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Peter A. Lane
Rodney Theodore
Mei Zhou
Angela Snyder

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Accuracy of ICD-9 Coding for Sickle Cell Disease (SCD) in Children and Adolescents: Results from the Georgia (GA) Rush Surveillance Project

Peter A Lane MD, Rodney Theodore MPH, Mei Zhou MS, Angela Snyder PhD

RESEARCH OBJECTIVE
To study the accuracy of using ICD-9 codes within administrative claims data to identify individuals with Sickle Cell Disease (SCD).

STUDY DESIGN
Retrospective study to evaluate the accuracy of the Registry and Surveillance for Hemoglobinopathies (RuSH) case definition in identifying true cases of SCD in administrative datasets. Probable cases required identification of ≥ 2 encounters with a SCD ICD-9 code (282.60-282.69, 282.41-282.42) plus 1 encounter with an SCD-TPC or CPT code from a predetermined list of SCD-associated treatments, procedures, and complications (SCD-TPC). Patients were classified into three groups according to the number of SCD ICD-9 codes: 1) ≤ 1 encounter, 2) ≥ 2 encounters with ≤ 2 SCD ICD-9 codes, and 3) ≥ 2 encounters with ≥ 3 SCD ICD-9 codes.

RESULTS
A total of 1,998 children and adolescents with ≥ 1 encounter with a SCD ICD-9 code in three administrative datasets: Georgia Medicaid, CHIP, and State Health Benefit Plan claims data from 2004-2008 were seen at least once at a CHOA facility and had medical records available for review.

CONCLUSION
Use of administrative claims data to identify children and adolescents with SCD based on ICD-9 coding can be useful to health services researchers, but the results should be interpreted with caution. Further research is needed to better understand the accuracy of ICD-9 coding for SCD and its impact on population health outcomes.

IMPLICATIONS FOR POLICY OR PRACTICE
Health services and outcomes research in SCD has been limited by inadequate population-based surveillance and reliance on ICD-9 codes to identify individuals with SCD. This study supports an administrative case definition that includes ≥ 3 separate ICD-9 codes in order to identify SCD with a high degree of accuracy and suggests it can be useful to assess quality of care. However, using administrative data, by design, excludes individuals who have less health care utilization and are therefore less costly. These limitations must be weighed against the benefits of using the data in future health services research.