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

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SUMMARY

This study evaluated the accuracy of ICD-9 coding for Sickle Cell Disease (SCD) in administrative datasets. Using a case definition of ≥ 3 SCD ICD-9 codes, the study found that SCD was confirmed in 1,763 (88.2%) cases, excluded in 196 (9.8%), and indeterminate in 39 (2.0%). The likelihood of having SCD significantly increased with an increasing number of SCD ICD-9 codes during both time periods. The 1-year period had better accuracy, but more missed cases. For the 5-year surveillance period, the accuracy of ≥ 2 SCD-coded encounters (93.7%) increased to (97.0%) with the addition of ≥ 1 encounter with SCD-TPC, but the number of missed cases increased from 28 (1.6%) to 51 (2.4%). The study supports using ≥ 3 SCD ICD-9 codes as a case definition in administrative datasets.

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 limitations are dependent on the research question. Accuracy of identification correlated directly with the number of SCD-coded encounters and indirectly with the length of the surveillance period. The addition of ≥ 1 encounter with SCD-TPC to a case definition of ≥ 2 encounters with SCD ICD-9 codes minimally improved specificity but resulted in a large number of missed cases, more than the simpler definition of ≥ 3 SCD-coded encounters.

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 SCD ICD-9 codes 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. Those limitations must be weighed against the benefits of using the data in future health services research.

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