Inpatient Health Care Use Among Adult Survivors of Chronic Childhood Illnesses in the United States

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Objectives: To describe the inpatient length of stay and related charges for adults in the United States with childhood-onset chronic disease and to examine patterns with respect to different hospital settings.

Design: We analyzed data from the 2002 Nationwide Inpatient Sample, a nationally representative data set of hospital discharges. We performed a case-mix–adjusted, sample-weighted regression analysis as well as descriptive statistics of hospital use among adults with childhood-onset chronic disease.

Setting: United States.

Participants: We identified hospitalizations for persons aged 18 years or older with a diagnosis of complex congenital heart disease, cystic fibrosis, sickle cell disease, or spina bifida.

Main Exposure: Childhood chronic illness.

Main Outcome Measures: Length of stay and total charges among pediatric, adult, and mixed hospitals.

Results: In multivariate adjusted analyses, patients with complex congenital heart disease and cystic fibrosis had a significantly longer length of stay in pediatric hospitals than in adult or mixed hospitals ($P<.001$); no similar difference was found for sickle cell disease and spina bifida. For all of the 4 conditions, hospital charges were significantly greater in pediatric hospitals than in adult or mixed hospitals ($P<.001$ for cystic fibrosis, complex congenital heart disease, and sickle cell disease, and $P<.01$ for spina bifida).

Conclusions: The vast majority of persons who have survived to adulthood with complex congenital heart disease, cystic fibrosis, spina bifida, or sickle cell disease are hospitalized in hospitals that predominantly care for adults, where charges for care appear to be lower than in pediatric hospitals.

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Throughout the last 30 years, life expectancy has climbed for many children with chronic illnesses. For example, in 1973, children with cystic fibrosis (CF) had an average lifespan of 7 years; by 2000, the median age of survival was 31 years.1 Similarly, the survival for sickle cell disease (SCD) has improved during the past 20 years primarily owing to the success of penicillin prophylaxis in children.2,3 As a result, there has been an increase in the number of patients with SCD entering their third decade of life.

With improved survival to adulthood today, the American Academy of Pediatrics, Elk Grove Village, Ill, American College of Physicians–American Society of Internal Medicine, Philadelphia, Pa, and American Academy of Family Physicians, Leawood, Kan, advocate the transitioning of adolescents with chronic conditions into an adult-centered health care system.3 This recommendation has also been supported by many subspecialty societies.5,6 Despite these recommendations, many adults continue to use the pediatric health care system.1 In fact, a recent study8 estimated that approximately 6.3% of total inpatient charges in pediatric hospital settings were attributable to care for adults.

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To our knowledge, no prior study has examined the health care use of adults with chronic childhood illnesses in the adult health care setting or has compared use in pediatric vs predominantly adult health care systems. In this study, we examine measures of hospital use (length of stay [LOS] and associated total charges) among adults (aged ≥18 years) with complex congenital heart disease (CCHD), CF, SCD, and spina bifida (SB) between predomi-
METHODS

SAMPLE

We used the 2002 Nationwide Inpatient Sample (NIS), a component of the Healthcare Cost and Utilization Project (HCUP), a set of health care databases developed through partnership among federal and state governments and health care institutions and sponsored by the Agency for Healthcare Research and Quality, Rockville, Md.11 The NIS is the largest publicly available all-payer inpatient database in the United States. The NIS contains deidentified, patient-level clinical and resource use data included in a standard discharge abstract. The 2002 NIS includes 7,893,982 sampled discharges representative of 37,804,021 discharges. These data reflect discharge data from 985 hospitals located in 35 states, approximating a 20%-stratified sample of nonfederal community hospitals including public hospitals, pediatric hospitals, and academic medical centers but excluding long-term hospitals, psychiatric hospitals, and chemical dependency treatment facilities. Stratification also includes the profit status for each hospital. The sampling frame for the NIS comprises approximately 90% of all hospital discharges in the United States. Sampling from the universe of US hospitals is stratified based on 5 hospital characteristics: US region, urban or rural location, ownership or control, bed size, and teaching status. Discharge weights are provided by the HCUP to permit national estimates of hospitalization frequencies. Documentation of the generation of discharge weights is available online through the HCUP.12 Total charges are expressed in 2002 US dollars. Analyses did not include Pennsylvania discharges because they did not have comorbidity codes specified.

IDENTIFICATION OF CASES

We searched for CCHD, CF, SCD, and SB discharges in any of the 13 diagnostic positions included for each discharge in the NIS among patients aged 18 years or older. Complex congenital heart disease was identified with the International Classification of Diseases, Ninth Revision, Clinical Modification13 (ICD-9-CM) codes 745.3, 745.39, 745.6-745.69, 745.7-745.89, 746.7-746.91, 747.1-747.49. As isolated atrial septal defect and ventricular septal defects are often followed up clinically and do not have as complex a course as tetralogy of Fallot or other significant malformations, we excluded individuals who were coded only for atrial septal defect or ventricular septal defect. The CF discharges were identified with the ICD-9-CM codes 770.00-770.09. The SCD discharges were identified with the ICD-9-CM codes 282.60-282.69. Spina bifida was identified with the ICD-9-CM codes 741.1-741.19 and 756.17. Pediatric hospitals were identified using NIS-provided hospital identifiers and were cross-referenced with listings from the National Association of Children’s Hospitals and Related Institutions, Alexandria, Va. For those hospitals not labeled in the NIS, if more than 75% of the discharges for any diagnosis (not just CCHD, CF, SCD, and SB) were for individuals younger than 18 years, the hospital was designated as a pediatric hospital. For those hospitals with more than 75% of the discharges for individuals older than 18 years, the hospital was categorized as an adult hospital. All of the others were designated as mixed hospitals. Hospitals classified via cross-referencing with the National Association of Children’s Hospitals and Related Institutions list were also checked with the age-at-discharge method. Of the 18 hospitals identified by the methods described earlier as possible pediatric hospitals, 5 National Association of Children’s Hospitals and Related Institutions–identified hospitals were pediatric hospitals within adult hospitals. Since the discharges from the pediatric hospital could not be separated from the adult hospital discharges, we coded these hospitals as mixed hospitals for purposes of this analysis.

CASE-MIX ADJUSTMENT

We used the comorbidity measure provided by the HCUP; it is a comprehensive set of 30 comorbidity measures developed for use with large administrative inpatient data sets that are associated with LOS, hospital charges, and in-hospital death in adults.14 Because of the small number of patients with CF identified with each specific comorbidity, initial regressions were run using individual dummy variables for comorbidities, then the dummy variables were consolidated to form a singular comorbidity composite (count) variable for the analyses. There were no differences in regression fit or in interpretation of the models with the individual comorbidity vs the composite form, so for consistency across diseases, we used the composite measure for all of the analyses.

Analyses were also adjusted for procedures reported during the hospitalizations that were identified via the ICD-9-CM procedure codes. We categorized procedures by those that were most frequently identified for patients with CCHD, CF, SCD, and SB because those were the diagnoses of chief analytic interest across conditions. Blood transfusions, venous catheterization, use of antibiotics, and cardiac catheterization or cardiac procedures were the most common, so these were included as separate procedures in analyses. Intubation was also coded separately because it would identify patients with severe illness requiring intensive care. All of the other procedures were collapsed into an “other” category. Procedures were categorized in mutually exclusive categories.

DATA ANALYSIS

We examined differences in LOS and total charges for each category of hospital (pediatric, adult, and mixed) and chronic condition, controlling for patient age and sex, procedures, mortality, payer type, comorbidity measures, hospital volume, and patient annual income by ZIP code. Race is not reported reliably in the NIS and was missing in approximately 36% of the sample, so we were unable to use race or ethnicity as a covariate. Hospital teaching status (as specified in the NIS) and hospital volume (for all of the diagnoses) were found to be colinear in the analysis, so hospital volume was used in the final analysis to control for both teaching status and differences in care accounted for by larger patient volumes. In our charge analy-
sis, we also included a model with LOS to determine the percentage of charge difference between hospital types that could be accounted for by LOS (see the “Comment” section).

Using Stata version 8.2 software (Stata Corp, College Station, Tex), we performed weighted linear regression on log-transformed total charges and LOS, controlling for the earlier-mentioned covariates. Taylor series linearization was used for variance estimation. Postregression adjustment of the log-transformed case-mix–adjusted charges and LOS was done to estimate real charges and LOS between hospital types.15 We considered alternative models for analyzing the significantly right-skewed dependent variable, such as Poisson and negative binomial regression, but the best-fit model was achieved in the log-transformed linear model.

Because pediatric hospitals care for few older adults compared with mixed and adult hospitals, we also ran the regression analysis limiting the age range from 18 to 35 years across all of the hospital types. Also, to address potential bias introduced by outliers, additional sensitivity analyses were done on subsets without procedures, eliminating charges greater than $100 000 and patients having LOS greater than 30 days. None of these separate analyses affected our model significantly. These are reported as additional analyses, the details of which can be requested directly from Dr Okumura.

We also attempted to conduct additional analysis of economic significance using the cost-to-charge information that has been released by the HCUP for the 2002 NIS. However, hospital-specific cost-to-charge information for our patients of interest was missing in approximately 30% of the cases and was disproportionately missing for pediatric hospitals; therefore, we state all of the economic findings in this article as charges.

RESULTS

SAMPLE CHARACTERISTICS

The analytic sample for the regression model included 5597 discharges (unweighted) with CCHD, 2182 with CF, 14 897 with SCD, and 3278 with SB. The numbers of unweighted discharges in the pediatric hospitals were 158 for CCHD, 137 for CF, 236 for SCD, and 152 for SB.

The weighted sample sizes and sociodemographic characteristics used for the multivariate analysis for patients hospitalized with these 4 conditions appear in Table 1 along with the mean ages per hospital type. Age ranges in the pediatric hospitals in this data set were as follows: 18 to 64 years for CCHD, 18 to 40 years for CF, 18 to 50 years for SCD, and 18 to 33 years for SB.

HOSPITAL CHARACTERISTICS

The hospital characteristics for each condition across hospital types are presented in Table 2. We report the survey-weighted proportions or averages of the differences be-
Table 3. Length of Stay for Adults With Chronic Conditions by Hospital Type*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cystic Fibrosis</th>
<th>Complex Congenital Heart Disease</th>
<th>Sickle Cell Disease</th>
<th>Spina Bifida</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Type</td>
<td>LOS for CCHD, d</td>
<td>LOS for CF, d</td>
<td>LOS for SCD, d</td>
<td>LOS for SB, d</td>
</tr>
<tr>
<td></td>
<td>Unadjusted</td>
<td>Adjusted†</td>
<td>Unadjusted</td>
<td>Adjusted†</td>
</tr>
<tr>
<td>Pediatric</td>
<td>7.7‡</td>
<td>7.7‡</td>
<td>10.9‡</td>
<td>12.0‡</td>
</tr>
<tr>
<td>Mixed</td>
<td>5.8</td>
<td>5.3</td>
<td>10.9</td>
<td>9.5‡</td>
</tr>
<tr>
<td>Adult</td>
<td>4.9</td>
<td>5.1</td>
<td>7.6</td>
<td>7.7</td>
</tr>
</tbody>
</table>

Abbreviations: CCHD, complex congenital heart disease; CF, cystic fibrosis; LOS, length of stay; SB, spina bifida; SCD, sickle cell disease.

*All of the data are weighted.
†Adjusted data reflect estimates adjusted for sex, age, whether inpatient death occurred, procedures, income, health insurance, and comorbidities.
‡P<.001.

After case-mix adjustment, LOS was significantly longer for patients with CCHD and CF in pediatric hospitals as compared with those in adult hospitals (both P<.001). There was no significant difference in LOS between adult and pediatric hospitals in patients treated for SCD or SB (Table 3).

Differences in LOS

After case-mix adjustment, LOS was significantly longer for patients with CCHD and CF in pediatric hospitals as compared with those in adult hospitals (both P<.001). There was no significant difference in LOS between adult and pediatric hospitals in patients treated for SCD or SB (Table 3).

Differences in Total Charges

Significant differences in total charges were found for all of the 4 study conditions across the hospital types (P<.001 for CF, CCH, and SCD, and P<.01 for SB), with pediatric hospital charges consistently higher than those of mixed hospitals.
mixed and adult hospitals (Table 4). To examine how much of the charge difference could be accounted for by LOS, LOS was included in the charge regression model as a covariate in separate analyses. Approximately 60% of the charge difference found between pediatric and adult hospitals could be accounted for by prolonged LOS in the pediatric hospitals for CF, and 44% was accounted for by LOS for CCHD. In comparison, less than 10% of the difference in charges across hospital categories could be attributed to LOS differences for SCD and SB discharges. In general, patterns in the mixed hospitals appeared to mirror patterns in the adult hospitals.

**AGE-STRATIFIED ANALYSES**

A subanalysis was performed by restricting the data set to discharges for patients aged 18 to 35 years to help control for other immeasurable factors that may be related to increased comorbidity rates in an aging population and to allow the subsamples to be more comparable across hospital types with respect to age. Length of stay remained significantly longer in pediatric hospitals for CCHD and CF. In addition, LOS was significantly longer in pediatric hospitals vs adult hospitals for SCD (7.0 vs 6.0 days, respectively; P=.004) in this subgroup. Total charges remained significantly higher in pediatric hospitals as compared with adult hospitals for all of the 4 diagnoses (all P=.001).

**COMMENT**

In this nationally representative sample, we found that case-mix–adjusted hospital charges were significantly higher for adult survivors of CCHD, CF, SCD, and SB in pediatric hospitals as compared with those admitted to other hospitals. Lengths of stay were significantly longer for individuals with CCHD and CF discharged from pediatric hospitals. In addition, the differences in total charges and LOS remained consistent or even more pronounced when limiting the analysis age group to ages 18 to 35 years. Overall, these findings have several implications for understanding patterns of hospital care for adult survivors of chronic conditions originating in childhood, and they raise additional questions about how care delivery differs by hospital type for individuals with the same diagnoses.

**DIFFERENCES IN LOS AND TOTAL CHARGES AMONG HOSPITAL TYPES**

We hypothesized that pediatric hospitals would have more experience with disease-specific care for patients with chronic illnesses of childhood whereas adult hospitals would have more experience in addressing more common comorbidities and care of adult patients. However, it was unclear how differences in familiarity with specific childhood diseases vs familiarity with general adult care would be related to hospital charges and LOS. Our findings suggest that there are processes of care differences that influence LOS and charge outcomes. Whether this is because of familiarity, practice variation between providers, hospital variation in provision of specific services, or other reasons could not be examined with these data and remains unknown.

This pattern contrasts with a prior article regarding SHD hospitalizations that indicated shorter LOS on pediatric services as compared with adult services. However, this earlier study did not separate children from adults in the analyses. Children, who stay almost exclusively in pediatric settings and pediatric ward services, would be expected to have shorter LOS than adults, who would tend to have more comorbidities that are often progressive in nature. For example, patients with SCD who survive to adulthood are more likely to have end organ damage than pediatric patients, typically resulting in longer admissions for adult patients.

Our findings are more similar to those in other studies that examined children treated in pediatric hospitals vs community hospitals or nonpediatric hospitals and found that charges were higher overall in pediatric hospitals as compared with nonpediatric hospitals, although LOS was similar. However, those studies considered acute diseases among children whereas we measured hospital use for chronic illnesses in the adult population.

Our study also has implications for the health economic impact of adult survivors of chronic conditions originating in childhood. Goodman et al estimated that adult survivors in pediatric hospitals with all diagnoses have at least $1 billion in annual charges. However, in our study, adults with SCD alone incurred inpatient charges exceeding $1 billion in 2002 nationally. Overall, higher total charges in pediatric hospitals are consistent with other recent studies that also found higher mean charges in pe-

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**Table 4. Mean Hospital Charges for Adults With Chronic Conditions by Hospital Type**

<table>
<thead>
<tr>
<th>Hospital Type</th>
<th>Hospital Charges for CCHD, Mean, $</th>
<th>Hospital Charges for CF, Mean, $</th>
<th>Hospital Charges for SCD, Mean, $</th>
<th>Hospital Charges for SB, Mean, $</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric</td>
<td>Unadjusted 68 345†</td>
<td>Adjusted 63 408†</td>
<td>Unadjusted 56 742†</td>
<td>Adjusted 69 213†</td>
</tr>
<tr>
<td>Mixed</td>
<td>34 160</td>
<td>34 312</td>
<td>35 108</td>
<td>31 831</td>
</tr>
<tr>
<td>Adult</td>
<td>29 687</td>
<td>28 904</td>
<td>32 766</td>
<td>30 668</td>
</tr>
</tbody>
</table>

Abbreviations: CCHD, complex congenital heart disease; CF, cystic fibrosis; SB, spina bifida; SCD, sickle cell disease.

*All of the data are weighted.

†Adjusted data reflect estimates adjusted for sex, age, whether inpatient death occurred, procedures, income, health insurance, and comorbidities.

‡P≤.001

§P<.01.
diagnostic hospitals as compared with nonpediatric hospitals across a fixed set of discharge diagnoses.

Such variation in charges may correspond to differences in quality of care or outcomes. Processes of care for the same diagnosis may vary substantively between adult and pediatric hospitals for reasons that are independent of LOS and subsequent charges. Moreover, there are several possible explanations for higher mean charges at pediatric vs other hospitals. It is possible that higher staffing ratios in pediatric hospitals or lower thresholds for intensive care service account for the difference in charges. Another hypothesis is that pediatric hospitals may provide more ancillary services for patients, such as child-life services and social work support, and hence the charges are higher for each patient. It is also plausible that higher charges in pediatric hospitals may be attributable to higher operational costs per discharge compared with adult-predominant institutions such that pediatric hospitals would need to charge greater amounts per discharge to cover overhead costs.

Although it is also possible that there are unmeasured comorbidities and disease severity that explain the differences we found, this seems unlikely because case-mix adjustment resulted in greater rather than smaller differences between the hospitals. However, if adult hospitals are systematically better at coding and reporting comorbid conditions, this could have resulted in biasing our results against pediatric hospitals. Unfortunately, we are not able to explore these hypotheses with this data set.

LIMITATIONS

This is an observational study in which we attempted to control for multiple factors that would potentially confound analyses of LOS and hospital charges. Optimally, we would be able to prospectively study differences of care for similar patients randomly assigned to admission to a pediatric hospital vs other hospital types, but such a study would not be feasible or ethical. As with any observational study, we cannot exclude the possibility that associations we described are confounded by unmeasured illness severity, even though our study controlled for a host of comorbidities and other patient attributes. It is also possible that some differences we observed between hospitals are attributable to patient selection bias, but our model remained robust despite additions of illness severity measures and case-mix adjustment. There are other pressures that may keep an adult in a pediatric hospital, such as treatment resource availability, personal provider, or special needs of the patient, but those cannot be measured in this data set.

We were also unable to determine in mixed and adult hospitals whether a patient was admitted to adult or pediatric ward services or whether subspecialty services were consulted and influenced practice variation. In addition, we could not ascertain within the pediatric hospitals group whether institutions had different policies regarding admission of adult patients; this limits the ability of our study to inform pediatric hospitals about their specific policies. Despite these limitations of our observational design, we feel that our study provides key insights to possible differences in care for adults with complex illness of childhood origin admitted to different care settings.

Data in the NIS are based on discharges, not on individual patients; therefore, we are unable to assess readmission rates or functional status after discharge. It is possible, for instance, that discharges for adults with CF from pediatric hospitals had longer LOS but lower rates of readmission than discharges from adult hospitals, resulting in comparable or even lower total annual charges at the person level. This may be true for patients with SCD because readmissions are common, especially among adults. A recent large prospective study reported that 50% of adult patients with SCD were readmitted within 1 month of discharge, but the hospital types were not compared in that study.

Finally, as with any study that relies on diagnostic codes for case findings, it is possible that there were attribution errors that led to misclassification of discharges in one analytic group or another. We believe, however, that this probability is mitigated by the clinical prominence of the conditions on which we focused. It should be noted that we only examined 4 disease states and therefore cannot generalize specific findings to all chronic illnesses of childhood.

CONCLUSIONS

Despite concerns that adult survivors of chronic childhood illnesses have difficulty accessing and continuing care in the adult health care setting, the vast majority of adults with chronic conditions originating in childhood receive inpatient care in the adult health care setting. Some practitioners may admit adults to a pediatric hospital with the assumption that their patients have specific disease care needs that require a pediatric hospital whereas other patients are still cared for in outpatient settings by pediatricians who admit to the ward services where they have privileges. Patient preference can also be a factor in the hospital to which a patient is admitted.

Our findings also indicate that adults cared for at pediatric hospitals have higher total charges and longer LOS than in adult hospitals despite case-mix adjustment. Currently, whether and how these hospital resource use differences translate into differences in quality of care, decreased morbidity, or future savings in health care expenditures is unknown. Of note, shorter LOS cannot be automatically equated with improved care.

Based on the increasing numbers of adult survivors with chronic conditions of childhood, further research is warranted to evaluate reasons for differences or similarities that are associated with better inpatient care. Although interest in the research and care of adults with illnesses originating in childhood has largely occurred in pediatrics, our findings are a reminder that pediatricians compose the minority of providers for this growing population. Further elucidation of the reasons for interinstitutional differences we have described offers the opportunity to improve care across hospitals with patients of all ages with chronic conditions.
Author Contributions: Study concept and design: Okumura, Nasr, and Davis. Acquisition of data: Okumura. Analysis and interpretation of data: Okumura, Campbell, and Davis. Drafting of the manuscript: Okumura. Critical revision of the manuscript for important intellectual content: Okumura, Campbell, Nasr, and Davis. Statistical analysis: Okumura. Obtained funding: Okumura. Administrative, technical, and material support: Okumura, Nasr, and Davis. Study supervision: Okumura, Nasr, and Davis.

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REFERENCES


Why call the vehicle for moving people an ambulance when walking cases are ambulance? An ambulance once brought the hospital to the patient. The French devised the term and applied it to their early field hospitals, which they called “hospitals ambulans.” From this name ambulance was applied to the vehicle and maintained when it reversed the process and brought patients to the hospital.

—From Why Do We Say It?, Castle Books, 1985