Identifying Sickle Cell Disease Cases Using Administrative Claims

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ABSTRACT

OBJECTIVE: To develop and test the accuracy of administrative claims method for identifying children with sickle cell disease (SCD) to enable quality of care assessments among children enrolled in Medicaid.

METHODS: All administrative claims with an SCD diagnosis were obtained from Michigan Medicaid from 2008 to 2011 for children ≤18 years, representing 1828 individuals. All Medicaid claims were obtained for these children and classified into categories on the basis of SCD care; these classifications were used to develop 37 alternative case definitions for identifying children with SCD. Children with ≥1 SCD claim in 2010 or 2011 were identified as confirmed SCD or not SCD using the gold standard of Michigan newborn screening administrative records. Measures of performance were calculated for each case definition for eligible children in 2010. Further validation of the case definitions was performed among eligible children in 2011.

RESULTS: In 2010, a total of 938 children met eligibility criteria and were linked to newborn screening records; 605 (59%) were confirmed SCD, and 333 (32%) were not SCD. Measures of performance varied among the 37 case definitions, and the 4 best case definitions on the basis of the sensitivity, specificity, and area under the receiver operating characteristic (ROC) curve were validated among 924 children meeting eligibility criteria in 2011. The case definition of at least 3 SCD claims in any position identified children with SCD with the most accuracy, with an area under the ROC curve of 0.91 (95% confidence interval 0.89, 0.93).

CONCLUSIONS: This definition can be used to facilitate a more accurate identification of children with SCD in future studies. Further investigation is necessary to determine whether this method translates to other populations besides Michigan Medicaid-insured children.

KEYWORDS: administrative claims; case identification; children; Medicaid; newborn screening; sickle cell disease

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SICKLE CELL DISEASE (SCD) is a chronic disease affecting mainly minority populations and is characterized by significant morbidity and mortality. SCD is estimated to currently affect 90,000 to 100,000 Americans (approximately 1 in 500 African American births), although variation exists among prevalence estimates.[1–4] SCD has multiple clinically significant forms, further complicating estimates of the true burden of disease. There are 6 sickle cell genotypes; however, the most common variants are sickle cell anemia (hemoglobin SS), hemoglobin (Hb) SC, HbS/β^0-thalassemia, and HbS/β^+-thalassemia.[5] Children with SCD are at risk for chronic symptoms that can seriously impact quality of life, including pain episodes, severe anemia, and pulmonary complications.[6,7] SCD can have devastating consequences among children if uncontrolled and can lead to potentially life-threatening complications. Children with SCD are 7 to 30 times more likely to be hospitalized, 2 to 6 times more likely to visit the emergency department, 300 times more likely to have a stroke, and 100 times more likely to develop pneumococcal infection; further, they have over 8 times the health care expenditures than their counterparts without SCD.[8–11]

Given these risks, it is essential that children with SCD have effective follow-up immediately after birth and that preventive services are obtained throughout childhood.[7,12–14] At birth, all children are screened for SCD through state newborn screening (NBS) programs; these results could potentially enable identification of cases for ongoing quality of care assessments. However, state Medicaid programs may not have the technical capacity or policies established to authorize links between NBS results and administrative claims to support quality of care assessments. Absent the capability to establish these linkages, a claims-based definition is necessary to identify SCD cases. Although quality of care assessments that use administrative claims data have been previously developed

for conditions such as asthma and diabetes,[15–19] a mechanism to identify SCD cases using claims has not been validated. If successful, a claims-based method offers important opportunities to evaluate population-based quality of care among children with SCD without requiring linkages to external data sources such as those maintained by state NBS programs. With that in mind, our objective was to develop and test the feasibility and accuracy of an administrative claims method for identifying children with SCD to enable quality of care assessments among children enrolled in Medicaid.

METHODS

We developed and tested alternative methods for identifying children with SCD using Medicaid administrative claims data. We used a 5-step process that included: 1) acquisition of all Medicaid administrative claims for any child with at least 1 SCD claim; 2) classification of claims into meaningful groups relevant to SCD care; 3) development of alternative case definitions using these variables; 4) identification of the testing population to validate the accuracy of the alternative case definitions; and 5) test of the accuracy of the alternative case definitions to identify children with SCD.

ACQUISITION OF CLAIMS

In partnership with the Michigan Department of Community Health, we obtained all Medicaid administrative claims with a SCD ICD-9 diagnosis code for children 18 years or younger. All children were included, regardless of Medicaid enrollment status, during the period 2008 to 2011. Consistent with other studies and Agency for Healthcare Research and Quality (AHRQ) Healthcare Cost and Utilization Project Single-Level Clinical Classification Software (HCUP CCS), we included claims with ICD-9 diagnosis codes for HbSS (282.60, 282.61, 282.62), HbSC (282.63, 282.64), HbSD (282.68, 282.69), and HbS β-thalassemia (282.41 and 282.42); we did not include sickle cell trait (282.5) or other hemoglobinopathies.[20–23]

A total of 66,274 SCD claims containing 304,289 revenue and/or procedure codes representing 1828 unique individuals were identified from 2008 to 2011. All Michigan Medicaid administrative claims data were acquired for these 1828 individuals for each year, including detailed enrollment characteristics (containing demographics and program eligibility information), provider information, and health services (including inpatient, outpatient, emergency department, and pharmacy). These data were linked to provide a comprehensive overview of paid services rendered to any child with an SCD claim. The claims tables included codes from all major health care coding schemes used to track patients and obtain reimbursement, including ICD-9-CM diagnosis codes, diagnosis-related groups, uniform billing (UB-92) codes, ICD-9-CM surgical codes, current procedural terminology (CPT) codes, Healthcare Common Procedure Coding System, and national drug codes. A de-duplication process was implemented, and claims were grouped together into events according to dates of service.

CLASSIFICATION OF CLAIMS

As a precursor to creating alternative case definitions, we classified individuals on the basis of claims history relevant to SCD care using the extracted SCD claims. Our classification approaches were derived from methodologies published by AHRQ, National Committee for Quality Assurance Healthcare Effectiveness Data and Information Set, and Centers for Medicare and Medicaid Services.[20,24,25] We started the process with a complete extraction of all SCD claims to maximize the likelihood that even diagnosis and procedure codes that were infrequently used would be given consideration in our approach. Interim results were shared among the team of investigators that included substantial expertise in Medicaid claims data analyses, chronic disease epidemiology, newborn screening, and statistical programming. Team members reviewed candidate case definitions based solely on one coding system (eg, an outpatient definition using CPT codes) and evaluated the incremental advantages or disadvantages of including other coding schemas (eg, an outpatient definition using both CPT and revenue codes). These considerations were aided by tabular frequency counts of the number of unique individuals and event counts for each code as well as visual representations (eg, Venn diagrams). These methods were jointly reviewed by team members to evaluate the degree of overlap between code groups and the unique contribution of each code group in capturing distinct individuals with SCD. We used an iterative approach to determine the degree to which each child had specific groups of claims representing meaningful categories of SCD care. We subsequently classified each child's claims from several perspectives, ranging from simple counts of SCD claims to claim counts on the basis of combinations of different SCD services.

DEVELOPMENT OF ALTERNATIVE CASE DEFINITIONS

From our analysis of SCD claims groupings, we identified 9 mutually exclusive claims categories: 7 health services categories (inpatient, outpatient, home health care, emergency department, blood transfusion), and 2 medication categories (antibiotic prophylaxis and hydroxyurea). In addition, 2 composite groups were formed: evaluation/consultation claims and an overall count of SCD claims (irrespective of type of service). Table 1 provides these categories and lists several additional categories that were considered but not included in the final case definitions. These categories served as the basis for the development of alternative case definitions to identify children with SCD from administrative claims. Table 2 illustrates the resultant 37 case definitions considered; the definitions reflect alternatives aimed at balancing inclusion of cases to maximize sensitivity with the addition of increasingly restrictive criteria to gain specificity. Alternative definitions were also considered on the basis of whether the diagnosis code for SCD was reported as the primary diagnosis or any mention of SCD for emergency department and inpatient claims.