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Research Article

Children with Special Health Care Needs: Resource Utilization in a Tertiary-Care Pediatric Intensive Care Unit -

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ABSTRACT

Objective: To identify the prevalence, demographics, resource utilization, and outcomes of Children with Special Health Care Needs (CSHCN) in a Pediatric Intensive Care Unit (PICU).

Methods: All children (< 21 years) admitted during a six-month period were included in the study. CSHCN were identified using the CSHCN screener and Federal Maternal and Child Health Bureau definition. Demographic data, Pediatric Index of Mortality (PIM-2), and hospital mortality were recorded. Resource utilization was assessed by the use of health care services, the cumulative Therapeutic Intervention Severity Score, and hospital charges.

Results: The prevalence of CSHCN in our PICU was 67.5%. Gender distribution and insurance status were similar in CSHCN and previously healthy children. African American children were more likely to be classified as CSHCN ($p < 0.002$). Mortality risk, as assessed with PIM-2, and median PICU and hospital lengths of stay were higher in the CSHCN group ($p < 0.05$ and $p < 0.01$; respectively). Resource utilization was higher among CSHCN, resulting in significantly higher hospital charges (median of $ 64,573 vs $ 27,319; $p < 0.001$). Compared to previously healthy children, CSHCN were more likely to receive intravenous medications, oral medications, antibiotics, bladder catheterization, arterial line placement, enteral tube feeding, central venous cannulation, and chest physiotherapy ($p < 0.05$). There was no statistical difference in mortality rate between the two groups (3% vs 2.1%; $p > 0.05$).

Conclusions: CSHCN represent a large proportion of PICU admissions and utilize significantly more intensive care resources. A higher proportion of African American children admitted to a PICU has special health care needs.

Keywords: Child hospitalized; Chronic disease; Critical illness; Pediatric intensive care unit; Needs assessment; Health resources; Health expenditures

ABBREVIATIONS

CSHCN, Children with Special Health Care Needs; PICU, Pediatric Intensive Care Unit; PIM, Pediatric Index of Mortality; TISS, Therapeutic Intervention Severity Scoring; VPS, National PICU Data Base

INTRODUCTION

Children with Special Health Care Needs (CSHCN) constitute a population with chronic physical, developmental, behavioral, or emotional conditions that requires health care services of an amount beyond that required by previously healthy children [1]. These children are almost three times more likely than previously healthy children to develop a severe acute illness requiring admission to a Pediatric Intensive Care Unit (PICU) [2]. Although there is extensive literature on the needs and utilization of health care services among CSHCN, there is no specific information about the prevalence of CSHCN, resource utilization, and outcomes among CSHCN who were treated in a PICU. These children are medically complex and may be at risk for poor outcome. The information obtained in this study may help promote strategies to maximize the quality and availability of hospital resources to CSHCN in the PICU.

It is estimated that 12.6 to 18 percent of US children are CSHCN [3,4]. CSHCN have higher levels of unmet needs for medical services than other children [3], and unmet needs for specialty care occur more frequently than unmet needs for routine care [5]. A number of studies noted that CSHCN uses more health care services and thus have greater health care expenditures than previously healthy children [4,6-10]. Based on these observations, we hypothesize that CSHCN admitted to the PICU utilize more health care resources and have worse outcomes compared to previously healthy children.

METHODS

Design

In this retrospective, case-control study, all children (age: 0-21 years) admitted to the tertiary-care PICU at Nicklaus Children's Hospital (previously, Miami Children's Hospital) during a six-month period (in 2006) were identified and included. The PICU is a tertiary care medical surgical unit without post-operative cardiac patients with an annual admission during the study period of 1200 to 1400 per year. We have used consecutive admissions during a six-month period. The study was approved for exemption from review and HIPAA waiver of authorization. Demographic and clinical data were collected from the hospital administrative database and electronic patient health care records.

These data sources include:

Hospital decision support database: Demographic information such as age, gender, race, and health insurance status, primary and secondary diagnoses, the source of admission, hospital and PICU lengths of stay, and hospital charges were retrieved from this database. Assignment for the race, gender, age, and insurance status was based on the information provided by caretakers at the time of admission and entered into the hospital database. For purposes of the analysis of race, the racial distribution among the patient population was determined and then the racial distribution among CSHCN was determined. For purposes of the analysis of age, the proportion of CSHCN and previously healthy children within each age group was determined.

VPS database: The PICU at Miami Children's Hospital participates in the national PICU database (VPS^{LLC}) for quality assurance. This database was used to collect the Pediatric Index of Mortality (PIM-2) scores.

Patient charts: All nursing and laboratory data, social worker and respiratory therapist notes (Sunrise Critical Care, Eclipsys, Atlanta, GA) and pharmacy orders (MedPoint™ - MedAdmin, Cerner Bridge Medical, Solana Beach, CA) are electronically charted at the point of care. Physician notes (History and Physicals, progress notes, and consultations) are either hand written or entered electronically (using i-Rounds, Teges Corporation, Miami, FL). These documents are scanned and electronically available for review. These electronic patient health care records were used to retrieve clinical data.

Readmission: Readmission to the PICU during the same hospital stay was considered as a separate admission, if it occurred more than 48 hours after transfer from the PICU to a general medical or surgical floor.

Identification of Children with Special Health Care Needs: CSHCN were defined by the criteria of the Federal Maternal and Child Health Bureau (MCHB) as those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health care related services of a type or amount beyond that required by children generally [1,4]. The tool used to identify CSHCN in this study, the CSHCN Screener [11], was designed based on this definition. Identifying data retrieved from electronic patient health care records such as primary diagnosis and home healthcare use (medications and technology assistance) were used to identify CSHCN.

Exclusion criteria: Children admitted with complex congenital heart disease for preoperative, operative, or post-operative management to the cardiac intensive care unit are routinely admitted to Cardiac Intensive Care Unit and were excluded from the study.

Outcome and utilization measures: Information on clinical findings, laboratory tests, diagnostic and therapeutic interventions, and outcomes was collected from the electronic patient health care records. Resource utilization was assessed by determining length of stay (PICU and hospital), use and duration of mechanical ventilation and adjunctive respiratory support, placement of arterial, central venous and bladder catheters, use and duration of inotropic support, use of blood products, use and duration of parenteral and enteral nutrition, use of dialysis, number and type of medications used, development of nosocomial infection, number of diagnostic procedures, number of subspecialty consultations, post-admission surgical interventions, cumulative Therapeutic Intervention Severity Scoring (TISS), and hospital costs, including all charges for non-physician services, laboratory tests, and diagnostic and therapeutic interventions. The outcome was assessed by determining the hospital survival.

The study used TISS-28 to estimate PICU resource utilization and nurse work burden. This abbreviated version of the Therapeutic Intervention Scoring System (TISS) has been used in the ICU setting to estimate ICU resource utilization and nurse work burden [12-14]. TISS-28 is a set of 28 bedside patient care activities performed in intensive care units. Points assigned to the activity are standardized and based on the complexity of the task. The score is calculated daily from the sum of the points and estimates the proportion of time spent on these activities per shift. Miranda, et al. [13] determined that one TISS point was equal to 10.6 minutes of each nurse's shift. According to the recommended standards, a nurse should be capable of managing 46 TISS points per shift.

Daily TISS-28 scores were calculated retrospectively using an online calculator [15]. The cumulative TISS-28 scores were calculated for each patient by adding daily scores for the duration of PICU stay. For those children with a PICU stay longer than 10 days, an average daily score was calculated from the cumulated 10-day score and multiplied by the length of stay.

STATISTICAL ANALYSIS

Data is summarized in tables using median with interquartile range for continuous variables and percentages for categorical variables. Demographic data was described as the median with interquartile range. Continuous data was analyzed with the Student's t-test or the Mann-Whitney U test, as appropriate. Chi-square test was used to compare categorical variables. Differences were considered statistically significant at $p < 0.05$.

RESULTS

Prevalence and demographics

During the study period, 551 patients accounted for 600 admissions to the PICU. There were 48 readmissions in the CSHCN group and 1 readmission in the previously healthy group (OR: 26.1; CI: 90.2 - 3.4). The prevalence of CSHCN in our PICU was 67.5%. Gender distribution and insurance status were similar between the two groups. The race/ethnic distribution among the population shows 53.8% of children classified as Hispanic, 18.5% White-Non-Hispanic, and 15.3% African-American. While Hispanic children represent the largest percentage of CSHCN, reflective of their distribution in our community as established by the US Census Bureau demographic profile in 2000 [16], African American children were more likely to be classified as CSHCN ($p < 0.002$). The average age among all the children was 7.39 ± 6.47 years. Analysis showed that the infant group had the highest proportion of healthy children ($p < 0.0001$) and the 10-14 year age group ($p < 0.02$) and the 15+ age group ($p < 0.001$) had the highest proportion of CSHCN. These demographic variables and the age distribution for CSHCN are shown in (Table 1). The PIM-2 risk of mortality was higher for CSHCN compared to previously healthy children (3.06% vs 2.48%; $p < 0.05$).

The majority of the patients admitted to our PICU were admitted there at the time of their initial hospital admission (58.2% from our hospital's Emergency Department (ED) and 4.8% following a transfer from another hospital's ED or PICU). The remaining PICU admissions were either transferred from our own hospital's general

Table 1: Prevalence and demographic characteristics of CSHCN admitted to a pediatric intensive care unit.

Demographic Variables	CSHCN	Healthy	Odds Ratio (95% CI)
Total	405 (67.5%)	195 (32.5%)	
Readmissions	48 (11.9%)	1 (0.5%)	26.1 (90.2-3.4)
Age, years			
< 1	57 (14.1%)	76 (39.1%)	3.9 (5.8-2.6)
1-4	111 (27.4%)	45 (23%)	NS
5-9	60 (14.8%)	25 (12.8%)	NS
10-14	91 (22.5%)	30 (15.4%)	0.63 (0.99-0.4)
>15	86 (21.2%)	19 (9.7%)	0.4 (0.69-0.24)
Gender			
Male	231 (57%)	104 (53.3%)	NS
Female	174 (43%)	91 (46.7%)	NS
Race/Ethnicity			
African American	75 (18.5%)	17 (8.7%)	0.42 (0.24-0.73)
White	80 (19.8%)	31 (15.9%)	NS
Hispanic	209 (51.6%)	114 (58.5%)	NS
Other	41 (10.1%)	33 (16.9%)	NS
Insurance			
Medicaid	261 (64.4%)	121 (62.1%)	NS
Insured	139 (34.3%)	69 (35.4%)	NS
Self-Pay	5 (1.2%)	5 (2.6%)	NS

Chi-square test was performed to compare demographic characteristics between CSHCN and previously healthy patients.

medical or surgical floor to address a need for higher level of care (15.7%) or immediately following a surgical procedure (21.3%). (Table 2) compares the source of admission between CSHCN and previously healthy children. CSHCN were more likely to be admitted to the PICU from the recovery room/operating room (28.4% vs 6.7%) and from the medical/surgical floor (19% vs 8.7%). CSHCN were less likely to be admitted to the PICU from the hospital ED (48.6% vs 78%) ($p < 0.01$).

Chronic Conditions: The documented diagnosis categories of CSHCN in this study are listed in (Table 3). The most frequently documented diagnosis category was neurological and neuromuscular disorders, including: seizure disorders, cerebral palsy, mental retardation, and scoliosis (n = 145). The second leading diagnosis category was respiratory system disorders, mainly asthma (n = 81). Hematological and oncological diseases, including sickle cell disease, leukemia, and solid tumors were documented as the third leading diagnosis category of CSHCN (n = 47). The fourth was genetic diseases and syndromes (n = 32).

Resource utilization

Analysis of our data indicates that CSHCN used higher levels of inpatient hospital services than previously healthy children. CSHCN were more likely to receive central venous cannulation (22.7% vs 14.4%), arterial line placement (26.9% vs 10.8%), bladder catheterization (37% vs 23.6%), chest physiotherapy (11.6% vs 5.1%), oral medications (86.7% vs 64.1%), IV medications (93.3% vs 77.4%), enteral tube feeding (24.7% vs 7.7%), and antibiotics (66.2% vs 48.2%) ($p < 0.05$) (Table 4).

CSHCN had longer median (interquartile range) PICU and hospital lengths of stay compared to previously healthy children [PICU: 2 (1.21 - 4) vs 1.71 (1.04 - 2.79) days; Hospital: 6 (3.5 - 12) vs 4 (3 - 8) days; $p < 0.01$]. Resource utilization, as measured by TISS-28, was higher (128 vs 90; $p < 0.0001$) among CSHCN. This measure emphasizes the extent to which care was provided by the nursing staff. In parallel with their greater use of health care services, CSHCN also had significantly higher hospital charges (median of $ 67,573 versus $ 27,319; $p < 0.001$) (Table 5).

Outcome

Although there were more nosocomial infections (8.4% vs 6.1%) and deaths (3% vs 2.1%) in the CSHCN group, nosocomial infection rate or mortality rate were not statistically significantly different between the two groups ($p > 0.05$).

DISCUSSION

This study provides current information concerning the use of health care resources and costs for the care of CSHCN admitted to our PICU. The prevalence of CSHCN in our PICU was 67.5%. African American children were more likely to be classified as CSHCN, and the mortality risk, as assessed with PIM-2, and median PICU and hospital lengths of stay were higher in the CSHCN group. Resource utilization was higher among CSHCN, resulting in significantly higher hospital charges in our cohort. Our findings validate those of previous studies, which reported similar leading causes of disability [7] and a higher prevalence of special healthcare needs among older children, boys, and African American children [3]. Overall, 12.6 to 18 percent of US children are CSHCN [3,4]. The higher prevalence in our study is consistent with a prior study which showed that CSHCN, compared to healthy children, have an excess risk of severe acute illness resulting in PICU admission [2].

PICU and hospital lengths of stay, cumulative TISS-28 score, hospital charges and the use of respiratory, cardiovascular, renal, CNS, and GI support were used as the indicators of resource utilization. Overall, we determined that CSHCN represents a large proportion of PICU admissions, utilize significantly more intensive care resources, and account for a disproportionate share of the nursing workload and health care expenditures (Table 5). These results also validate those of previous studies: that CSHCN use more health care services and

Table 2: Source of admission among CSHCN in a pediatric intensive care unit.

Source of Admission	CSHCN	Healthy	Odds Ratio (95% CI)
Emergency Room	197 (48.6%)	152 (78%)	0.27 (0.18-0.4)
Medical or Surgical Floor	77 (19%)	17 (8.7%)	2.4 (1.4-4.2)
Referring Hospital	16 (4%)	13 (6.7%)	NS
Recovery or Operating Room	115 (28.4%)	13 (6.7%)	5.4 (3.0-9.4)
Total	405	195	

Chi-square test was performed to compare source of admission between CSHCN and previously healthy patients.

Table 3: Leading causes of special health care needs among CSHCN in a pediatric intensive care unit.

Special Needs	CSHCN
Neurologic	134 (33%)
Respiratory	81(20%)
Malignancy	35 (9%)
Genetic	32 (8%)
Endocrinologic	28 (7%)
Other*	95 (23%)
Total	405

*Craniofacial, Hematologic, Neuromuscular, Renal, Developmental, Rheumatologic, Psychiatric, Gastrointestinal, Cardiovascular and Orthopedic.

Table 4: Resource utilization and outcomes among CSHCN in a pediatric intensive care unit.

Utilization measures	CSHCN	Healthy	Odds Ratio (95% CI)
Enteral Tube Feeding	100 (24.7%)	15 (7.7%)	3.9 (2.7-6.7)
Central Venous Cannulation†	92 (22.7%)	28 (14.4%)	1.8 (1.1-2.8)
Arterial Line Placement	109 (26.9%)	21 (10.8%)	3.1 (1.8-4.9)
Bladder catheterization	150 (37.0%)	36 (23.6%)	2.6 (1.7-3.9)
Chest Physiotherapy	47 (11.6%)	10 (5.1%)	2.4 (1.2-4.7)
Oral Medications	351 (86.7%)	125 (64.1%)	3.6 (2.4-5.5)
IV Medications	378 (93.3%)	151 (77.4%)	4.1 (2.4-6.7)
Antibiotics	268 (66.2%)	94 (48.2%)	2.1 (1.5-3.0)
Invasive Procedures	31 (7.7%)	34 (17.4%)	0.4 (0.2-0.7)
Mechanical Ventilation*	96 (23.7%)	41 (21%)	1.2 (0.8-1.8)
Dialysis*	9 (2.2%)	3 (1.5%)	1.5 (0.4-5.4)
Blood products*	66 (16.3%)	30 (15.4%)	1.1 (0.7-1.7)
CPR*	5 (1.2%)	1 (0.5%)	2.4 (0.3-21)
Nosocomial Infection*	34 (8.4%)	12 (6.1%)	1.4 (0.7-2.8)
Death*	12 (3%)	4 (2.1%)	1.5 (0.4-6.3)

*$p < 0.02$; *NS; otherwise $p < 0.001$

Chi-square test was performed to compare resource utilization and outcomes between CSHCN and previously healthy patients. Fisher-Exact test was used for values less than 6 in any cell.

Table 5: The distribution pattern of hospital charges, resource utilization, and length of stay for CSHCN compared to previously healthy children in a pediatric intensive care unit.

Measures of variability	Expenditure ($)		TISS-28 Score		Lengths of Stay (Days)			
					Hospital		PICU	
	Healthy	CSHCN	Healthy	CSHCN	Healthy	CSHCN	Healthy	CSHCN
25th percentile	17,255	30,630	17	26	3	3.5	1	1.2
Median	27,319	64,573**	24	40**	4	6**	1.7	2.0*
75th percentile	56,906	154,915	45	73	8	12	2.8	4
Minimum	6,194	4,954	6	8	1	1	0.5	0.25
Maximum	2,188,507	2,057,570	2,092	3,450	140	450	62	144

*$p < 0.01$; **$p < 0.001$
Mann-Whitney U test was utilized to compare continuous variables between CSHCN and previously healthy patients.

thus have greater health care expenditures than previously healthy children [4,6-10]; and that, compared to previously healthy children, CSHCN were four times more likely to be hospitalized and spent eight times more days in the hospital [6].

In the face of increasing demand for intensive care services, as well as the high cost of delivering these services, strategies can be developed to ensure optimal utilization and allocation of resources. For example, policy-making can design a system to triage PICU patients in an effort to guide staffing of health-care providers. Ideally, in an ICU, the nurse to patient ration should be 1:1. Identifying three levels of care in the PICU enables hospital administrators to determine the appropriate nurse to patient ratio, create a flexible staffing pattern and lead to a more efficient utilization of resources. Budgeting can maximize the quality and availability of resources which are most utilized by CSHCN such as respiratory care, medications, and enteral nutrition. Quality improvement initiatives for the use of indwelling bladder catheters and central venous catheters could reduce the risk of nosocomial infection.

Children with a variety of chronic conditions have been shown to be at an increased risk of dying during childhood [17,18]. Given the significant difference in the PIM-2 score in the CSHCN group compared to previously healthy children, it was anticipated that CSHCN would be at greater risk for complications and poor outcomes. It was interesting to note that the mortality risk, as assessed by PIM-2 (3.06% vs 2.48%), was compatible with the mortality rate (3% vs 2.1%). However, our study shows an insignificant trend towards increased risk of nosocomial infection rates and mortality rates among CSHCN ($p > 0.05$). Because of lower overall mortality rate in PICUs, a much larger sample size may be needed to show the significant difference in mortality between CSHCN and previously healthy children.

The results of this study reflect the changing trends in inpatient pediatric care and emphasize the scope of the problem for the care of CSHCN in the PICU. The increased requirement for hospitalization by CSHCN is related to acute exacerbations or complications of their chronic condition, scheduled admissions for elective procedures, and acute illnesses that are unrelated to their chronic condition [2]. Furthermore, CSHCN shows an increased risk of severe acute illness requiring PICU admission [2]. Armed with this information, administrators can advocate for this population in fiscal planning and policy-making.

Our observations identify two different subgroups whose excess risks suggest distinct preventive and management strategies. Using this information, we can integrate subspecialty and primary care and offer a bridge to continuity. Our study shows that infants had the highest proportion of healthy children and children 10 years of age and older had the highest proportion of CSHCN (Table 1). This infant group provides a unique opportunity to identify children at risk of developing a chronic health care need. Recently, Newacheck developed a conceptual model to identify these children and offered ideas for primary and secondary prevention [19]. Also offering a unique opportunity for intervention is the older CSHCN who are preparing for the transition to adult care. A 2005-2006 National Survey of parents of nearly 18,200 CSHCN of 12-17 years of age identified four future needs: adult health providers, adult health care needs, changes in health insurance, and child responsibility for his/her care, showing that only 41% of youth with special health care needs met all four components of such transition [20].

Our study shows that there is a greater proportion of CSHCN among African-American children admitted to the PICU compared to any other racial or ethnic group. In fact, African-American children suffer disproportionately from many health problems. The incidence of pre-term and low birth weight is significantly higher among African American infants [21], which may contribute to the higher proportion of children with CSHCN. Furthermore, infant, child, and adolescent mortality rates are higher for African Americans than for any other racial or ethnic group [21]. Racial inequalities in general health, chronic illness, access to healthcare and preventive care among children are well known and have been reported [21-23]. Studies confirm that poor African American families are more likely to have a child classified as CSHCN [3,4]. Currently there are community and government initiatives aimed at increasing awareness and promoting efforts to improve health outcome and reduce these disparities [23].

Few studies to date have examined, in a tertiary care PICU, differences in resource utilization and outcome between those populations. This study improves our understanding of the needs and outcomes of CSHCN admitted to a PICU in an effort to develop an efficient treatment system for this vulnerable population. The unique characteristics of our patient population or our institutional policies may not make our findings applicable to other settings. Nevertheless, we believe the results of this study will be useful to clinicians who take care of children in a PICU and administrators who want to identify quality improvement opportunities. Profiling the needs of CSHCN admitted to a PICU will help to better allocate hospital resources, thereby improving healthcare resource utilization and outcomes of CSHCN in the critical care environment.

CONCLUSION

CSHCN comprise an important and a large segment of the hospital patient population, particularly in the PICU. CSHCN utilize more intensive care resources. Significantly a higher proportion of African-American children admitted to a PICU has special health care needs. This study contributes to a profile of CSHCN and provides new insights into their access to care and opportunities to promote integrated systems of care to enhance the quality of care for this vulnerable population in the critical care environment.

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