Integration of Administrative Data and Chart Review for Reporting Health Care Utilization Among Children With Sickle Cell Disease

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Abstract
Health care utilization of children with sickle cell disease (SCD) has been well documented due to an increase in the use of administrative data sets. While use of such data sources is relatively efficient and low cost, questions remain as to whether they provide sufficient information to fully characterize health care use. The aim of this study was to determine whether administrative data have the capacity to fully assess health care utilization among children with SCD. We studied the health care utilization of 154 low-income children with SCD in a managed care organization combining administrative data and medical record review. In our comparison, we found that administrative claims provided key information on the scope and location of health service use and that sole reliance on medical record review may undercount unique members and encounters.

Keywords
sickle cell disease, health care utilization

Introduction
Sickle cell disease (SCD) is an inherited hemoglobinopathy that occurs in 1 in every 500 African American births (National Institutes of Health, 2002). Clinical complications of SCD include vaso-occlusive pain crises, anemic episodes, infections, and stroke (Frank, Allison, & Cant, 1999; Smith, 1989). Health care utilization for children with SCD has been well documented largely due to an increase of studies using administrative claims data (Grosse, Boulet, Amendah, & Oyeku, 2010). Children with SCD have mean expenditures 8.8 times that of children in general (Bilenker, Weller, Shaffer, Dover, & Anderson, 1998). Relative to children with other chronic illnesses, children with SCD have a higher frequency of hospitalizations and longer mean length of stay (Irey, Anderson, Shaffer, & Neff, 1997). In addition, children with SCD have rehospitalization rates as high as 23% (Brousseau, Owens, Mosso, Panepinto, & Steiner, 2010). The average medical fee for a child with SCD during childhood (age 0-18 years) is approximately US$1,354,000 (Kauf, Coates, Huazhi, Mody-Patel, & Hartzema, 2009). Cumulatively, these studies indicate that despite progress in the evaluation and management of SCD (Halasa et al., 2007; Steinberg et al., 2003; Vichinsky, Hurst, Earles, Kleman, & Lubin, 1988), care of affected children continues to be high-cost and resource-intensive (Amendah, Mvundura, Kavanagh, Sprinz, & Grosse, 2010; Leschke et al., 2012; Mvundura, Amendah, Kavanagh, Sprinz, & Grosse, 2009; Raphael et al., 2009; Raphael, Mei, Mueller, & Giordano, 2012; Sobota, Graham, Neufeld, & Heeney, 2012).

While the relative efficiency and low cost of claims data have yielded new insights into health care utilization for pediatric SCD, uncertainties remain as to whether routine claims data may lack sufficient information to fully characterize medical service use. A number of past studies have questioned the utility of administrative claims data for assessing health care utilization and quality given well-documented limitations including coding errors and misclassifications of health care use (Iezzoni, 1997; Newschaffer, Bush, & Penberthy, 1997; Parkinson, 2002; Steinwachs et al., 1998). However, few studies have focused on a single chronic condition (Pawlson, Scholle, & Powers, 2007). While medical record review may provide more clinical data relative to administrative claims, it is limited particularly when records are only available from a

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subset of institutions where an individual may receive care. In the case of SCD, even when children receive care at comprehensive sickle cell centers, they may also seek services outside these institutions.

The overall aim of this pilot study was to determine whether administrative data are sufficient to fully assess health care use among children with SCD. To evaluate the health care utilization of children with SCD who were enrolled in a Medicaid managed care program, we compared administrative claims data with medical record chart review. Our specific study questions were (a) whether medical record review supplements administrative claims data for SCD and (b) the degree to which children with SCD concurrently receive care at multiple institutions.

**Method**

**Study Design**

A retrospective, cross-sectional descriptive analysis was conducted based on claims data from Texas Children’s Health Plan (TCHP) and medical record review from Texas Children’s Hospital (TCH) to assess health care utilization of children with SCD. TCHP is a health maintenance organization for children with public insurance and the largest provider of care for children with Medicaid and the State Children’s Health Insurance Plan (SCHIP) in the greater Houston area. TCH is a large, tertiary freestanding children’s hospital in Houston, Texas. The study was approved by the institutional review board at the Baylor College of Medicine.

**Study Population**

The goal of selection was to identify children with SCD who were TCHP members and also received medical services at TCH. SCD was identified using *International Classification of Disease, 9th Revision, Clinical Modifications* (ICD-9CM) code 282.6 which encompasses sickle cell hemoglobinopathies. Medical services were defined as emergency care (ER), hospitalizations, hematologic visits, primary care physician (PCP) visits, and radiologic imaging. The initial target population consisted of children ages 0 to 18 years who received health care services paid by TCHP at any time during 2007 and had a minimum of one medical service at TCH during the same period. We then excluded members who had less than 10 months of contiguous enrollment within TCHP during the calendar year, as done in a prior study (Raphael et al., 2009). From this process, we identified 154 unique members who comprised our study sample.

**Administrative Database**

The study used administrative data from TCHP for the calendar year 2007 that included diagnoses and medical services. A third-party software was used to collect demographic and utilization data for members with SCD and migrate them to a relational database containing chart review data. To protect patient confidentiality, we created an interface between the administrative claims and chart review data that permitted an individual patient’s data to be merged but which de-identified the matched data at the time of the analysis.

We collected demographic data and medical service use. Patient characteristics consisted of age, gender, race/ethnicity, sickle cell phenotype, receipt of comprehensive care at TCH, public insurance type, continuous enrollment months in calendar year, and distance from TCH. Age was divided into categories of <1 year (infant), 1 to 4 years (preschool age), 5 to 12 years (school age), and 13 to 18 years (adolescence). Racial/ethnic information was categorized as White, Black, Hispanic, Asian, Native American, or Other. For each patient, we determined whether they received comprehensive hematologic care at TCH. For the purpose of this study, receipt of comprehensive hematologic care was defined as a minimum of one routine visit to the sickle cell center at TCH. Public insurance was categorized as Medicaid versus SCHIP. Continuous enrollment in the study calendar year was grouped as 10, 11, or 12 months. Finally, for each patient, we calculated the distance from their home to TCH by using distances between zip codes.

For medical service use, we recorded ER visits, hospitalizations, and routine hematologic visits for SCD. We also assessed PCP encounters, both preventive visits and urgent care visits. Finally, we recorded Transcranial Doppler Ultrasound (TCD) screening, a recommended annual screening test for children with SCD to assess stroke risk (National Institutes of Health, 2002).

**Supplemental Medical Record Review**

Using unique identifiers from TCHP administrative claims, we matched and identified medical record numbers for TCHP members with SCD who received care at TCH. While TCH has the largest children’s hospital in Houston, children with SCD enrolled in TCHP have access to non-TCH institutions within the city. A diagnosis of SCD from the administrative claims was verified with TCHP medical records to minimize misclassification errors. A chart review was conducted to determine documentation of all health care utilization occurring at TCH for the study period.

**Statistical Analysis**

Descriptive statistics were used to summarize patient demographics and health care utilization. For health care utilization, we calculated total encounters per unique member separately for claims data and medical record review. This ratio was calculated by dividing the total number of a given encounter type by the total number of unique members having that encounter. All analyses were conducted using STATA 9.0.
Table 1. Study Population Demographics (N = 154).

| Variable                          | n (%)     |
|----------------------------------|-----------|
| **Child characteristics**        |           |
| Age                              |           |
| <1                               | 3 (2.0)   |
| 1-4                              | 78 (50.6) |
| 5-12                             | 57 (37.0) |
| 13-18                            | 16 (10.4) |
| Gender                           |           |
| Male                             | 82 (53.3) |
| Female                           | 72 (46.7) |
| Race/Ethnicity                   |           |
| White                            | 6 (3.9)   |
| Black                            | 65 (42.2) |
| Hispanic                         | 66 (42.9) |
| Asian                            | 9 (5.8)   |
| Native American                  | 1 (0.6)   |
| Unknown                          | 7 (4.6)   |
| Sickle cell phenotype            |           |
| HbSS                             | 31 (20.1) |
| Sickle Beta 0                    | 5 (3.3)   |
| Sickle Beta Thal+                | 5 (3.3)   |
| SC                               | 13 (8.4)  |
| Other variant                    | 4 (2.6)   |
| Unknown                          | 96 (62.3) |
| Comprehensive care at TCH        |           |
| Yes                              | 58 (37.7) |
| No                               | 96 (62.3) |
| Insurance                        |           |
| Medicaid                         | 133 (86.4)|
| SCHIP                            | 21 (13.6) |
| Continuous months enrolled       |           |
| 10                               | 30 (19.5) |
| 11                               | 25 (16.2) |
| 12                               | 99 (64.3) |
| Distance to TCH (miles)          |           |
| 0-10                             | 25 (16.2) |
| 11-20                            | 81 (52.6) |
| 21-30                            | 33 (21.5) |
| 31-40                            | 8 (5.2)   |
| 41+                              | 7 (4.5)   |

Note: HbSS = hemoglobin SS disease; SC = sickle-hemoglobin C disease; TCH = Texas Children’s Hospital; SCHIP = State Children’s Health Insurance Program.

Results

**Patient Demographics**

Patient demographics are summarized in Table 1. The mean age of patients was 5.7 years. Children ages 1 to 4 years accounted for half of all patients. African American and Hispanic children comprised more than 80% of the study sample. The majority of children did not receive comprehensive care at TCH. Most children were insured through Medicaid. Almost 70% of the study sample lived within 20 miles of TCH.

**Medical Service Utilization—Claims Versus Chart Review**

Results comparing administrative claims with chart review data are shown in Table 2. For ER visits, the ratio of total encounters per unique member was 2.2 for claims compared with 1.5 for medical record review. The total encounters per unique member ratio was also higher for claims relative to medical record review for routine hematology visits. Outpatient hematology care demonstrated notable patterns. A total of 49 members generated 226 visits with hematology according to TCHP claims data. Within TCH alone, 51 members (including 2 members not identified in claims data) accounted for 158 visits with hematology according to TCH chart review. For PCP visits, 154 unique members accounted for 654 PCP visits, or 4.3 claims per person. Health care utilization at TCH only accounted for a fraction of these encounters. According to medical record review, 14 PCP encounters were documented among 6 unique members, or 2.3 visits per person. Of the PCP visits, 57% (373/654) were coded as preventive and 42% (281/654) were coded as urgent according to claims review (data not shown). Of 154 members, 20 did not have any office visits with a PCP according to claims review. Of this group, 7 members had at least 1 office visit with a hematologist. For hospitalizations, the total encounters per unique member were lower for claims relative to medical record review. No differences in the ratio were found for TCD screening. Only 17% (26/154) of unique members underwent TCD screening according to TCHP claims data. Only 8 of the 26 TCDs were documented at TCH.

In addition to assessing the total encounters per unique member, we also assessed the utilization patterns of frequent users of medical services. For members (n = 17) who were identified as having 3 or more ER visits, we compared the occurrences at TCH with other institutions. Two thirds (58/87) of ER visits occurred at TCH while the remainder occurred at outside institutions. For members (n = 7) with 3 or more inpatient hospitalizations, approximately 70% (19/27) of their hospitalizations occurred at TCH.

Discussion

Our pilot study provides novel data on the potential benefit of combining administrative claims data and medical record review to assess health care use and fragmentations in care among children with SCD. This study demonstrates findings consistent with past studies, documenting significant use of medical care, inadequate access to hematology services, and underutilization of TCD screening (Carroll, Haywood, Fagan, & Lanzkron, 2009; Mvundura et al., 2009; Raphael...
et al., 2009; Raphael, Shetty, Liu, Mahoney, & Mueller, 2008; Shankar et al., 2005; Shankar et al., 2008). It also shows that medical review, alone, conducted at one institution, can quite dramatically undercount unique individuals and encounters. Chart review only showed benefit in the case of routine hematology visits where it picked up additional 2 members (49 → 51) who had encounters. These claims were potentially missed due to inaccurate coding or errors in filing or reporting. To achieve the most complete picture of health care utilization, claims data that cover an entire state or region may offer the most accurate data source.

This work highlights potential fragmentation in care for children with SCD. For high-acuity care, TCHP members sought care at TCH and other health care institutions. While these utilization patterns may have been driven by convenience and proximity to health care services, they nonetheless raise concern about how children with SCD navigate the health care system. Receipt of care in multiple environments can be problematic for children with SCD. They may be cared for by staff unfamiliar with their extensive histories and diverse needs or unfamiliar with SCD in general. Physicians may inappropriately repeat tests and interventions. Such practices may have adverse consequences on individual patient health and generate unnecessary health care costs.

This pilot study had several methodological limitations. Only medical records at TCH were reviewed. We did not have access to records at other acute care institutions. This limited our ability to verify and fully assess the nature of encounters at all sites of acute and hematology care. It also limited our ability to determine the exact sickle cell phenotype for the majority of our sample. We also did not have access to the visit policies of the individual PCPs. These policies could encourage or discourage fragmentation. If the PCP advised patients in need of acute care to use geographically convenient facilities or those more closely affiliated with their practice, it would artificially appear that fragmentation of care was occurring. However, these policies may have other benefits of convenience and proximity to PCPs and patients. In our study sample, 31% of children lived 20 miles or farther from TCH. Use of TCH may have been especially difficult for these families.

This study demonstrates the benefits of administrative claims data in documenting the health care utilization of children diagnosed with SCD. Administrative claims data provides key insights into the scope of health service use, including how and where services are being used. This study also highlights the limitations of sole reliance on medical record review. In the future, integration of chart review may have a more central role (Pawlson et al., 2007). Historically, chart review has been limited by its resource and time-intensive nature. However, with federal efforts to implement electronic medical records across integrated health care systems, review of medical records may be more of a viable option in the future.

**Declaration of Conflicting Interests**

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**Table 2. Claims Versus Chart Review for 154 Children With Sickle Cell Disease.**

| Utilization       | Total encounters from claim | Total unique members from claims | Total encounters per unique member (claims) | Total encounters from MR | Total unique members from MR | Total encounters per unique member (MR) |
|-------------------|-----------------------------|---------------------------------|--------------------------------------------|--------------------------|----------------------------|----------------------------------------|
| ER visits         | 165                         | 73                              | 2.2                                        | 31                       | 21                         | 1.5                                    |
| Hospitalizations  | 34                          | 34                              | 1                                          | 31                       | 23                         | 1.3                                    |
| Hematology visits | 226                         | 49                              | 4.6                                        | 158                      | 51                         | 3.1                                    |
| TCD screening     | 26                          | 26                              | 1                                          | 8                        | 8                          | 1                                      |
| PCP visits        | 654                         | 154                             | 4.3                                        | 14                       | 6                          | 2.3                                    |

Note: MR = medical record; ER = emergency care; TCD = Transcranial Doppler Ultrasound; PCP = primary care physician.
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