Utilization and Costs for Children Who Have Special Health Care Needs and Are Enrolled in a Hospital-Based Comprehensive Primary Care Clinic

Steve Berman, MD*; Michael Rannie, RN, MS‡; Laurie Moore, MPH§; Ellen Elias, MD*; Leonard J. Dryer, MBA‡; and M. Douglas Jones, Jr, MD*

ABSTRACT. Objective. When deciding how much hospital resources should be allocated to comprehensive primary care clinics for children with multisystem disorders, it is important to consider all of the non–primary care revenue streams associated with these children as well as the effects of a comprehensive primary care program on access and quality. The objectives of this study were, first, to determine costs as well as the payments associated with hospital ambulatory and inpatient services for children with multisystem disorders followed by a comprehensive primary care clinic; and, second, to determine the effect of enrollment in a hospital-based comprehensive primary care clinic on ambulatory and inpatient utilization patterns and expenditures for children with multisystem disorders.

Methods. The study population for the payment analysis consisted of 1012 children of all ages who were seen in the Special Primary Care Clinic (SPCC) in 2001. For these children, outcomes included direct costs, total (direct plus allocated overhead) costs, and payments per patient per 365 days after their first SPCC visit in 2001. A total of 175 of these patients were 4 years of age or older and had no SPCC visit before their first visit in 2001. We compared utilization and expenditures for the 175 children during the year before enrollment in SPCC with those in the year after enrollment. The Children’s Hospital administrative database was used to document direct costs, total costs, and payments by type of service for 365 days after an index visit. Ambulatory services included medical and surgical ambulatory, inpatient, emergency department (ED), and ancillary services. We determined the proportion of children who had visits; the visit rates per 100 child-years; and the average total and direct costs per visit, per child with a visit, and per child-year. Inpatient services data included non–intensive care and intensive care hospitalization rates per 100 child-years; the proportion of children hospitalized; their average length of stay; and the average total and direct costs per hospitalization, per patient hospitalized, and per child-year of total patients in the cohort.

Results. For 1012 children who were seen in SPCC in 2001, the hospital overall loss per child-year was $956. The loss per child-year for outpatient services was $1554. This loss was partially offset by a gain from inpatient services of $598. For the 175 patients for whom data were available to compare costs before and after enrollment in the SPCC, there were no significant differences in hospitalization or in direct costs per patient for patients who were hospitalized. The average length of stay was lower after enrollment (4.8 vs 11.7). In the surgical specialty analysis, children were more likely to see a surgeon after enrollment (41% vs 21%) and had a higher rate of visits per 100 child-years (102.3 vs 51.4). Differences in medical subspecialty, ancillary, and ED services did not achieve statistical significance.

Conclusion. This study suggests that children with multisystem disorders are medically fragile and require frequent hospitalizations and ED visits even with improved primary care. Enrollment in a comprehensive primary care program was associated with a decreased length of stay for non–intensive care hospitalizations and with increased use of surgical services. Pediatrics 2005; 115:e637–e642. URL: www.pediatrics.org/cgi/doi/10.1542/peds.2004-2084; evaluation, firearms, health promotion, injury prevention and control, intervention.

ABBREVIATIONS. CSHCN, children with special health care needs; ED, emergency department; SPCC, Special Primary Care Clinic; FTE, full-time employee; LOS, length of stay; SSI, Supplemental Security Income.

Children with special health care needs (CSHCN), especially children with multisystem disorders, require comprehensive primary care as well as medical and surgical consultative services. Hospital-based primary care programs for children with multisystem disorders have been expanding for several reasons. First, families prefer to have “one-stop shopping” for primary care, hospital care, emergency department (ED) access, ambulatory medical and surgical consultations, and ancillary therapies. Second, primary care physicians, especially family physicians, are concerned that they lack the expertise to care for these complex patients, especially when the care is technology dependent. Physicians are also concerned about the time-consuming and often frustrating administrative demands of caring for these children. Administrative responsibilities include such things as completing paperwork related to referrals, diagnostic procedures, high-cost therapies and out-of-formulary medications, monthly home health care orders, school forms, and durable medical equipment. Third, many children with multisystem disorders are enrolled in Medicaid and some primary care pediatricians and family physicians in private practice are unwilling to care for these children because Medic-
aid payment rates often fail to cover practice overhead costs.

Despite the need to develop or expand comprehensive primary care programs for children with multisystem disorders, hospitals and pediatric departments are reluctant to invest in these programs because the revenue is insufficient to cover hospital costs and clinician salaries. However, when deciding how much hospital and departmental resources should be allocated to comprehensive primary care clinics for children with multisystem disorders, it is important to consider non–primary care revenue streams. In addition, the effects of a comprehensive primary care program on rates of ED visits and hospitalization as well as access to needed specialty and ancillary care need to be determined.

Few published data on these comprehensive primary care clinics are currently available to help decision makers consider the financial and quality impact of these clinics. These issues are relevant to quality improvement research efforts. An Institute of Medicine publication entitled “Priority Areas for National Action: Transforming Health Care Quality” cited CSHCN and care coordination as 2 of the priority areas in this research.1

The study had two aims: first, to determine expenditures as well as the payments associated with all hospital ambulatory and inpatient-provided services for children who have multisystem disorders and are followed by a comprehensive primary care clinic. Our hypothesis was that the difference between payments and expenditures for non–primary care–related hospital services would cover any deficit in primary care–related services. The second aim was to determine any effect of enrollment in a hospital-based comprehensive primary care clinic on ambulatory and inpatient utilization patterns and expenditures for children with multisystem disorders. One hypothesis was that children who are enrolled in Special Primary Care Clinic (SPCC) would have lower rates of inpatient ward and intensive care hospitalization and costs, as well as lower ED visit rates and costs. Another hypothesis was that these children would have different patterns of utilization of medical and surgical specialty care as well as ancillary services.

METHODS

Study Setting

During 2000 and 2001, the SPCC at the Children’s Hospital of Denver served ~1000 children with multisystem disorders and their siblings. The clinic provided comprehensive primary care, which included care coordination and case management components. In addition, the physicians who provided ambulatory care in SPCC cared for their patients when they required non-intensive care hospitalization.

Staffing of the SPCC included 7 physicians contributing 2.7 full-time employees (FTEs). There were 2 general pediatricians (1 FTE), 1 developmental/behavioral pediatrician (0.4 FTE), 1 geneticist/neurodevelopmental pediatrician (0.4 FTE), 1 neonatologist (0.2 FTE), 1 family physician (0.2 FTE), and 1 child psychiatrist (0.1 FTE). In addition, there were 3 pediatric nurse practitioners (1.8 FTEs), 3 pediatric RNs (2.5 FTEs), 1 social worker (0.8 FTE), 1 appointment scheduler (1 FTE), and 2 secretaries (1.2 FTEs). The services of nutritionists and physical therapy, occupational therapy, and respiratory therapy were available during selected clinic sessions. A behavioral clinic was held 1 afternoon weekly and was staffed by a child psychiatrist in addition to the behavioral psychiatrist.

In 2000, the children who were served in SPCC could be classified into the following nonexclusive groups: infants who were born prematurely (32%); infants, children, youths, and adolescents with severe neurologic conditions such as cerebral palsy and hypoxic ischemic encephalopathy (20%); children with genetic disorders including chromosomal abnormalities and other metabolic and genetically based syndromes (22%); children who have chronic special health care needs and do not fit into 1 of the other categories (eg, status post organ transplant, immunodeficiency disorders, severe asthma) (18%); and siblings of the children described above (19%). The population was diverse with respect to race/ethnicity. Although race was not identified in 18% of children, 33% of the children were Hispanic, 14% were black, and 32% were non-Hispanic white. The age distribution of the SPCC population was also diverse, with large numbers of patients in all age groups (47% <5 years, 15% >5–13 years, and 38% >13 years). The majority of SPCC patients were from low-income families; 85% of patients were Medicaid beneficiaries. Approximately half of the Medicaid beneficiaries were enrolled in a Medicaid HMO, and the remainder were enrolled in fee-for-service Medicaid.

Procedure

We used the Children’s Hospital of Denver administrative database (Sunrise Decision Support Manager; Eclipsys Corporation, Boca Raton, FL) to identify children who received SPCC services anytime during a 2-year period from January 2000 to December 2001. This Children’s Hospital’s administrative database includes general ledger, payroll, medical records, and cost data from the hospital’s clinical and financial systems to build a comprehensive decision support system. Direct costs included costs associated with providing services, whereas total costs included direct costs plus allocated overhead costs. Costs rather than charges were reported because of the large variations in cost-to-charge ratios among hospitals. Medicaid reimbursed for hospitalizations with diagnosis-related group–based payments and other services at 72% of cost.

Laboratory and radiologic studies that were done on the day of an ambulatory visit were assigned to that visit, whereas studies that were done on another day were separate. Inpatient surgical procedures were included in the hospitalization category, whereas outpatient procedures were reported separately. We assessed ambulatory utilization and costs for medical subspecialty, surgical specialty, ED, and ancillary services. We determined the proportion of children who had visits; the visit rates per 100 child-years; and the average total and direct costs per visit, per child with a visit, and per child-year. We also determined the inpatient utilization and costs. This included non-intensive care and intensive care hospitalization rates per 100 child-years; children hospitalized; their average length of stay (LOS); and the average total and direct costs per hospitalization, per patient hospitalized, and per child-year of total patients in the cohort.

Study Populations

Payment Analysis

The study population for the payment analysis consisted of 1012 children of all ages who were seen in SPCC in 2001. For these children, we determined the direct costs, total costs, and payments per patient per 365 days after their first SPCC visit in 2001.

Pre-SPCC and Post-SPCC Enrollment Comparison

In 2001, there were 1012 SPCC patients, 555 of whom were 4 years or older. As shown in Fig 1, we identified 175 of these patients who had no SPCC visit before their first visit in 2001. The study population for this analysis was the 175 children who were 4 years or older and had not been seen in SPCC during 2000–2001 but were seen in 2001–2002. We compared utilization and expenditures for the 175 children during the year before enrollment in SPCC with the year after enrollment. We selected children who were 4 years and older for the study because the variation in hospitalization in a relatively small group of younger children is large. Table 1 displays the diagnoses that were coded at an index visit for these 175 patients.
Statistical Methods

In each subanalysis (pre-SPCC vs post-SPCC), $\chi^2$ tests of association were used for the proportion of children who had visits or hospitalizations. The Cochran-Mantel-Haenszel statistic was used to compare the number of hospitalizations. Wilcoxon 2-sample tests were used for costs per patient visit or hospitalization. Comparisons between LOS and costs per visit or hospitalization in the non-SPCC and SPCC cohorts were made using the Wilcoxon 2-sample test. In the pre-SPCC and post-SPCC cohorts, these comparisons were made using mixed-effects models that assumed compound symmetry for measures obtained during repeated hospitalizations. Finally, the average cost per child in each cohort was calculated by summing total costs per hospitalization and dividing by the number of patients in each cohort, a method that does not allow for a test of statistical significance.

RESULTS

Payment Analysis

For 1012 children who were seen in SPCC in 2001, direct costs, total costs, and payment per patient per 365 days after their first SPCC visit in 2001 are displayed in Table 2. The hospital loss per child-year (total costs minus payments per child-year) was $956. The loss per child-year for outpatient services was $1554. This loss was partially offset by a gain of $598 from inpatient services. As shown in Table 3, whereas payments exceeded direct costs for all types of outpatient services except ancillary services, only radiology payments exceeded total costs ($25 per child-year). The losses per child-year, based on total costs, were $421 for ancillary services, $403 for primary care services, $213 for Medical subspecialty services, $179 for surgical specialty services, $29 for ED services, and $1 for laboratory services.

The data show that inpatient hospital payments covered approximately one third of the outpatient per child-year losses based on total costs. However, payments exceeded direct costs by $3212.

A high proportion of costs are related to outpatient services; outpatient services accounted for 46% of direct costs and 44.2% total costs, whereas payments were only 31.4% of payments. Primary care services in Table 3 accounted for 21% of per-child direct costs and 18.9% of per-child total costs but only 16.3% of revenue.

Pre-SPCC and Post-SPCC Enrollment Comparisons

Table 4 compares the non-intensive care hospitalization rates, average LOS, and direct costs for the 175 children during the year before enrollment in SPCC with the year after enrollment. There were no significant differences between the groups in the percentage of patients hospitalized, the hospital rate, or the direct costs per patient hospitalized. There was 1 outlier in the pre-SPCC cohort, who was hospitalized for 171 days at a cost of $369 077. When the outlier was excluded from the analysis, the average non-intensive care hospitalization costs per child-year were $1038 for the pre-SPCC and $556 post-SPCC cohorts. Table 4 also compares the intensive care hospitalization rates, average LOS, and direct costs for the 2 cohorts. There were no significant differences between the groups in the percentage of patients hospitalized, the hospital rate, the average LOS, or costs per hospitalization or per patient hospitalized. There was 1 outlier in the pre-SPCC cohort, who was hospitalized in the intensive care unit for 46 days at a cost of $106 866. When the outlier was excluded from the analysis, the average intensive care hospitalization costs per child-year were $450 for the pre-SPCC and $325 post-SPCC cohorts.

Table 5 displays the utilization and direct costs for medical subspecialty, surgical specialty, ancillary, and ED services. There were no significant differences between the groups for any of the measures related to medical subspecialties services. In the surgical specialty analysis, children in the pre-SPCC cohort compared with those in the post-SPCC cohort had a lower proportion with surgical visits (21% vs 41%; $P < .0001) and a lower rate of visits per 100
child-years (102.3 vs 51.4; \( P = .005 \)). In the ancillary services analysis, there were no significant differences between the groups for any of the measures. In the ED analysis, there were no significant differences between the groups for any of the measures.

**DISCUSSION**

Studies of CSHCN have described methods of identifying or defining this population\(^2\)–\(^6\) and their sociodemographic characteristics,\(^7\)–\(^12\) patterns of insurance coverage,\(^13\),\(^14\) and health services utilization and expenditures.\(^15\)–\(^19\) These studies analyzed state or national data sets and do not directly deal with the financial and quality issues addressed in this study. Our study population seems similar to children who are enrolled in Supplemental Security Income (SSI), who have high Medicaid expenditures as reported by Kuhlthau et al.\(^15\) from Georgia, Tennessee, Michigan, and California. High expenditures were defined as more than $10 000 in 1992. Cerebral palsy was a diagnosis in 21% to 38% of the SSI children and 20% of our Denver SPCC children. Congenital anomalies were present 10% to 26% of SSI children and 22% of the SPCC children, and asthma was a diagnosis in 14% to 25% of SSI children and 18% of SPCC children. The mean hospital expenditures for the SSI high-expenditure children were $5615 in Tennessee, $8466 in Michigan, $13 426 in Georgia, and $19 292 in California, whereas SPCC children had inpatient hospital payments of $6053.

The Denver SPCC children had more severe conditions than CSHCN who are identified with the CSHCN screener reported by McPherson et al.\(^2\) This explains why annual hospital-related expenditures for the children who were enrolled in the Children’s Hospital SPCC were considerably greater than for children with disabilities reported by Newacheck et al.\(^16\) from the Medical Expenditure Panel Survey 1999–2000. Children with disabilities, defined as children who were limited in or unable to perform age-appropriate social roles because of a chronic physical or mental health problem (7.3% of children younger than 18 years), had inpatient hospital expenditures of $670 (SE: $120). ED services for SPCC children were also higher in our study group ($296 vs $91). Expenditures of nonphysician ancillary services were lower in SPCC children ($73 vs $173), but the Medical Expenditure Panel Survey data include non–hospital-based ancillary services that were not included in this study.
Williams et al 18 reported utilization and expenditures of CSHCN in the military health system using the CSHCN screener to identify CSHCN. There were 361 children whose parents responded yes to the question, “Is your child limited or prevented in any way in his or her ability to do the things that most children of the same age can do?” The hospitalization rate for these children was 10.6, which is lower than the post-SPCC rates of 19.5. The average length of stay (LOS) was 7.9 days, whereas the non-intensive care LOS was 4.8 days in our post-SPCC cohort. It is not clear that these are comparable populations, and the higher hospitalization rates may reflect differences in severity of disease/conditions or standards of care. This subgroup of CSHCN followed in the military had 2.38 specialist visits per year and 0.61 ED visits per year, whereas our post-SPCC children had 1.75 specialty visits per child-year and 0.42 ED visits. Weller et al 17 reported findings from the 1994 National Health Interview Survey on Disability. The proportion of children who were aged 5 to 17 and identified as disabled by the survey and were hospitalized was 6.4% compared with 10% in our study. The proportion who had an ED visit was 23.9% in the Weller study and 23.0% in our study.

There are a number of limitations to this study. First, we do not have an independent ascertainment of the accuracy of the administrative database. Although administrative data may not be totally accurate, these systems provide the best available information and are used for financial decision making. Second, it is not possible to generalize these findings to other children’s hospitals because of variations in patient conditions, payer mix, methods of calculating direct and total costs, and payment levels for Medicaid and private insurers. In addition, cost allocation methods that are used to determine total costs differ considerably from one institution to another. Third, inpatient and outpatient services received at other facilities were not identified or included in the analyses. Although we believe that, with the exception of emergency services, care was delivered within Denver Children’s Hospital, because alternatives in this region are limited, it is possible that some children received services at other facilities. Fourth, the reasons that children with multisystem disorders were not seen in SPCC during the previous year are unknown. It is possible that they only recently received a diagnosis or had moved to the Denver metropolitan area. If this is the case, then utilization and costs of the pre-SPCC children would be lower than actual. Fifth, we could not separate the impact of having SPCC faculty provide general inpatient care from other aspects of the comprehensive ambulatory primary care. Finally, as with any “pre- and post-” design, factors other than the SPCC may influence outcomes. The main challenge to addressing this issue is the difficulty in establishing similar comparative cohorts because it is virtually impossible to design a prospective, randomized clinical trial.

Although the hospital had a loss of $403 per child-year providing comprehensive primary care for children with multisystem disorders, the loss was covered by a positive inpatient hospital gain in payments over total costs of $598. Unfortunately, inpatient hospital payments covered only approximately one third of the outpatient losses related to both primary and specialty care. These data show that the Medicaid hospital reimbursement for outpatient services is considerably lower than for inpatient reimbursement. This places the hospital at increasing financial risk as care shifts for this population from inpatient to outpatient settings and more sophisticated technologies are used in the outpatient set-

<table>
<thead>
<tr>
<th>TABLE 5. Utilization and Direct Costs for Medical Subspecialty, Surgical Specialty, Ancillary, and ED Services for the 175 Children During the Year Before Enrollment in SPCC With the Year After Enrollment</th>
<th>Non-SPCC</th>
<th>Post-SPCC</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical subspecialty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. (%) of patients with visits</td>
<td>71 (41)</td>
<td>73 (41)</td>
<td>1.00</td>
</tr>
<tr>
<td>Visits per 100 child-years</td>
<td>125.7</td>
<td>114.3</td>
<td>.67</td>
</tr>
<tr>
<td>Average cost per visit</td>
<td>$255</td>
<td>$520</td>
<td>.35</td>
</tr>
<tr>
<td>Average cost per patient with visit</td>
<td>$1074</td>
<td>$1481</td>
<td>.08</td>
</tr>
<tr>
<td>Average cost per child-year</td>
<td>$436</td>
<td>$618</td>
<td>NA</td>
</tr>
<tr>
<td>Surgical specialty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. (%) of patients with visits</td>
<td>37 (21)</td>
<td>71(41)</td>
<td>&lt;.0001</td>
</tr>
<tr>
<td>Visits per 100 child-years</td>
<td>51.4</td>
<td>102.3</td>
<td>.005</td>
</tr>
<tr>
<td>Average cost per visit</td>
<td>$100</td>
<td>$112</td>
<td>.48</td>
</tr>
<tr>
<td>Average cost per patient with visit</td>
<td>$259</td>
<td>$286</td>
<td>.65</td>
</tr>
<tr>
<td>Average cost per child-year</td>
<td>$55</td>
<td>$116</td>
<td>NA</td>
</tr>
<tr>
<td>Ancillary</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. (%) of patients with visits</td>
<td>23 (13)</td>
<td>30 (17)</td>
<td>.37</td>
</tr>
<tr>
<td>Visits per 100 child-years</td>
<td>96.0</td>
<td>86.3</td>
<td>.80</td>
</tr>
<tr>
<td>Average cost per visit</td>
<td>$188</td>
<td>$199</td>
<td>.68</td>
</tr>
<tr>
<td>Average cost per patient with visit</td>
<td>$948</td>
<td>$1144</td>
<td>.73</td>
</tr>
<tr>
<td>Average cost per child-year</td>
<td>$150</td>
<td>$162</td>
<td>NA</td>
</tr>
<tr>
<td>ED</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No. (%) of patients with visits</td>
<td>36 (21)</td>
<td>40 (23)</td>
<td>.70</td>
</tr>
<tr>
<td>Visits per 100 child-years</td>
<td>33.7</td>
<td>42.3</td>
<td>.36</td>
</tr>
<tr>
<td>Average cost per visit</td>
<td>$157</td>
<td>$143</td>
<td>.62</td>
</tr>
<tr>
<td>Average cost per patient with visit</td>
<td>$263</td>
<td>$275</td>
<td>.17</td>
</tr>
<tr>
<td>Average cost per child-year</td>
<td>$54</td>
<td>$63</td>
<td>NA</td>
</tr>
</tbody>
</table>

NA indicates not applicable.
tings. Poor physician Medicaid reimbursement for primary care and outpatient specialty also creates a financial disincentive to provide care coordination and case management.

We found a significant difference in average length of non-intensive care stay between the pre-SPCC and post-SPCC enrollment. We were not able to demonstrate significant differences in average costs per non-intensive care hospitalization, patient hospitalized, or per child-year, although there were substantial differences in costs. We cannot say whether having SPCC clinics serve as inpatient attendings for their SPCC patients or other factors lead to a reduction in LOS. There were no differences in any of the intensive care outcomes, but there were only a few ICU hospitalizations each year. Therefore, the findings of this study are inconclusive as to whether a comprehensive primary care clinic reduces general and intensive care hospitalizations.

Our findings do show that a greater proportion of children who were followed in SPCC had surgical specialty services and a higher number of surgical visits per child-year. Differences in Medical sub specialty, ancillary, and ED services did not achieve statistical significance. Finding that ED visits were not decreased after enrollment in SPCC may have reflected appropriate use of these services by these families.

CONCLUSIONS

This study confirms that children with these multi-system disorders are medically fragile and require frequent hospitalizations and ED visits even with focused primary care. Although the reimbursement covered the direct costs of care for this population, it did not cover total costs. Enrollment in a comprehensive primary care program was associated with a decreased LOS for non-intensive care hospitalizations and increased use of surgical specialty services. These findings are consistent with reports that SSI children fare better with enhanced care coordination and case management.

REFERENCES


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Pediatrics 2005;115:e637
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