Gaps in Insurance Coverage for Pediatric Patients With Acute Lymphoblastic Leukemia

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Abstract

Purpose: Continuous insurance coverage is an important component of effective health care. Evaluation of insurance gaps in pediatric cancer care is an understudied area.

Methods: We conducted a retrospective analysis of payer data from outpatient oncology encounters at Primary Children’s Hospital (Salt Lake City, UT) over the first 2 years of therapy for pediatric patients with acute lymphoblastic leukemia diagnosed from 1998 to 2010 (N = 380). Using logistic regression, we evaluated demographic and clinical predictors (age at diagnosis, sex, ethnicity, high/standard acute lymphoblastic leukemia risk, and rural/urban county of residence at diagnosis) of a gap in health insurance.

Results: The median age at diagnosis was 4 years (interquartile range, 3 to 8 years), and 172 patients (45%) were girls. In the first 2 years of treatment, 45 patients (12%) experienced a gap in health insurance. The odds of having a gap in insurance coverage decreased by 16% each year from 1998 to 2010 (odds ratio, 0.84; 95% CI, 0.76 to 0.93; test for trend, P = .001). Public insurance at diagnosis was associated with a four-fold increased likelihood of experiencing an insurance gap (odds ratio, 4.09; 95% CI, 1.98 to 8.44; P < .001) compared with patients with private insurance at diagnosis.

Conclusion: Gaps in insurance coverage during pediatric cancer treatment are not uncommon, which highlights the importance of discussing insurance status at diagnosis and throughout a patient’s treatment course to help patients and their families prepare for any changes and avoid unnecessary financial burden. Future research should focus on examining the effect of insurance gaps on patient outcomes and evaluating likelihood of gaps in insurance after health care reform.

Introduction

Stable health insurance coverage is an important predictor of receiving regular primary care and having medical needs met among children.1,2 A health insurance gap for any length of time is associated with compromises in health care such as delayed urgent care or having no regular source of preventive care for low-income children.3 Few studies, however, have examined insurance gaps in acute and high-cost pediatric conditions, such as cancer. An estimated 15,780 children younger than age 19 years were diagnosed with cancer in the United States in 2014, and this number is expected to increase.4 To date, insurance coverage across the duration of treatment has not been evaluated in a pediatric cancer population, for whom consistent treatment is an important component of long-term health.

At children’s hospitals, pediatric patients with conditions such as cancer are often treated regardless of insurance status through charity programs or are provided support by the hospital to enroll on public insurance.5 Despite these programs, uninsured patients create a substantial burden on the health care system. In addition, uninsured patients’ follow-up and primary care may be affected.6 Even with insurance coverage, many families of children with cancer report significant financial strain as a result of the direct and indirect costs of cancer treatment.7 Families report borrowing money and income losses as a result of reduction or termination of parental employment because of caretaking needs.8-11 Moreover, changes in parents’ employment status can result in the loss of, or changes in, employer-sponsored health insurance coverage.

Of children diagnosed with cancer in the United States in 2014, approximately 30% were diagnosed with leukemia, the most common of which is acute lymphoblastic leukemia (ALL).12,13 Treatment and follow-up for ALL requires several years of outpatient and hospital-based care. During this time, families of children with ALL report substantial stress related to the financial and emotional burden of treatment.11,14,15 A loss of health insurance may result in increased direct costs of cancer care as a result of greater out-of-pocket costs, further increasing the family’s financial burden and compromising continuity of care for the patient.

The current study examines health insurance coverage and gaps for pediatric patients with ALL diagnosed at age less than 18 years from 1998 to 2010 and treated at a single children’s hospital, using payer information from a large integrated health care system. We examine insurance status among this cohort during the first 2 years of cancer treatment and investigate patient predictors of gaps in health insurance.

Methods

Patient Sample
We partnered with Intermountain Healthcare (IH), which operates a nonprofit system of 22 hospitals and more than 185 clinics including Primary Children’s Hospital (PCH), a state-
of-the-art tertiary care center located in Salt Lake City, Utah.\textsuperscript{16} PCH serves as the primary pediatric oncology care center for Utah and draws patients from six neighboring states (Idaho, Wyoming, Montana, Nevada, Colorado, and Arizona).\textsuperscript{15} The institutional review boards of IH and the University of Utah approved this study.

IH maintains an enterprise data warehouse (EDW), a data repository that integrates both clinical and administrative data from IH electronic medical records. The EDW is a collection of various data marts including financial, claims and eligibility, laboratory, pharmacy, and other system sources. The EDW includes the IH cancer registry, which captures diagnosis and treatment information for all patients with cancer in the IH system to report to the Utah Cancer Registry, a designated National Cancer Institute Surveillance, Epidemiology, and End Results program site.

Using the IH cancer registry, we identified patients diagnosed with ALL before the age of 18 years between January 1, 1998, and December 31, 2010, who received part or all of their treatment at PCH (patients diagnosed before 1998 were excluded because of electronic data quality concerns). Four hundred eighteen patients were identified through the cancer registry. The IH cancer registry provided diagnosis data (eg. age at diagnosis, specific diagnosis), which we supplemented with clinical records from the EDW to obtain other patient demographics (eg. sex, zip code at diagnosis, insurance). Of the 418 potential study patients, 38 were excluded because zip code at diagnosis was missing (n = 9) or because they were infants at diagnosis (n = 9), were lost to follow-up before 2 years after diagnosis (n = 11), or were uninsured throughout (n = 9). We excluded infants because they have a different treatment trajectory than older patients, and we excluded patients who were uninsured throughout treatment because of our interest in gaps in insurance.

Data were obtained for all outpatient encounters in the pediatric oncology clinic at PCH after the diagnosis date. These frequent outpatient encounters over the course of therapy allow for accurate tracking of payer information across time. The observation period was defined as from the date of diagnosis to 2 years after diagnosis (or date of death if it occurred before 2 years after diagnosis) because treatment is relatively standard across sexes for the first 2 years.

Demographic and Clinical Measures

Because of the retrospective nature of the current analyses, demographic and clinical variables were limited to those available in the patient records and included sex, age at diagnosis, ethnicity, zip code at diagnosis, risk of relapse, and insurance at diagnosis (public, private, or uninsured). Zip code was used to assign rural or urban designation based on Rural-Urban Commuting Area codes,\textsuperscript{18} combining the large rural and urban categories versus all other categories. ALL risk group (high \(v\) standard) was assigned using the current National Cancer Institute criteria based on age at diagnosis, WBC count, and lineage (B cell vs T cell).\textsuperscript{19} We also calculated the total number of outpatient encounters in the PCH oncology clinic over the observation period for each patient.

A census tract measure of area-level household income, derived from zip code, was not associated with the insurance gaps in preliminary analyses and was excluded from final analyses.

We used two data sources to assign ethnicity.\textsuperscript{20} First, we matched patient surnames with the 1990 Census Heavily Hispanic Surname list.\textsuperscript{21-23} Patients with hyphenated names were matched based on either last name. Second, we used the ethnicity classification stored in the statewide Utah Population Database. The Utah Population Database collects ethnicity data from various sources including birth certificates, driver’s licenses, and medical records and combines them into a single coding system to facilitate research. If a patient was Hispanic according to either source, we classified the patient as Hispanic. Combining classification methods results in less error than any single method alone.\textsuperscript{24}

Insurance Coverage Gaps

Payer information is available for each outpatient encounter in the IH system. A patient or family member can list up to four different payers at each visit. After any and all insurance companies are billed, the family is held accountable for remaining charges. Importantly, the hospital billing department verifies each payer for each encounter and allows for retrospective changes in records to ensure records reflect accurate eligibility at the time of the encounter. For each encounter, we assigned a primary payer (public, private, or uninsured). In the instance of multiple or dual coverage, we assigned the primary payer based on the following hierarchy of coverage: private (eg, United Health Care), public (Medicaid, Medicare), and uninsured.\textsuperscript{25}

To describe insurance coverage, we created the following four-level mutually exclusive categorical variable: patients who were continually insured through private insurance; patients who were continually insured with public insurance; patients who were continually insured but had a mixture of public and private coverage; and patients who experienced any gap in insurance within 2 years from the date of diagnosis.\textsuperscript{25} We determined that a patient had a gap in insurance if the patient experienced at least one uninsured encounter.

Statistical Analyses

To test for differences in demographic variables, we performed \(\chi^2\) tests (and Fisher’s exact tests, as necessary) by the four-level insurance variable. We compared number of deaths and total encounters between those who were continually insured versus those who experienced a gap using the Fisher’s exact test and \(t\) test, respectively.

To evaluate demographic and clinical predictors of experiencing a gap in insurance, we performed a multivariable logistic regression to obtain odds ratios (ORs) and 95% CIs. The likelihood of having a gap may be affected by the number of encounters. In addition, patients who died in the first 2 years after diagnosis could have fewer encounters because of shorter follow-up. Therefore, we adjusted the regression for encounters
Health Insurance Gaps in Pediatric Patients With ALL

and deaths. The outcome was a binary variable set to 1 if the patient experienced at least one gap in insurance and set to 0 otherwise.

To explore change in insurance coverage across diagnosis years, we fit the proportion of patients in each category of the four-level insurance variable as the outcome variable in a multinomial logistic regression model with year of diagnosis as the predictor. Finally, for patients who experienced a gap in insurance, we calculated the percentage of their total encounters in which they did not have insurance.

All analyses were performed using Stata 13 (Stata, College Station, TX). Statistical significance for all analyses was set at \( \alpha = .05 \).

Results

Demographic and Clinical Factors and Insurance Coverage

Our sample consisted of 380 patients. As shown in Table 1, the majority of patients had an insurance provider at every encounter (n = 335, 88%), with 229 patients (60%) continually privately insured, 62 patients (16%) continually publically insured, and 44 patients (12%) continually insured through a combination of public and private insurers. Forty-five patients (12%) experienced a gap in insurance; that is, they had at least one outpatient encounter in which they had no insurance coverage within 2 years from diagnosis. There were no statistically significant differences among the insurance groups with regard to sex, age at diagnosis, ethnicity, ALL risk, or Rural-Urban Commuting Area classification.

Within the 2-year observation period, the average number of outpatient encounters was similar between those who experienced a gap in insurance (21.3 encounters; standard deviation, 5.9 encounters) and those who were continually insured (20.8 encounters; standard deviation, 5.3 encounters) and those who experienced a gap in insurance. The median percentage of their total encounters in which they did not have insurance was 12% (interquartile range, 7.1% to 29.1%).

Discussion

To our knowledge, this study is the first to use hospital billing data to examine gaps in insurance coverage for a large group of pediatric patients with ALL. Although most patients maintained insurance continually during the observation period, 12% of patients experienced a gap in health insurance during their first 2 years of cancer therapy. Including patients who were uninsured throughout the observation period (who were not included in this analysis), 14% of patients experienced a period with no health insurance. Despite the difference in study design, we found that the prevalence of insurance gaps across a 2-year time period was similar to that observed in studies that have used survey-based methods in national pediatric samples. Although the direct causes of these insurance gaps are not known, our earlier studies have demonstrated that there are substantial direct and indirect (eg, negative effects on parents’ employment and income, transportation expenses) costs associated with pediatric cancers.

As a result of these costs, pediatric cancer families may face financial stresses during therapy that could affect their insurance coverage. The findings from this study add to a growing understanding of the financial burden experienced by families of children with cancer. Additionally, this study contributes to the understanding of insurance coverage for pediatric patients with cancer before major changes in the insurance landscape in the United States. Our data are from a period before the implementation of key Affordable Care Act (ACA) provisions (eg, state and federal exchanges, Medicaid expansion in certain
Understanding the state of insurance coverage before the ACA is critical for measuring the success of the ACA provisions, particularly as they apply to children with chronic illness, because earlier studies found that survivors of childhood cancer demonstrate low knowledge of the insurance-related protections under the ACA. Our results inform ongoing conversations regarding health care coverage at a state, as well as national, level by providing necessary baseline data that can be used for comparison to insurance coverage after the ACA and to identify areas of success or failure of the ACA for high-risk patients.

We found that patients with ALL who were publicly insured at diagnosis were four times more likely to experience a gap in insurance coverage compared with patients who had private insurance at diagnosis. Low enrollment in Medicaid or the Children’s Health Insurance Program for eligible children typically occurs as a result of either dropout or lack of initial enrollment. Utah is similar to several other states (such as Nebraska, Colorado, Vermont, and Kansas) in that low enrollment of eligible children in public insurance is a result of lower than average uptake and higher than average retention. Utah is similar to several other states (such as Nebraska, Colorado, Vermont, and Kansas) in that low enrollment of eligible children in public insurance is a result of lower than average uptake and higher than average retention. Importantly, the time and energy requirements to re-enroll on public insurance are much higher than private insurance. Intuitively, patients with cancer and their families have a much higher incentive to maintain health insurance coverage because of high health care system utilization for ongoing therapy. However, retaining coverage requires time and effort from caregivers who already face significant burdens to provide care for their child during cancer therapy. Our findings echo the trend reported previously of an increased likelihood of those with gaps in insurance to have public insurance.

Ten percent of our sample was Hispanic. According to the 2010 Census (the year our sample collection ended), Utah’s Hispanic population was 13%, compared with 16% nationally. Hispanic ethnicity was not associated with a gap in insurance in our analyses. However, future studies should further examine race/ethnicity differences in insurance coverage gaps because earlier pediatric cancer studies have demonstrated that Hispanic patients and patients of nonwhite race are less likely to be insured.

It is promising that fewer patients had a gap in insurance over time and, at the same time, the likelihood of public insurance continuity increased. During our study time frame, there were statewide policy and organizational changes in public insurance programs that may explain some of these trends. In 2006, Utah implemented the Utah Premium Partnership for Health Insurance to provide subsidies for low-income workers and their children enrolled in employer-sponsored insurance. Moreover, Utah experienced statewide organizational changes. However, retaining coverage requires time and effort from caregivers who already face significant burdens to provide care for their child during cancer therapy.

Table 1. Demographic and Clinical Characteristics and Insurance Coverage for Patients With ALL During the First 2 Years of Treatment

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>All Patients (N = 380)</th>
<th>Private (n = 229)</th>
<th>Public (n = 62)</th>
<th>Mix of Public and Private (n = 44)</th>
<th>Experienced Any Gap (n = 45)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td>No. (%)</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>208 (55)</td>
<td>124 (54)</td>
<td>39 (63)</td>
<td>23 (62)</td>
<td>22 (49)</td>
<td>.49†</td>
</tr>
<tr>
<td>Female</td>
<td>172 (45)</td>
<td>105 (46)</td>
<td>23 (37)</td>
<td>21 (48)</td>
<td>23 (51)</td>
<td></td>
</tr>
<tr>
<td>Age at diagnosis, years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.99†</td>
</tr>
<tr>
<td>1-5</td>
<td>221 (58)</td>
<td>130 (57)</td>
<td>36 (58)</td>
<td>27 (61)</td>
<td>28 (62)</td>
<td></td>
</tr>
<tr>
<td>6-10</td>
<td>84 (22)</td>
<td>51 (22)</td>
<td>15 (24)</td>
<td>9 (20)</td>
<td>9 (20)</td>
<td></td>
</tr>
<tr>
<td>10-17</td>
<td>75 (20)</td>
<td>48 (21)</td>
<td>11 (18)</td>
<td>8 (18)</td>
<td>8 (18)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.61†</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>342 (90)</td>
<td>209 (91)</td>
<td>54 (87)</td>
<td>40 (91)</td>
<td>39 (87)</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>38 (10)</td>
<td>20 (9)</td>
<td>8 (13)</td>
<td>4 (9)</td>
<td>6 (13)</td>
<td></td>
</tr>
<tr>
<td>ALL risk group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.75†</td>
</tr>
<tr>
<td>Standard</td>
<td>258 (68)</td>
<td>155 (68)</td>
<td>43 (69)</td>
<td>32 (73)</td>
<td>28 (62)</td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>122 (32)</td>
<td>74 (32)</td>
<td>19 (31)</td>
<td>12 (27)</td>
<td>17 (38)</td>
<td></td>
</tr>
<tr>
<td>County of residence at diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.09†</td>
</tr>
<tr>
<td>Urban</td>
<td>334 (88)</td>
<td>207 (90)</td>
<td>49 (79)</td>
<td>40 (91)</td>
<td>38 (84)</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>46 (12)</td>
<td>22 (10)</td>
<td>13 (21)</td>
<td>4 (9)</td>
<td>7 (16)</td>
<td></td>
</tr>
<tr>
<td>Insurance at diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>277 (73)</td>
<td>229 (100)</td>
<td>29 (66)</td>
<td>19 (42)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>97 (25)</td>
<td>62 (100)</td>
<td>15 (34)</td>
<td>20 (44)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uninsured</td>
<td>6 (1)</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>6 (13)</td>
<td></td>
</tr>
</tbody>
</table>

NOTE. Dashes indicate not applicable.

Abbreviation: ALL, acute lymphoblastic leukemia.

* The χ² test was used to detect differences across insurance coverage.
† The Fischer’s exact test was used to detect differences across insurance coverage.
Table 2. Multivariable Logistic Regression Model for Predictors in Insurance Gaps Among Patients With ALL During the First 2 Years of Therapy, Adjusted for No. of Encounters and Vital Status

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds Ratio</th>
<th>95% CI</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>1.58</td>
<td>0.77 to 3.24</td>
<td>.21</td>
</tr>
<tr>
<td>Age at diagnosis*</td>
<td>0.97</td>
<td>0.88 to 1.08</td>
<td>.63</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.45</td>
<td>0.48 to 4.32</td>
<td>.51</td>
</tr>
<tr>
<td>ALL risk group</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>1.57</td>
<td>0.63 to 3.91</td>
<td>.33</td>
</tr>
<tr>
<td>RUCA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>0.80</td>
<td>0.26 to 2.45</td>
<td>.70</td>
</tr>
<tr>
<td>Diagnosis year*</td>
<td>0.84</td>
<td>0.76 to 0.93</td>
<td>.001</td>
</tr>
<tr>
<td>Insurance at diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>Reference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>4.09</td>
<td>1.98 to 8.44</td>
<td>&lt;.001</td>
</tr>
</tbody>
</table>

Abbreviations: ALL, acute lymphoblastic leukemia; RUCA, rural-urban commuting area.
* Fit as a continuous variable.

changes, including rolling out a comprehensive online case-management system that links eligibility and benefits across all safety net programs (eg, Supplemental Nutrition Assistance Program, Medicaid) that clients can access from any Internet-accessible computer. In addition, Utah has experienced strong economic growth over the last decade, including lower unemployment rates than the national average during the most recent recession.37

Our study improves on previous self-report surveys of insurance instability in that our data are derived from verified payer information from a large pediatric hospital billing system. However, there are certain limitations of these data. First, because of the nature of administrative data, we had limited information on patient or family socioeconomic status. We incorporated census area-level data, which may not fully capture the true variation in socioeconomic status of individual patients and may misclassify patient and family income, which may be why income was not associated with insurance gaps in preliminary analyses. Also, we defined a gap in insurance as an encounter with no insurance. If a patient did not come into the clinic during a period of no insurance, we were unable to detect the gap. Although this is possible, it is not likely because of the high frequency of regular clinic visits during ALL therapy and the policy of PCH to treat regardless of insurance status.

The average number of outpatient encounters was similar between those continually insured versus those who experienced a gap. Children without insurance are less likely to receive regular primary care, and it is the policy of PCH to treat children regardless of insurance status. Although we are unable to determine the exact length of insurance gaps, we reported the percentage of uninsured encounters over 2 years. Finally, the 5-year survival rate for pediatric ALL has increased substantially in recent decades. Because the survival rate is so high, we have insufficient sample size to study the association between gap in insurance and important clinical outcomes, such as death.

This important study is the first, to our knowledge, to describe insurance coverage not only at diagnosis but also over the critical initial treatment period for a cohort of pediatric patients with ALL. Gaps in insurance during treatment are not uncommon, and patients with public insurance are more likely to experience a gap in health insurance coverage. These findings highlight the importance of addressing insurance coverage at diagnosis and throughout a patient’s treatment course to help patients and their families prepare for any anticipated changes, with the goal of avoiding insurance gaps and reducing unnecessary burden. Future research should address the impact of insurance gaps on health and psychosocial outcomes for the patient and family and identify strategies to ensure that publically insured families retain their insurance coverage. In addition, we did not incorporate patients who never had insurance or those lost to follow-up, because we were interested in identifying gaps in coverage. Thus, future studies should evaluate insurance stability among the most underserved pediatric patients with cancer and how the changing health care landscape in the United States affects the incidence or likelihood of gaps in insurance.

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