

**Title:** Healthcare Utilization and Spending by Children with Cancer on MedicaidEmily L Mueller, MD, MSc<sup>1,2</sup>Matt Hall, PhD<sup>3</sup>Jay G Berry, MD, MPH<sup>4</sup>Aaron E Carroll, MD, MS<sup>2</sup>Michelle L Macy, MD, MS<sup>5,6</sup>

1. Section of Pediatric Hematology Oncology, Department of Pediatrics, Indiana University, Indianapolis, IN 46202
2. Center for Pediatric and Adolescent Comparative Effectiveness Research, Indiana University, Indianapolis, IN 46202
3. Children's Hospital Association, Overland Park, KS 66202
4. Department of Medicine, Division of General Pediatrics, Boston Children's Hospital, Harvard Medical School, Boston, MA 02115
5. Child Health Evaluation and Research (CHEAR) Unit, Division of General Pediatrics, Department of Pediatrics and Communicable Diseases, University of Michigan, Ann Arbor, MI, 48109
6. Department of Emergency Medicine, University of Michigan, Ann Arbor, MI 48109

## Correspondence:

Emily L Mueller, MD, MSc

410 West 10th Street, Suite 2000A

Indianapolis, IN 46202

Cell: 312-399-0245 Fax: 317-321-0128

elmuelle@iu.edu

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## Abbreviations:

ALL	Acute lymphoblastic leukemia
AML	Acute myelogenous leukemia
CMC	Children with medical complexity
CNS	Central nervous system tumors
CRG	Clinical Risk Group
ED	Emergency department
FN	Fever and neutropenia
PMPM	Per-member-per-month

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**Abstract**

**Background:** Children with cancer are a unique patient population with high-resource, complex health care needs. Understanding their healthcare utilization could highlight areas for care optimization.

**Procedure:** We performed a retrospective, cross-sectional analysis of the 2014 Truven Marketscan Medicaid Database to explore clinical attributes, utilization, and spending among children with cancer who were Medicaid enrollees. Eligible patients included children (ages 0-18 years) with cancer (Clinical Risk Group 8). Healthcare utilization and spending (per-member-per-month) were assessed overall and across specific health care services.

**Results:** Children with cancer (n=5,405) represent less than 1% of the 1,516,457 children with medical complexity in the dataset. Children with cancer had high services use: laboratory/radiographic testing (93.0%), outpatient specialty care (83.4%), outpatient therapy/treatment (53.4%), emergency department (43.7%), hospitalization (31.5%), home health care (9.5%). Per-member-per-month spending for children with cancer was \$3,706 overall and \$2,323 for hospital care.

**Conclusion:** Children with cancer have high healthcare resource use and spending. Differences in geographic distribution of services for children with cancer and the trajectory of spending over the course of therapy are areas for future investigation aimed at lowering costs of care without compromising on health outcomes.

## **Background**

Children with cancer represent a unique patient population with high resource, complex health care needs.<sup>1-5</sup> Prior to diagnosis, these children may interact minimally with the healthcare system; upon diagnosis, their needs dramatically change. However, little research has been devoted to understanding healthcare utilization in this population. Children with cancer, often excluded from analyses in prior studies of children with medical complexity (CMC), are a novel population with healthcare utilization that warrants further study.

Children with cancer have the potential to experience a wide range of life-threatening complications from their cancer or associated therapy.<sup>6-9</sup> For example, fever and neutropenia (FN) is a common complication of cancer therapy that requires timely evaluation<sup>7,10-12</sup> in the emergency department (ED) or outpatient center, with high rates of admission.<sup>1,2</sup> Rapid access to acute care and supportive treatments received within the healthcare system are likely integral to the improved survival of this population.<sup>13</sup>

As with other CMC, the majority of pediatric oncology care is provided at urban, tertiary care centers, but patients are spread geographically. This may lead families to seek ED care and outpatient care at local facilities that do not possess the specialty services of the institutions where children receive their cancer treatment. Payor claims data, such as Medicaid, that include both community and tertiary care facility information not available in other large datasets, may allow for a comprehensive assessment of care received by children with cancer. In the United States, children can be enrolled on Medicaid if their

family's income meets the state determined poverty line or they can be enrolled on Children's Health Insurance Program which covers uninsured children in families with incomes that are modest but too high to qualify for [Medicaid](#).<sup>14</sup> In some states, children with cancer may qualify for Medicaid if they meet criteria for disability or by the loss of income or resources due to the financial burden on families of children with cancer.<sup>15,16</sup>

Previous analyses of Medicaid data have revealed that among all children, those with medical complexity account for half of Medicaid's spending on hospital care.<sup>17</sup> Yet, detailed healthcare utilization of children with cancer has not yet been explored. The objectives of this study are to 1) describe the clinical attributes of children with cancer who are covered by Medicaid, 2) evaluate their healthcare utilization and spending and 3) compare the distribution of utilization and spending by type of cancer.

## **Methods**

### *Study Design and Setting*

We performed a retrospective, cross-sectional analysis of the Truven *Marketscan*® *Medicaid Database* (Ann Arbor, MI). The *Marketscan*® *Medicaid Database* includes complete paid medical and prescription drug claims from ten states. Truven maintains data validity and integrity through audits conducted to assess and remove invalid diagnosis and procedure codes. The Indiana University IRB determined this study is exempt from review due to de-identified data status. There were 6,792,909 children ages 0-18 years enrolled in Medicaid in the year 2014 residing in 10 de-identified states from the database representing all geographic regions of the U.S.

*Study Population/Identification of Cases*

The Clinical Risk Group (CRG) software v.1.3 (3M Health Information Systems) was used to assign each Medicaid recipient to a single, mutually exclusive CRG based on the individual's diagnoses and health services utilization over a period of time.<sup>18-21</sup> We used the CRG classification to select the population of interest: children with cancer (CRG 8; all malignancies). We used three years of claims data to properly assign CRG categories.<sup>22,23</sup>

*Outcome and Exploratory Variables*

The main outcomes of interest were healthcare utilization and spending. We assessed the outcomes overall and by specific health services, including: emergency department, home health/durable medical equipment, inpatient, outpatient laboratory testing, pharmacy (outpatient only), primary care, specialty care (including all outpatient specialty care), therapy/treatment (including procedures, physical, occupational, and all outpatient therapies), mental health/substance abuse (all professional and facility claims), and dental. Of note, emergency department charges are included within inpatient charges for those patients admitted from the ED. Spending was the payment made by Medicaid for each health service. We evaluated healthcare spending in the following ways: overall per year, per-member-per-month (PMPM) spend (calculated by summing the specific spend of a population over a year, dividing by 12, then dividing by the number of enrollees in the population), and by specific health services. We chose to evaluate PMPM spending

since not all patients in this cohort were enrolled on Medicaid for the entire 12 months evaluated. PMPM spending is a standard metric used by payors to track utilization since insurance enrollment is on monthly basis.

We assessed the types of the children's cancer using 3M's CRG Episode Disease Category (EDC) for acute lymphoblastic leukemia (ALL), acute myelogenous leukemia (AML), central nervous system tumors (CNS), solid tumors (non-CNS), Hodgkin lymphoma, and non-Hodgkin lymphoma. Patients with non-specified malignancies, more than one type of cancer, or rare cancers were placed into an "Other" category.

Demographic characteristics included age, gender, race/ethnicity (White, Non-Hispanic; Black, Non-Hispanic; Hispanic; and Other), and eligibility type (blind/disabled, other).

### *Statistical Analyses*

We summarized patient and encounter characteristics using frequencies and percentages. We also evaluated healthcare utilization and spending - overall and by specific health services. We then stratified the healthcare utilization analyses by type of cancer. Analyses were performed on enrollees from all 10 states in the database using SAS version 9.3 (SAS Institute, Cary, North Carolina).

## **Results**

### *Study Population Characteristics*

In 2014, there were 5,905 children with cancer identified in the 10 states participating in the Marketscan Medicaid database, which accounted for 0.2% of all patients in the dataset. Children with medical complexity (CMC) comprised 22.3% (N=1,516,457) of the Medicaid population in the dataset, and therefore children with cancer were 0.3% of CMC. The mean age of the children with cancer enrolled in Medicaid was 11.2 years (Table 1). About 40% of the children with cancer who were Medicaid enrollees were eligible due to disability or blindness. Regarding types of cancer, 27.2% of children had ALL, 26.8% had a non-CNS solid tumor, 24.7% had a CNS tumor, 2.6% had AML, 1.0% had Non-Hodgkin lymphoma, 0.4% had Hodgkin lymphoma, and 16.7% were categorized as “other” cancer type.

### *Health Services Utilization and Spending*

Figure 1 demonstrates the percent of the population that utilized each service type, percent of spend, and PMPM spending on each of the types of healthcare services for children with cancer. We found that 31.5% of children with cancer utilized inpatient care. For patients who utilized inpatient care over the one-year studied, children with cancer had a median inpatient stay of 10 days (range 4-28). Children with cancer used the following services: laboratory and radiographic testing (93.0%), outpatient specialty care (83.4%), outpatient therapy/treatment (53.4%), emergency care (43.7%), and home health care (9.5%).

The overall per-member/per-month (PMPM) spending was \$3,706 for children with cancer, with the majority (62.7%) spent on inpatient hospital care (\$2,323) and

medications (\$504). Conversely, children with cancer had a low percent of spending on outpatient specialty care (3.5%).

### *Comparing Health Service Spending by Type of Cancer*

When evaluating the percent of spending and PMPM within each type of cancer, those with Non-Hodgkin lymphoma had the highest total PMPM spending (\$4,999) and the highest percent (77.7%) of total spending on inpatient hospital care (PMPM \$3,883) (Table 2). Children with ALL and AML had similar PMPM spending on medications (ALL \$351 vs AML \$352). Children with ALL had the highest percent spending for medications (18.2%) and outpatient therapy/treatment (10.6%, PMPM \$205). Patients with Hodgkin lymphoma had the highest percent of their spending on laboratory and radiographic testing (17.0%), but patient's with CNS tumors had the highest PMPM on testing (\$236).

### **Discussion**

Within this multi-state Medicaid population analysis, we documented spending patterns for children with cancer. We revealed that the greatest amount of spending by children with cancer was on inpatient services and the highest spending PMPM was for children with Non-Hodgkin lymphoma. Further investigation is needed to characterize fully all children with cancer who receive Medicaid coverage, as some of these patients may have been prior Medicaid recipients, some may have enrolled at diagnosis, and others may obtain coverage after loss of private health insurance due to financial stressors of caregivers. Future research efforts could also focus on further evaluation of inpatient care



costs to potentially identify novel cost-effectiveness strategies for those conditions that are not life-threatening, but contribute substantially to the financial burden of care.

When evaluating the health care utilization patterns of children with cancer, several interesting findings were revealed. The high inpatient utilization (31.5%) demonstrates that children with cancer have high inpatient care needs, likely due to admissions for scheduled chemotherapy combined with the management of sequelae related to their disease and treatment. The use of outpatient therapy/treatment is consistent with clinical expectations since the majority of oncology therapy includes the infusion of chemotherapy in the outpatient setting and procedures (such as lumbar punctures for the administration of intrathecal chemotherapy). Lab and imaging studies, in conjunction with clinical exam findings, are clinically necessary to stage disease, monitor response to treatment (i.e. achieving remission and monitoring for disease recurrence), and screen for chemotherapy side effects. The utilization of home health care by children with cancer is likely explained by the need for home administration of intravenous or subcutaneous chemotherapy or supportive medications (such as granulocyte colony stimulating factor injections). The majority of children with cancer have a central line that requires maintenance by the caregivers in the home with education on care provided by home health nursing. Further, patients may utilize home health care for supportive care measures such as drawing labs in between clinic visits and intravenous fluid administration during times of poor oral intake due to chemotherapy induced nausea and vomiting.

When evaluating the PMPM spending by children with cancer, the largest amount of spending was for inpatient hospital care, followed by medications. There is a wide range of reasons children with cancer require inpatient hospital care including the administration of chemotherapy and the management of cancer related or therapy induced complications, such as fever and neutropenia (FN). FN is a common reason for admission among children with cancer,<sup>3,4</sup> but there is evidence to suggest that we could reduce or shorten the length of inpatient stays for low-risk patients.<sup>24</sup> It is imperative to take the financial impact of outpatient therapy for FN into account, especially for those patients and families with limited resources (including financial and travel). Transitioning the inpatient management of FN to outpatient care might require that patients visit the clinic several days in a row for reassessment, which can be especially difficult for those who live far away from their treating institution, especially if the cost of travel or lodging would be out of pocket.

ED utilization by children with cancer was higher (43.7%) than the general pediatric population with Medicaid coverage during 2014 (22.9%).<sup>25</sup> This high utilization of the ED would suggest that future research efforts are needed to understand better the reasons for ED visits and frequency of admissions, as well as the patient experience of these populations related to their acute care needs. This knowledge will allow for the design of interventions to improve ED care for this population in a meaningful way. It will be important to determine variations in care of this high needs population, either between the care received at a community ED versus a tertiary care institution or even between different tertiary care institutions. These investigations could lead to an improvement in

the quality of care and health outcomes for children with cancer who have acute care needs.

When we evaluated spending by type of cancer, patients with a diagnosis of NHL had the highest overall spending, likely reflecting high inpatient hospital care usage. Patients with certain types of Non-Hodgkin lymphoma, including Burkitt lymphoma, are at very high risk for tumor lysis syndrome at diagnosis, and some of the high costs may be related to expensive medications used to treat tumor lysis (i.e. rasburicase), intensive care unit requirements for the management of complications, and length of hospital stays when these complications occur.<sup>8</sup> Further studies exploring patient-level hospital records could elucidate a more detailed explanation for such high spending by this population.

Furthermore, future research endeavors could focus on the trajectory of care for children with cancer to understand their patterns of healthcare utilization throughout the course of their therapy. Patients with Hodgkin lymphoma had the highest percent of their spending on laboratory and radiographic testing, which is expected given that their disease status is monitored closely using imaging studies, such as CT scans and PET-CT scans.<sup>26</sup> Children with CNS tumors had the highest PMPM spending on laboratory and radiographic testing, likely due to the higher costs of MRIs, which are the preferred imaging modality to assess brain tumors.

Whether children are enrolled on Medicaid simply because of a qualifying diagnosis of cancer or due to family financial constraints is not completely clear. We found that a large proportion of children with cancer are eligible due to disability/blindness (40.4%).

Yet, there is literature to support that the financial burden of a diagnosis of childhood cancer is substantial.<sup>16</sup> It is possible that novel interventions among the Medicaid patient population could help offset some of the inpatient costs, while making outpatient management more feasible for patients and their families who have low resources. If Medicaid paid for lodging and food for those patients who travel long distances for their oncology care, transitioning inpatient care to outpatient care might result in lower total costs to the healthcare system and to the families of children with cancer. Hospitals and insurance companies may benefit from delving further into the financial status and constraints faced by the population of children with cancer within their facilities or under their coverage to reveal methods in which cost-savings might be achieved through alternatives to hospitalization.

Our analysis of spending and healthcare utilization by children with cancer enrolled on Medicaid does not have direct correlations with the quality of care or outcomes associated with Medicaid coverage. Yet, recent calls to action for improvements in the care of children with cancer in low- to middle-income countries includes enhancing financial coverage of childhood cancer treatment.<sup>27</sup> As more countries, such as Mexico,<sup>28-30</sup> are initiating and adjusting their financial coverage for childhood malignancies, the Medicaid model of continual payment for care throughout the trajectory of treatment could serve as a role model.

### *Limitations*

There are several important limitations of this study. We included all patients enrolled on Medicaid within the dataset who had visits associated with a diagnosis of cancer, but were not able to capture the spending trajectory for these patients from the date of diagnosis through treatment. We were also not able to differentiate the reasons for inpatient hospital care or outpatient services, such as whether the visits were routine follow-up versus sick visits. Also, ED utilization may be underestimated as the charges for ED visits are included within inpatient charges for those patients admitted from the ED. The Truven dataset contains information from 10 states; therefore our analysis may not represent the healthcare utilization of all children throughout the United States and may not be generalizable to systems of healthcare delivery outside of the United States. The healthcare utilization by children with cancer enrolled on Medicaid may not be generalizable to those with private or no health insurance. Yet, the clinical scenarios are typically similar regardless of the patient's insurance status and therefore some of the overarching findings may hold true, such as the large spending occurring on inpatient services. It is also important to point out that the administrative nature of this database encompasses costs and health services utilized, but does not indicate health outcomes or quality of care. While the de-identified nature of the dataset does not allow us to determine in which 10 states the patients resided and received care, it is likely that many of these states have similarities in the fact that pediatric oncology care is provided in only a few urban settings to patients who are geographically dispersed throughout the state.

## **Conclusion**

In summary, children with cancer have high health care utilization, especially inpatient hospital care. Healthcare systems and health insurance providers, including Medicaid, could benefit from performing a more detailed analysis of children with cancer within their systems and considering novel interventions to offset inpatient hospital care costs. Future studies that combine data from a variety of sources to obtain a complete picture of health care utilization, including an understanding of the geographical scope of care provided to children with cancer, combined with clinical outcomes, would be useful in determining current patterns of care delivery for this unique population and its impact on health outcomes.

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**Figure Legend**

Figure 1. Health Care Utilization and Spending for Children with Cancer in Medicaid

TABLE 1. Demographics and Characteristics of Children in Medicaid, Both Overall and for Children with Cancer to Children

	Overall N=1,516,457	Cancer N=5,905
	N (%)	
Age (years): Mean (95% CI)	10.7 (10.7-10.7)	11.2 (11.1-11.4)
0-4	274,176 (18.1)	842 (14.3)
5-9	395,562 (26.1)	1,622 (27.5)
10-14	388,434 (25.6)	1,482 (25.1)
15-18	458,285 (30.2)	1,959 (33.2)
Gender		
Male	825,647 (54.4)	3,129 (53)
Female	690,810 (45.6)	2,776 (47)
Race		
White	708,226 (46.7)	2,826 (47.9)
Black	504,540 (33.3)	1,081 (18.3)
Hispanic	107,074 (7.1)	452 (7.7)
Other	196,617 (13)	1,546 (26.2)
Basis of Eligibility		
Due to disability/blind	146,523 (9.7)	2,386 (40.4)
Other	1,369,934 (90.3)	3,519 (59.6)
Enrollment Months: Mean (95% CI)	11.3 (11.3-11.3)	11.1 (11.0-11.1)

TABLE 2. Percentage of Total Expenditures for Top 5 Services for Children with Cancer on Medicaid, by Type of Cancer

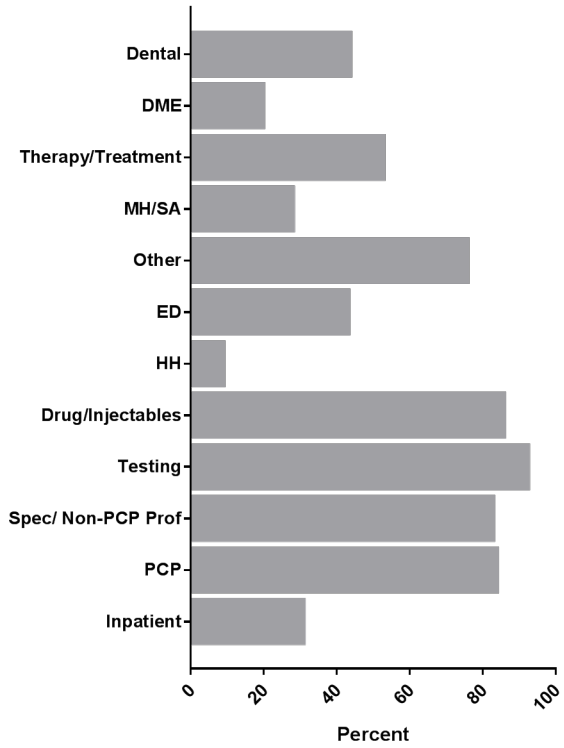
Total No. = 5,905	ALL		Solid tumor, non-CNS		CNS		AML		Non-Hodgkin Lymphoma		Hodgkin Lymphoma	
No. (%)	1,609 (27.2%)		1,585 (26.8%)		1,458 (24.7%)		153 (2.6%)		60 (1.0%)		26 (0.4%)	
Type of Service	% Spend	PMPM	% Spend	PMPM	% Spend	PMPM	% Spend	PMPM	% Spend	PMPM	% Spend	PMPM
Total		\$1,930		\$2,946		\$2,614		\$2,862		<b>\$4,999</b>		\$1,118
Hospital Care	52.3	\$1,010	67.2	\$1,980	51.8	\$1,354	69.5	\$1,990	<b>77.7</b>	<b>\$3,883</b>	48.4	\$541
Medications	<b>18.2</b>	\$351	9.0	\$266	15.8	\$414	12.3	<b>\$352</b>	8.9	\$443	10.7	\$120
Outpatient therapy/treatment	<b>10.6</b>	<b>\$205</b>	4.9	\$145	6.8	\$178	4.3	\$124	2.3	\$114	8.4	\$94
Laboratory and radiographic testing	4.3	\$84	7.8	\$231	9.0	<b>\$236</b>	4.4	\$125	4.5	\$224	<b>17.0</b>	\$190
Outpatient specialty care	4.0	\$77	4.0	\$119	<b>6.0</b>	<b>\$157</b>	2.9	\$82	2.7	\$136	2.0	\$22

Top 5 services were based on overall trends among children with cancer

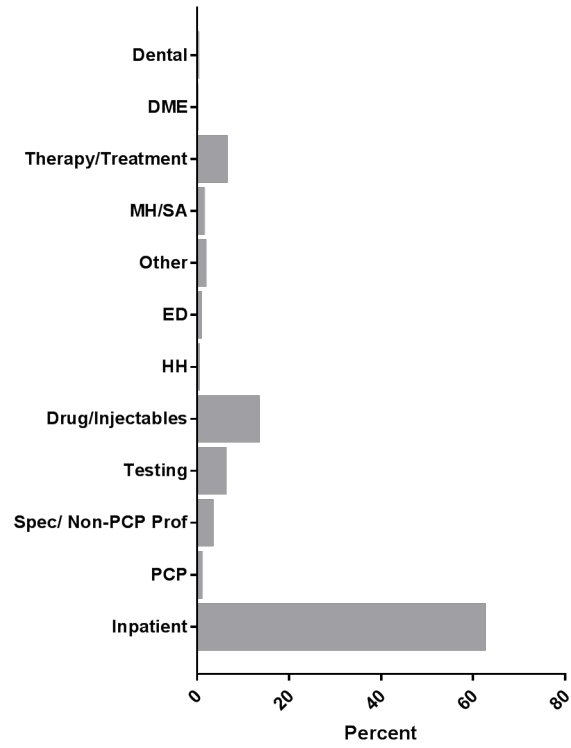
**Bolded** indicates highest percentage of total expenditure or highest per-member-per-month (PMPM) spending per type of service

ALL=Acute lymphocytic leukemia, CNS=Central nervous system, AML=Acute myelogenous leukemia

Percent Utilizers



Percent of Spend



PMPM

