range.
• Examination of insurance & financial burden in national childhood cancer samples.
Accessibility & affordability of healthcare

National Health Interview Survey 2010-2014

- Insured: 89.8% vs. 92.2%
- Problems paying medical bills: 22% vs. 16%
- Worried about medical bills: 16% vs. 9%
- Delayed medical care: Survivors vs. Comparison
- Unable to afford prescriptions: Survivors vs. Comparison
- Unable to afford follow-up care: Survivors vs. Comparison
- Unable to afford specialist care: Survivors vs. Comparison

Kuhlthau 2016 J Cancer Surv
Utah data resources and survivors
• What are the healthcare experiences of young cancer survivors in Utah and the Mountain West?

• What data resources are available to investigate these questions?
Utah Population Database + Utah Cancer Registry

• Cohort to investigate pediatric and adolescent cancer in our catchment area
  • Healthcare needs & experiences of survivors
  • Healthcare utilization
  • Costs of care
  • Late effects
## Pediatric, Adolescent and Young Adult Cancer Patients

1/1/86-present

Ages 0-25 at diagnosis

N=6900

### Clinical & Payer

**SelectHealth**
- Pharmacy claims
- Medical claims
- Enrollment

**Intermountain Medical Records**
- Beginning 1998
- Inpatient & outpatient encounters
- Discharge diagnoses
- Cost and Charges
- Billing info (Insurance)

### State & National Data

**Utah Population Database**
- Residency
- Birth/Death Certificate
- Driver's license
- Marriage/Divorce records

**Utah DOH**
- Beginning 1996
- Statewide ambulatory surgeries
- Statewide inpatient discharge data

**Other:**
- University of Utah Data
- All Payer Claims Data
- Vaccination registry

**National Death Index**
- Mortality
- Death Date
- Cause of death

- Siblings
- General Population
<table>
<thead>
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<td>0-4</td>
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<td>20.4</td>
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<td>Insurance at Diagnosis*</td>
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<tr>
<td>Public</td>
<td>107</td>
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<tr>
<td>Uninsured</td>
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*Leukemia patients only
## Hospitalization Risk – all cancers

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<th>Number of admissions</th>
<th>Length of stay (days)</th>
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<td>Rate Ratio</td>
<td>95% CI</td>
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<td><strong>General pop (ref)</strong></td>
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<tr>
<td><strong>All Survivors</strong></td>
<td>1499</td>
<td>1.67</td>
<td>1.58-1.77</td>
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<td><strong>Diagnoses</strong></td>
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<td>Leukemia</td>
<td>273</td>
<td>1.84</td>
<td>1.65-2.05</td>
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<td>Lymphoma</td>
<td>263</td>
<td>1.83</td>
<td>1.65-2.04</td>
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<td>CNS</td>
<td>230</td>
<td>1.71</td>
<td>1.53-1.92</td>
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</table>

Adjusted for age at survey, sex, rurality, & years since diagnosis

Kirchhoff 2014 CEBP
Pulmonary-related ED visits

New Cases (0-<5 yrs)
- Any Pulmonary: 1.18 (0.73, 1.89)
- Asthma: 4.31 (3.79, 4.92)*
- Respiratory Disease: 4.43 (3.02, 6.49)*
- Respiratory Infection: 4.96 (4.27, 5.76)*

Early Survivors (5-<10 yrs)
- Any Pulmonary: 2.04 (1.57, 2.64)*
- Asthma: 4.27 (1.63, 11.19)*
- Respiratory Disease: 1.26 (0.70, 2.27)
- Respiratory Infection: 2.19 (1.62, 2.98)*

Late Survivors (10-18 yrs)
- Any Pulmonary: 1.85 (1.31, 2.60)*
- Asthma: 1.54 (0.52, 4.51)
- Respiratory Disease: 1.90 (1.01, 3.56)*
- Respiratory Infection: 1.95 (1.25, 3.04)*

* Significant at p<0.05

Ramsay in press
Next Steps – All Payer Claims Data

Estimated to represent >90% covered by group or individual commercial health insurance plans

1. Determine the ability to link APCD records to individual cancer patient identifiers in the UCR to populate cancer treatment summaries.

2. Evaluate the utility of APCD claims to identify AYA cancer treatment information.
# SEER Reportable Cancers, Diagnosed in Utah 2013, Linked to 2013 APCD Records

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<td>9441</td>
<td>82</td>
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<td><strong>Age at Diagnosis</strong></td>
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<tr>
<td>&lt;18</td>
<td>167</td>
<td>93</td>
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<tr>
<td>18-29</td>
<td>302</td>
<td>89</td>
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<tr>
<td>30-49</td>
<td>1497</td>
<td>89</td>
</tr>
<tr>
<td>50-64</td>
<td>3160</td>
<td>87</td>
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<tr>
<td><strong>Insurance Status</strong></td>
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</tr>
<tr>
<td>Private</td>
<td>4043</td>
<td>92</td>
</tr>
<tr>
<td>Medicaid</td>
<td>376</td>
<td>97</td>
</tr>
<tr>
<td>Medicare</td>
<td>2488</td>
<td>79</td>
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<tr>
<td>Medicare + Medicaid</td>
<td>590</td>
<td>73</td>
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<tr>
<td>Uninsured</td>
<td>250</td>
<td>68</td>
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<tr>
<td>Other</td>
<td>202</td>
<td>41</td>
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<tr>
<td>Unknown</td>
<td>1492</td>
<td>81</td>
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</table>
Future directions

• Unknown future of ACA and impact on childhood cancer survivors
  • Insurance changes, out of pocket costs
  • Access to survivor-focused healthcare

• Statewide data resource
  • Healthcare utilization and costs/charges
  • Statewide immunizations registry to examine HPV vaccination
Financial Hardship and the Economic Effect of Childhood Cancer Survivorship


Advancing Childhood Cancer Care and Quality of Survival through Late Effects Research

Published online June 6, 2018

This Special Series Issue of Journal of Clinical Oncology highlights knowledge about long-term and late-onset adverse outcomes (late effects) after treatment of pediatric malignancies, their impact on quality of survival, and ongoing efforts to address the unique biomedical and psychosocial needs of the growing population of childhood cancer survivors. Inarguably, the desire to mitigate late effects has played a substantial role in the evolution of therapeutic strategies for children with cancer.

In this issue

- Cardiovascular Disease in Survivors of Childhood Cancer: Insights Into Epidemiology, Pathophysiology, and Prevention
  Armenian et al
- Risk, Risk Factors, and Surveillance of Subsequent Malignant Neoplasms in Survivors of Childhood Cancer: A Review
  Turcotte et al
- Endocrine Late Effects in Childhood Cancer Survivors
  Chemaitilly et al
- Improving Male Reproductive Health After Childhood, Adolescence, and Young Adult Cancer: Progress and Future Directions for Survivorship Research
  Kerney et al
- Reproductive Function and Outcomes in Female Survivors of Childhood, Adolescence, and Young Adult Cancer: A Review
  van Dorp et al
- Neurocognitive Outcomes and Interventions in Long-Term Survivors of Childhood Cancer
  Kruijl et al
- Psychological Symptoms, Social Outcomes, Socioeconomic Attainment, and Health Behaviors Among Survivors of Childhood Cancer: Current State of the Literature
  Brinkman et al
- Financial Hardship and the Economic Effect of Childhood Cancer Survivorship
  Nathan et al
- Premature Physiologic Aging as a Paradigm for Understanding Increased Risk of Adverse Health Across the Lifespan of Survivors of Childhood Cancer
  Ness et al
- Surveillance for Late Effects in Childhood Cancer Survivors
  Landier et al
- Models of Care for Survivors of Childhood Cancer From Across the Globe: Advancing Survivorship Care in the Next Decade
  Tonorezos et al
- New Agents, Emerging Late Effects, and the Development of Precision Survivorship Care
  Chow et al
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• St. Baldrick’s Foundation
• Intermountain/Primary Children’s Hospital Foundation
Thank you!

http://uofuhealth.utah.edu/huntsman/labs/kirchhoff/
anne.kirchhoff@hci.utah.edu

Instagram kirchhoff_hci
Survey Content

• Current Coverage & Coverage History
• Current Employment
• Health Care Utilization
• Perceived Coverage Quality
• Supplemental Security Income and Social Security Disability Insurance – Current and Former Coverage
• Health Care Reform & Insurance-Related Protections
Survey Administration: 5/11-4/12

Survivors
Mailed questionnaires
(n = 1,101)

Did not respond (n = 260)
Deceased (n = 8)
Lost to follow-up (n = 114)
Refused (n = 21)

Returned (n = 698)

Insured (n = 619)
Uninsured (n = 79)

Siblings
Mailed questionnaires
(n = 360)

Did not respond (n = 111)
Deceased (n = 0)
Lost to follow-up (n = 34)
Refused (n = 4)
Canadian (n = 1)

Returned (n = 210)

Insured (n = 189)
Uninsured (n = 21)
Importance of plan coverage, features and costs

<table>
<thead>
<tr>
<th></th>
<th>Survivors N=698</th>
<th>Siblings N=210</th>
<th>p value</th>
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<tbody>
<tr>
<td><strong>PLAN COVERAGE</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Primary Care</td>
<td>94.3</td>
<td>89.7</td>
<td>.02</td>
</tr>
<tr>
<td>Dental Care</td>
<td>67.4</td>
<td>65.8</td>
<td>.22</td>
</tr>
<tr>
<td>Vision Care</td>
<td>60.7</td>
<td>50.0</td>
<td>.01</td>
</tr>
<tr>
<td><strong>PLAN FEATURES</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No Waiting Period</td>
<td>79.0</td>
<td>69.0</td>
<td>.01</td>
</tr>
<tr>
<td>Choice of PCP</td>
<td>76.5</td>
<td>66.7</td>
<td>.01</td>
</tr>
<tr>
<td>Ability to Self Refer</td>
<td>55.7</td>
<td>50.0</td>
<td>.15</td>
</tr>
<tr>
<td><strong>PLAN COST</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Affordable premiums</td>
<td>88.1</td>
<td>83.7</td>
<td>.10</td>
</tr>
<tr>
<td>No added expense-PEC</td>
<td>87.2</td>
<td>69.8</td>
<td>.01</td>
</tr>
<tr>
<td>Low Deductible</td>
<td>73.8</td>
<td>66.2</td>
<td>.01</td>
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Park 2015, JCO; Park in development
Young adult cancer patients post-ACA

<table>
<thead>
<tr>
<th>Type of Health Insurance Coverage</th>
<th>Patients Aged 18 to 25 Years</th>
<th>Patients Aged 26 to 29 Years</th>
<th>Difference in Difference</th>
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<tbody>
<tr>
<td></td>
<td>Before, %</td>
<td>After, %</td>
<td>Difference</td>
</tr>
<tr>
<td>Any health insurance</td>
<td>83.5</td>
<td>85.4</td>
<td>1.9c</td>
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<tr>
<td>Medicaid health insurance</td>
<td>18.2</td>
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Abbreviations: ACA, Patient Protection and Affordable Care Act; After, October 2010 to December 2012; Before, January 2007 to September 2010; SEER, Surveillance, Epidemiology, and End Results.

a Represents the net change in each health insurance type for patients with cancer who were aged 18 to 25 years after the early implementation of the ACA; estimates are from generalized mixed effect models with random intercepts for each cancer registry state using the logit link function adjusting for time period, age group, time period*age group, sex, race/ethnicity, marital status, cancer site, and stage of disease at diagnosis.

b P value of the interaction term for time period*age.

c Statistically significant at P <.01 as derived from chi-square tests.

Parsons 2016, Cancer