

# Frequent Emergency Department Utilizers Among Children with Cancer

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**Background.** Pediatric frequent emergency department (ED) utilizers contribute a significant proportion of ED visits, but no studies specifically address children with cancer. **Methods.** A retrospective study of Pediatric Health Information System analyzing ED visits for children with cancer, including ED visits within 365 days from the first inpatient encounter with a discharge diagnosis code for malignancy. We defined frequent ED utilizers as those with four or more visits in the year (top 10th percentile). Patient characteristics and ED services (medications, laboratory, or imaging) for discharged children were assessed. Factors associated with being a frequent ED utilizer were examined with multivariable regression. **Results.** Frequent utilizers accounted for 58% of ED visits. Frequent utilizers differed from infrequent utilizers in terms of type of cancer; 39.3% of frequent utilizers had acute lymphoblastic leukemia (ALL) and 16.0%

had central nervous system (CNS) tumors compared with infrequent utilizers (21.9% had ALL and 24.8% CNS tumors,  $P$ -value < 0.001). Frequent utilization was associated with age 5–9 years (odds ratio [OR] = 1.4, 95% confidence interval [CI] 1.2–1.6) or 1–4 years (OR = 2.1, 95% CI 1.8–2.4) or <1 year (OR = 2.2, 95% CI 1.9–2.6) compared to 15–19 years and Hispanic ethnicity (OR 1.3, 95% CI 1.1–1.5) compared to white, non-Hispanics, and urban residence (OR = 1.5, 95% CI 1.3–1.7). Few children with cancer received no medication, laboratory, or imaging during their ED visit (frequent 11.0% vs. infrequent 12.5%,  $P$  = 0.01). **Conclusions.** The ED is integral to the care provided to children with cancer. The subset of frequent utilizers should be the focus of future research and quality improvement efforts. *Pediatr Blood Cancer* 2016;63:859–864. © 2016 Wiley Periodicals, Inc.

**Key words:** adolescent; child; oncology; supportive care

## BACKGROUND

Children with cancer represent a unique population of patients who have the potential to experience life-threatening complications of their cancer or associated therapy.[1–4] The ability to receive urgent evaluation and management is likely integral in the improved survival of this population.[5]

Our previous analysis of a nationally representative emergency department (ED) database, Nationwide Emergency Department Sample (NEDS), revealed that there was a large range of reasons children with cancer present to the ED.[6] This analysis was limited by the lack of patient-specific identifiers within the NEDS, which did not allow the determination of the number and frequency of ED visits per patient. Previous literature has demonstrated that there are certain populations of pediatric patients who utilize the ED to a greater extent than the general population,[7,8] but this has not been explored within the pediatric oncology population.

The frequent use of ED services is defined as recurrent ED use over a period of time by specific individuals.[9,10] The rate of repeat visits to the pediatric ED has been proposed as a quality improvement metric, with the assumption being that frequent ED utilizers are receiving suboptimal healthcare necessitating recurrent ED visits. Pediatric oncology frequent ED utilizers could either represent a population where better anticipatory guidance could decrease ED use or this may represent a population with acute or time-sensitive healthcare needs such that the ED is an essential aspect of their care, in coordination with the oncology team.

The objectives of this study were to (a) evaluate patient and ED encounter characteristics of frequent ED utilizers among children with cancer, and (b) quantify healthcare services for frequent ED utilizers.

## METHODS

### Study Design and Setting

A retrospective cohort study was performed using data from the Pediatric Health Information System (PHIS), an administrative and resource utilization database from 45 freestanding children's hospitals. Participating hospitals were located in non-competing markets of 27 states plus the District of Columbia

Abbreviations: ALL, acute lymphoblastic leukemia; AML, acute myelogenous leukemia; CNS, central nervous system; ED, emergency department; ICD-9-CM, International Classification of Diseases, Ninth Edition, Clinical Modification; NEDS, Nationwide Emergency Department Sample; PHIS, Pediatric Health Information System

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and account for ~15% of all pediatric hospitalizations in the United States. Data for these analyses were extracted between January 1, 2011 and September 30, 2013. Only hospitals that submitted ED data to PHIS throughout the study period were included, resulting in data from 39 hospitals. The PHIS database contains data as follows: patient-level data (demographic characteristics, diagnoses, and procedures) and billing data (all medication, diagnostic imaging, laboratory, and supply charges to individual patients). All data are deidentified before inclusion into the database; however, encrypted medical record numbers allow for continual tracking of individual patients across multiple encounters at the same hospital. The Children's Hospital Association (Overland Park, KS) and participating hospitals monitor the quality and integrity of data jointly, as described previously.[11] The data for this analysis were deidentified and therefore were considered exempt from institutional review board approval by Indiana University School of Medicine.

### Study Population/Identification of Cases

The cohort of children with cancer was defined based on the identification using the International Classification of Diseases, Ninth Edition, Clinical Modification (ICD-9-CM) codes for malignancy (140.x–209.x, 235.x–239.x). First, we identified the index encounter as the inpatient encounter with an ICD-9-CM code for malignancy with no prior cancer hospitalization within the prior 365 days. We then analyzed ED visits for each patient over the following 1 year (365 days) after inpatient discharge from the index encounter. Patients between the ages 0–19 years were included in this analysis.

### Outcome and Exploratory Variables

The primary outcome of interest was ED utilization, categorized as frequent versus infrequent ED utilizers. In order to identify frequent ED utilizers, we evaluated the number of ED visits by children with cancer and found that the median was 1 (interquartile range 0–2), with the 90th percentile of four visits. The criterion for “frequent ED utilizer” was chosen as the top 10th percentile.

We assessed the patient factors associated with being a frequent compared to infrequent ED utilizer. The following patient characteristics were included: gender, age (<1 year, 1–4 years, 5–9 years, 10–14 years, 15–19 years—based on clinical differences in development and types of cancers), race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, Asian, or other), most common types of childhood cancers (acute lymphoblastic leukemia [ALL], acute myelogenous leukemia [AML], central nervous system [CNS] tumors, solid tumors (non-CNS), Hodgkin lymphoma, and non-Hodgkin lymphoma), transplant status flag (defined using Feudtner's complex chronic condition codes, included stem cell transplant),[12] primary payer (public/governmental, private, other), median income quartile per ZIP code, and urban/rural patient residence (based on the Rural Urban Commuting Area code of the patient's home ZIP code).[13]

We were interested in quantifying the ED services provided to children with cancer, specifically those whose visits that resulted in discharge to home (with no inpatient admission). Healthcare services were evaluated for all ED visits that resulted in discharge to home including medication administration (other than

acetaminophen or ibuprofen), laboratory testing, or radiologic imaging performed. We further identified visits where antibiotics were administered, either in combination with laboratory testing and/or imaging. Medication delivery was determined using the National Drug Code Directory,[14] and laboratory testing or radiologic imaging was determined using charges for such services, as had been done previously on general pediatric population.[15]

### Statistical Analyses

We summarized patient and encounter characteristics using frequencies and percentages, and compared them across groups (frequent vs. infrequent ED utilizers) using chi-square tests.

We used multivariable logistic regression to estimate factors associated with frequent ED utilization for pediatric patients with cancer while accounting for clustering of patients within hospitals through the inclusion of a random hospital intercept. Variables included in our model were based on clinical judgment a priori: gender, patient's age category, dichotomous variables for the presence or absence of each of the most common cancer diagnoses, presence of a transplant flag, primary expected payer, median income quartile per ZIP code, and urban/rural patient residence. A significance level of 0.05 was utilized for all analyses without adjustment for multiple comparisons. All analyses were performed using SAS v9.4 (SAS Institute, Cary, NC).

## RESULTS

### Characteristic of the Study Population

We identified 17,943 children with cancer who received care at 39 children's hospitals in the United States, and followed this cohort for 1 year to assess ED utilization. Over the 1-year time span that followed an index inpatient admission, there were 26,770 ED visits. There were 2,631 frequent ED utilizers who had four or greater ED visits within 1 year (top 10th percentile). Frequent ED utilizers accounted for 58% of ED visits.

Table I demonstrates the patient level characteristics of children with cancer who presented to the ED, stratified by frequent ED utilization status. Children with cancer under the age of 5 years represented a larger proportion of the frequent ED utilizers (47.6% vs. 32.6% among infrequent utilizers,  $P \leq 0.001$ ). Among the frequent ED utilizers, there were higher proportions of Hispanic patients (23.8% vs. 19%,  $P \leq 0.001$ ), patients with ALL (39.3% vs. 21.9%,  $P \leq 0.001$ ) or NHL (6.5% vs. 6.0%,  $P \leq 0.001$ ), public or governmental insurance primary payers (50.1% vs. 44.8%,  $P \leq 0.001$ ), median household income per ZIP codes in the second quartile (24.5% vs. 22.1%,  $P = 0.02$ ), and living in an urban area (86.6% vs. 80.3%,  $P \leq 0.001$ ).

### Factors Associated With Frequent ED Utilizers Among Children With Cancer

In a multivariable analysis (Table II), factors associated with significantly increased odds of being a frequent ED utilizer among children with cancer included age category of 5–9 years (odds ratio [OR] = 1.4, 95% confidence interval [CI] 1.2–1.6) or 1–4 years (OR = 2.1, 95% CI 1.8–2.4) or <1 year (OR = 2.2, 95% CI 1.9–2.6) compared to ages 15–19 years, Hispanic race/ethnicity (OR 1.3, 95% CI 1.1–1.5) compared to white,

**TABLE I. Patient Level Characteristics of Children with Cancer Presenting to the Emergency Department (ED) by Frequent ED Utilizer Status—January 2011 to September 2013**

	Overall n = 17,943	Frequent ED user n = 2,631	Infrequent ED user n = 15,312	
	N (%)			P-value
Patient level characteristics				
Gender				0.03
Female	8,154 (45.4)	1,247 (47.4)	6,907 (45.1)	
Age (years)				<0.001
0–1	2,425 (13.5)	446 (17.0)	1,979 (12.9)	
2–4	3,818 (21.3)	804 (30.6)	3,014 (19.7)	
5–9	4,017 (22.4)	573 (21.8)	3,444 (22.5)	
10–14	4,057 (22.6)	447 (17.0)	3,610 (23.6)	
15–20	3,626 (20.2)	361 (13.7)	3,265 (21.3)	
Race/Ethnicity				<0.001
White, Non-Hispanic	9,921 (55.3)	1,408 (53.5)	8,513 (55.6)	
Black, Non-Hispanic	1,754 (9.8)	247 (9.4)	1,507 (9.8)	
Hispanic	3,529 (19.7)	625 (23.8)	2,904 (19)	
Asian	580 (3.2)	78 (3)	502 (3.3)	
Other	2,159 (12)	273 (10.4)	1,886 (12.3)	
Type of cancer				<0.001
Acute lymphoblastic leukemia	4,393 (24.5)	1,034 (39.3)	3,359 (21.9)	
Acute myelogenous leukemia	1,191 (6.6)	99 (3.8)	1,092 (7.1)	
Solid tumor	6,302 (35.1)	848 (32.2)	5,454 (35.6)	
Central nervous system tumor	4,211 (23.5)	421 (16)	3,790 (24.8)	
Hodgkin lymphoma	748 (4.2)	57 (2.2)	691 (4.5)	
Non-Hodgkin lymphoma	1,098 (6.1)	172 (6.5)	926 (6.0)	
Transplant				<0.001
Yes	811 (4.5)	50 (1.9)	761 (5.0)	
Primary payer				<0.001
Public/governmental	8,176 (45.6)	1,319 (50.1)	6,857 (44.8)	
Private	8,919 (49.7)	1,163 (44.2)	7,756 (50.7)	
Other	848 (4.7)	149 (5.7)	699 (4.6)	
Median household income per ZIP code				0.02
First quartile	3,695 (21.8)	516 (20.1)	3,179 (22.1)	
Second quartile	3,803 (22.4)	630 (24.5)	3,173 (22.1)	
Third quartile	4,296 (25.4)	647 (25.2)	3,649 (25.4)	
Fourth quartile	5,148 (30.4)	777 (30.2)	4,371 (30.4)	
Urban vs. rural patient residence				<0.001
Urban	14,574 (81.2)	2,278 (86.6)	12,296 (80.3)	

non-Hispanics, and living in an urban area (OR = 1.5, 95% CI 1.3–1.7) as compared to rural.

### Discharge Rates Among Children with Cancer

Overall, 43.9% of children with cancer were discharged to home from the ED. Discharge rates differed by frequent ED utilizer status (frequent 44.7% vs. Infrequent 42.7%,  $P \leq 0.001$ ).

### Healthcare Services for ED Encounters that Resulted in Discharge to Home

Of the 11,748 ED encounters that resulted in discharge to home (no inpatient admission), 11.6% received no medications (other than acetaminophen or ibuprofen), laboratory testing, or radiologic imaging (Table III). Among children with cancer, 34.2% of patients discharged from the ED received laboratory testing and antibiotic administration. Discharge ED encounters among frequent ED utilizers were significantly more likely to

have received antibiotics and laboratory testing (with or without imaging).

### DISCUSSION

In this study using administrative data from 39 U.S. children's hospitals, we found that frequent ED utilizers (the top 10th percentile by ED visit frequency) accounted for the majority of visits (58%). Frequent ED utilizers were more likely to be younger in age (less than 9 years old), of Hispanic ethnicity, and have ALL than infrequent utilizers. Few children with cancer (overall 11.6%) had an ED visit without associated medication use and laboratory or radiologic testing. This is in contrast with a previous study of the general pediatric population that found that 8% of children accounted for 24% of ED visits in 1 year and 32% had visits without medication use and laboratory or radiologic testing.[15] This study contributes to our understanding of ED utilization by children with cancer by demonstrating the characteristics of frequent ED utilizers. The findings

**TABLE II. Multivariable Logistic Regression to Evaluate Factors Associated with Frequent Emergency Department (ED) Utilizers Among Pediatric Patients with Cancer**

Factors	Adjusted odds ratio (OR)	95% CI	P-value
Gender			
Female	<b>1.1</b>	<b>1.0–1.2</b>	<b>0.047</b>
Age (years)			
15–19	Ref		
10–14	1.1	0.9–1.2	0.42
5–9	<b>1.4</b>	<b>1.2–1.6</b>	<b>&lt;0.001</b>
2–4	<b>2.1</b>	<b>1.8–2.4</b>	<b>&lt;0.001</b>
0–1	<b>2.2</b>	<b>1.9–2.6</b>	<b>&lt;0.001</b>
Race/ethnicity			
White, Non-Hispanic	Ref		
Black, Non-Hispanic	0.9	0.8–1.1	0.52
Hispanic	<b>1.3</b>	<b>1.1–1.5</b>	<b>&lt;0.001</b>
Asian	1.0	0.8–1.3	0.84
Other	1.1	0.9–1.3	0.38
Type of cancer			
Acute lymphoblastic leukemia	Ref		
Acute myelogenous leukemia	0.3	0.3–0.4	<0.001
Solid tumor	0.5	0.5–0.6	<0.001
Central nervous system tumor	0.4	0.3–0.4	<0.001
Hodgkin lymphoma	0.3	0.3–0.5	<0.001
Non-Hodgkin lymphoma	0.7	0.6–0.8	<0.001
Transplant			
Yes	0.4	0.3–0.5	<0.001
Primary payer			
Public/governmental	Ref		
Private	0.9	0.8–1.0	0.007
Other	1.1	0.8–1.4	0.56
Median household income per ZIP code			
Fourth quartile	Ref		
Third quartile	0.9	0.8–1.0	0.11
Second quartile	1.0	0.8–1.1	0.61
First quartile	0.8	0.7–1.0	0.02
Urban vs. rural patient residence			
Urban	<b>1.5</b>	<b>1.3–1.7</b>	<b>&lt;0.001</b>

Bold font indicates statistical significance with increased odds of being a frequent ED user.

**TABLE III. Services Delivered During the Emergency Department (ED) Encounter With Discharge to Home, Overall, and by Frequent ED Utilizer Status**

	Overall	Frequent ED utilizer	Infrequent ED utilizer	P-value
ED visit with discharge to home (n)	11,748	6,943	4,805	
No laboratory tests	29.6%	28.3%	31.5%	<0.001
No medications <sup>1</sup>	28.1%	25.7%	31.6%	<0.001
No imaging	66.4%	67.2%	65.1%	0.02
No laboratory tests, medications <sup>1</sup> , or imaging	11.6%	11.0%	12.5%	0.01
Received antibiotics + laboratory tests	34.2%	35.7%	32.1%	<0.001
Received antibiotics + laboratory tests + imaging	9.8%	10.2%	9.1%	0.04

<sup>1</sup>Other than acetaminophen or ibuprofen.

from this study may be used to identify the children with cancer who are more likely to become frequent ED utilizers, based on demographic characteristics available in administrative datasets, in order to perform targeted prospective studies aimed at better understanding the patient experience and identifying measures to improve their care.

The definition of a frequent ED utilizer has varied substantially in the literature, but has commonly been defined as at least

four visits within a 1 year time frame.[9,16–22] In this study, we chose a frequent utilization cutoff based on the distribution of the number of ED visits among children with cancer, which happened to align with at least four visits in the year. We revealed that frequent ED utilizers among children with cancer (the top 10th percentile) contributed more than half of ED visits. Yet, unlike adult ED literature focused on quality improvement to decrease ED usage by frequent utilizers whose needs could be

served in the primary care setting, we suspect that the ED is an integral aspect of care for children with cancer. It is likely that the ED utilization by frequent utilizers with cancer is due to increased risk of critical illness and complications of therapy that require emergent evaluation, rather than overuse of the ED system unnecessarily. Therefore, we believe that frequent ED utilizers need to be further explored in order to evaluate the appropriateness of their ED utilization. Specific information that should be collected and incorporated into future analyses includes chief complaint for ED visit, current cancer therapy, patient's comorbid conditions, and laboratory data obtained during the ED encounter. This form of comprehensive evaluation of frequent ED utilizers could help identify possible targets for interventions that could provide safe alternatives to ED visits and subsequent admissions.

Younger age and a diagnosis of ALL were important factors associated with increased odds of being a frequent ED utilizer. Several explanations could account for these findings. First, younger children are developmentally less able to relay their complaints, and therefore caregivers may be more likely to seek medical evaluation. Second, the most common childhood malignancy is ALL, which has the highest incidence peak at ages 1–4 years.[23] The risk-adapted therapies for ALL typically are mainly outpatient-based therapies that last for 2–3 years, but the most intense phases occur within the first year of therapy. Therefore, while children with ALL are exposed to treatment for a longer duration of time under which they may require emergent evaluations, the ED needs noted in this study may be greater than those after the first year of treatment. This is in comparison to AML therapy that is of shorter duration and predominately inpatient based. Unfortunately, our dataset does not include information related to disease characteristics (stage or risk stratification) or current phase of treatment. Exploring associations between these factors and ED utilization will be a key for future investigations.

Socioeconomic factors were significantly associated with meeting criteria for frequent ED utilization among children with cancer. Importantly, there were a higher proportion of frequent ED utilizers with public insurance and Hispanic ethnicity. Yet, there was no significant association with being a frequent ED utilizer for those with Black, non-Hispanic, and other race/ethnicity or among those living in ZIP codes with the lowest median household incomes. These findings may be representative of patient- or family-specific socioeconomic factors that are not readily available in this dataset, but are important factors influencing ED utilization that will need to be explored in further detail. Specifically, it will be imperative to incorporate patient travel distance and transportation barriers into future evaluations of ED utilization. Furthermore, socioeconomic differences may impact parental knowledge or comfort level with outpatient management, thus contributing to increased use of the ED among children with cancer. Studies to explore whether language barriers contribute to increased use of the ED is a specific area for further investigation, as language barriers can add a layer of complexity to phone triaging that may be performed by the oncology team prior to referral to the ED.[21,24]

This analysis provides a unique perspective of ED care by children with cancer at children's hospitals in the United States. In contrast to adult oncology, most children with cancer receive their oncology care in urban settings at tertiary care hospitals.

Yet, they may live in areas that are geographically dispersed throughout an entire state in some regions of the country. A future analysis of the impact of distance from the children's hospital on ED usage and ED disposition is warranted to truly understand the complicated interaction between children with cancer and emergency care.

Our assessment of the healthcare resources used during the ED encounters for children with cancer highlight the high degree of testing and treatment that children with cancer undergo when they seek care in the ED. It is possible that the use of laboratory and/or radiology testing is considered a necessary part of the evaluation of the patient in order to facilitate decision making related to ED disposition. Specifically, children with cancer who present with fever are treated significantly different depending on the current immunologic function, typically measured through laboratory testing to assess the absolute neutrophil count.[25,26] Fevers in children with cancer also represent a unique situation where the administration of parental antibiotics aids in the ability to treat the patient in the outpatient setting. Conversely, the small proportion of children with cancer that does not require testing or treatment may be amenable to targeted outpatient management.

## LIMITATIONS

While this study adds insight into characteristics of and ED services received by frequent ED utilizers among children with cancer, there are several important limitations. For our analysis, children with cancer were captured by identifying the first inpatient encounter with an associated ICD-9-CM code for malignancy and then they were followed for 365 days. It is possible that we are not accurately capturing all ED usage if the patient was not admitted at the beginning of their diagnosis, such as with Hodgkin lymphoma patients who may be diagnosed and started on therapy as outpatients. This is likely an underrepresentation of the entirety of ED usage by children with cancer because community ED visits are not captured in the PHIS database. Given that data are only collected from tertiary care facilities, we are also not able to evaluate if or what care may have been provided to the patient prior to their encounter within the PHIS database. Finally, it is important to note that diagnoses and procedures for ED and inpatient care are bundled together for those patients who were admitted from the ED. Yet, our analysis revealed that frequent ED utilizers among children with cancer represent the majority of ED visits with high use of healthcare resources (laboratory testing, imaging, and medications).

## CONCLUSIONS

In conclusion, frequent ED utilizers (the top 10th percentile) accounted for over half of the ED visits by children with cancer. Factors that significantly impacted whether a patient had frequent ED utilization at a children's hospitals included younger age, Hispanic ethnicity, and living in an urban area. Only about one in 10 children with cancer received no medications (other than acetaminophen or ibuprofen), laboratory testing, or radiologic imaging when they sought care in the ED. The ED is an integral part of the care provided to children with cancer with high healthcare services used during each visit. Future research should be aimed at understanding quality of ED care provided

and outcomes (both patient centered and hospital based) for ED visits among children with cancer.

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