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Accuracy of *ICD*-9 Codes for Identifying Children With Cerebral Sinovenous Thrombosis

Meredith R. Golomb, MD, MSc, Bhuwan P. Garg, MBBS, and Linda S. Williams, MD

Childhood sinovenous thrombosis is rare, making it difficult to study; *International Classification of Diseases*, ninth revision (*ICD*-9), code searches across multiple hospitals would permit the identification of large numbers of children with sinovenous thrombosis. However, the accuracy of these codes for identifying childhood sinovenous thrombosis has not been established. We performed a retrospective search of admissions records for Riley Hospital for Children in Indianapolis, Indiana, from January 1999 to June 2005 using *ICD*-9 codes 325 (cerebral sinovenous thrombosis, excluding nonpyogenic cases and cases associated with pregnancy and the puerperium), 437.6 (cerebral venous thrombosis of nonpyogenic origin), and 671.5 (cerebral venous thrombosis in pregnancy or the puerperium) in any position. During this period, there were 47 042 admissions. *ICD*-9 code 325 identified 61 admissions on 56 children. Only 13% were of pyogenic origin. Fifty-two (92.9%) had "possible, probable, or definite" sinovenous thrombosis, but only 76.9% of those had "probable or definite" sinovenous thrombosis. Uncertainty in diagnoses stemmed from limitations in imaging and disagreement over interpretation of imaging studies. *ICD*-9 code 325 in the primary position identified 7 children; all had possible (n = 1), probable (n = 1), or definite (n = 5) sinovenous thrombosis. *ICD*-9 code 437.6 identified a single admission on a single case of probable cerebral venous thrombosis; it was unclear whether this case was "nonpyogenic." *ICD*-9 code 671.5 did not identify any children. *ICD*-9 code 325 is useful for identifying children likely to have sinovenous thrombosis, but it is not useful for differentiating pyogenic and nonpyogenic cases, and uncertainty in clinical diagnosis makes it difficult to gauge the true accuracy. Furthermore, it is important to search for the code in any position as limiting searches to the primary position misses most cases.

Keywords: sinovenous thrombosis; *ICD*-9 codes; accuracy

Cerebral sinovenous thrombosis in children is rare, making data collection on large numbers of patients difficult. The Canadian Pediatric Ischemic Stroke Registry, a nationwide database of Canadian children with stroke, collected data on 160 children with sinovenous thrombosis over a 6-year period and estimated an incidence of 0.67 per 100 000 children per year.[1] In the United States, studies of the National Hospital Discharge database using the *International Classification of Diseases*, ninth revision (*ICD*-9), codes would permit the collection of data on significant numbers of patients. However, the accuracy of *ICD*-9 codes for identifying children with sinovenous thrombosis is not known.

From the Division of Pediatric Neurology (MRG, BPG) and the Department of Neurology (LSW), Indiana University School of Medicine, Indianapolis; Roudebush VAMC HSR&D, Indianapolis, Indiana (LSW); and the Regenstrief Institute, Indianapolis, Indiana (LSW).

This work was done at Riley Hospital for Children in Indianapolis, Indiana.

Address correspondence to: Meredith R. Golomb, MD, MSc, Indiana University School of Medicine, Building XE-040, 575 West Drive, Indianapolis, IN 46202; e-mail: mgolomb@iupui.edu.

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Methods

We identified all inpatients seen at the Riley Hospital for Children between January 1, 1999, and June 10, 2005, who received 1 of the following 3 discharge codes: 325 (cerebral venous thrombosis, excluding cases of nonpyogenic origin or complicating pregnancy, childbirth, or the puerperim), 437.6 (cerebral venous thrombosis of nonpyogenic origin), or 671.5 (cerebral venous thrombosis complicating pregnancy, childbirth, or the puerperium) in any position. Our hospital identifies a primary diagnosis and up to 50 additional diagnoses. The charts of all identified patients were reviewed by a pediatric neurologist with fellowship training in pediatric stroke (M.R.G.) to determine the accuracy of the diagnosis. Cases were classified as possible, probable, or definite based on chart review and evaluation of radiologic findings and the evaluations of attending physicians. Cases in which the diagnosis was unclear owing to limitations of imaging were included in possible sinovenous thrombosis; radiology reports usually described the findings using terms such as "could be indictative of" or "may suggest" sinovenous thrombosis, and the uncertainty of the diagnosis was recorded in the medical record. Cases in which physicians disagreed on the diagnosis were also included in possible sinovenous

thrombosis. Probable sinovenous thrombosis was defined as cases in which the radiographic imaging was highly suggestive of the diagnosis; the clinical picture usually also supported the diagnosis. Definite sinovenous thrombosis was defined as cases in which the radiographic imaging was clearly diagnostic and there was absolutely no doubt about the diagnosis. Most cases of definite sinovenous thrombosis had repeated radiographic imaging, which confirmed the diagnosis. This study was approved by our Institutional Review Board (study 0207-55).

Results

There were 47 042 admissions to Riley Hospital during this period (mean 7307 per year). *ICD*-9 code 325 identified 61 admissions on 56 patients. *ICD*-9 code 437.6 identified a single admission on 1 patient. *ICD*-9 code 671.5 did not identify any patients.

Code 325 was the primary diagnosis code for 7 admissions on 7 patients. Fifty-two of the 56 patients (92.9%; 95% confidence interval, 82.7-98.0) identified by code 325 had possible, probable, or definite cerebral sinovenous thrombosis. Thirty-two of these children were neonates and 20 were older (median age 5.5 years; range, 0.1-16 years). Associated diagnoses for these children are listed in Table 1 and Table 2. Seven of the 52 children identified by *ICD*-9 code 325 (13%) had likely pyogenic cerebral sinovenous thrombosis (3 neonates with meningitis or encephalitis, 4 infants or children with mastoiditis); thus, 87% of those coded with code 325 had nonpyogenic thrombosis.

Twelve patients with *ICD*-9 code 325 were classified as possible sinovenous thrombosis (21.4% of patients identified by code 325; 23.1% of sinovenous thrombosis patients). In 5 cases, the clinical history, together with initial noncontrast head computed tomography (CT) was suggestive, but magnetic resonance imaging (MRI) >24 hours later did not confirm the diagnosis; in 4 cases, initial magnetic resonance venography (n = 1) or MRI (n = 3) was suggestive but not confirmatory; in 2 cases, noncontrast head CT was suggestive, but follow-up MRI or CT with contrast was not performed; and in 1 case, physicians did not agree on the interpretation of the magnetic resonance venography. Forty patients (71.4% of those defined by *ICD*-9 code 325, 76.9% of sinovenous thrombosis patients) had probable or definite sinovenous thrombosis. Cases were diagnosed by magnetic resonance venography (n = 29), MRI without magnetic resonance venography (n = 17), CT with and without contrast (n = 4), and CT without contrast alone (n = 2).

ICD-9 code 325 in the primary position identified 7 cases. All cases (100%) had possible, probable, or definite sinovenous thrombosis; 6 cases (85.7%) had probable or definite sinovenous thrombosis.

Four patients without sinovenous thrombosis were picked up by code 325. Their diagnoses were frontal lobe ischemia with unremarkable magnetic resonance venography (n = 1), clinical suspicion of sinovenous thrombosis but unremarkable magnetic resonance venography (n = 1), schizencephaly with subdural hemorrhages (n = 1), and cavernous malformation (n = 1).

For the single patient picked up by code 437.6 (nonpyogenic cerebral sinovenous thrombosis), this code was a secondary diagnosis. The child had probable cavernous sinus thrombosis, and it was unclear whether the etiology was infectious. He had flulike symptoms for several days and then developed ptosis, proptosis, and limited medial, lateral, and downward gaze of the left eye. He improved after treatment with antibiotics and steroids. Code 437.6 missed the 45 cases of nonpyogenic sinovenous thrombosis that were identified by code 325.

Table 1. *ICD*-9 Code 325: Associated Conditions in Neonates With Sinovenous Thrombosis (n = 32)

Condition	n	%
Etiology unclear[a]	10	31.3
Cardiac malformation	6	18.8
Dehydration	5	15.6
Meningitis/encephalitis	3	9.4
Endocrine abnormality	2	6.3
Hypocalcemia/electrolyte imbalance	2	6.3
Chromosomal abnormality	2	6.3
Factor V Leiden mutation	2	6.3; 12.5 of those tested[b]
Brain malformation	1	3.1

NOTE: *ICD*-9 = International Classification of Disease, 9th revision.
a. Etiology/precipitating factors of sinovenous thrombosis is unclear.
b. Significance unclear; 16 tested, 2 positive. One of the 2 positives also had dehydration.

Table 2. *ICD*-9 Code 325: Associated Conditions in Infants and Children With Sinovenous Thrombosis (n = 20)

Condition	n	%
Acute lymphoblastic leukemia/L-asparaginase	5	25
Mastoiditis	4	20
Renal disease/nephrotic syndrome	3	15
Head trauma	2	10
Urinary tract infection	1	5
Extracorporeal membrane oxygenation	1	5
Chickenpox	1	5
Choroid plexus cyst	1	5
Plasminogen activator inhibitor–1 mutation	1	5
Ulcerative colitis	1	5

NOTE: Eleven children tested for factor V Leiden mutation, none were positive.

Discussion

ICD-9 codes can be a powerful tool, but their utility is limited by their accuracy. We found that the *ICD*-9 code 325 is accurate in identifying children with possible, probable, or definite sinovenous thrombosis, but it is not accurate for differentiating pyogenic versus nonpyogenic

origin, and almost a quarter of identified patients had diagnoses that were unclear owing to limitations of imaging or variations in interpretation. Code 437.6 identified only a single patient, and it was not clear that the etiology was actually nonpyogenic. We evaluated code 671.5 because we thought it might be used to code children who had sinovenous thrombosis in the perinatal period, but that was not the case in our hospital; apparently, it is used only to code women with cerebral sinovenous thrombosis in the puerperium.

Diagnosing sinovenous thrombosis is not an exact art in adults or in children. A hypoplastic left sinus may look like a thrombosed sinus, or slow flow may give the appearance of thrombosis. Neonates have higher hematocrit levels, which may give the impression of thrombosis in a noncontrast head CT.[2] In our clinical experience, it is not uncommon for senior neurologists and neuroradiologists to disagree on the interpretation of a radiographic study. While 92.9% of the patients identified by *ICD*-9 code 325 had possible, probable, or definite sinovenous thrombosis, only 71.4% had probable or definite sinovenous thrombosis. Most of the possible images were for patients with lesser degrees of sinovenous thrombosis; inclusion or exclusion of those patients could have dramatic results on outcome studies. Identifying patients with code 325 only in the primary position improved the accuracy to 100%, but this strategy missed more than 85% of cases.

We are not aware of any previous studies of the accuracy of *ICD*-9 codes 325, 437.6, and 671.5 in adults, but several centers have studied the accuracy of *ICD*-9 stroke codes 430 to 438 for identifying adults with acute ischemic stroke, with varying results. Benesch et al[3] found problems with Academic Medical Center Consortium coding using *ICD*-9 codes 433 (occlusion and stenosis of precerebral arteries), 434 (occlusion of cerebral arteries), 435 (transient cerebral ischemia), and 436 (acute but ill-defined cerebrovascular disease). For example, 85% of patients identified with code 433 in any position were asymptomatic, and in one third of those patients, the reviewers could find no evidence in the medical record of occlusion and stenosis of precerebral arteries. When only patients with code 433 as a primary diagnosis were analyzed, 77% were asymptomatic. Code 434 worked better: 85% of patients identified by code 434 had a stroke during their index admission; if this code was in the primary position, the number rose to 90%. Goldstein[4] used codes 433 to 436 in the primary position to identify patients at the Durham Veterans Affairs Medical Center with acute ischemic stroke and found that 15% to 20% actually had other diagnoses. Leone et al[5] looked at coding of patients in the Italian Sistema Informative Sanitaro Regionale and found that stroke codes 430 to 438 had an overall sensitivity of 89% but that individual codes had much lower sensitivities, ranging from 16% to 87%. Rinaldi et al[6] looked at discharge coding in the hospital of Lugo di Romagna in Ravenna province, Italy, and found that stroke codes 434 and 436 had an overall sensitivity of 82%. Reker et al[7] pointed out that variations in *ICD*-9 sampling algorithms could lead to varying results in large studies.

The International Statistical Classification of Diseases and Related Health Problems, 10th edition (*ICD*-10), was introduced in 1993. Gillum[8] suggested that variations between the *ICD*-9 and *ICD*-10 might also contribute to variations in the accuracy of patient selection and in data analysis. However, we could not study this issue as our hospital has never used the *ICD*-10.

Our study has several limitations. Coding at our hospital may be less accurate than at other hospitals. However, our hospital has had a pediatric stroke clinic since 1995, which has led to increased awareness of pediatric stroke among the staff, so we believe that stroke coding here is as accurate or more accurate than at other children's hospitals. We cannot calculate the positive and negative predictive values of *ICD*-9 codes 325, 437.6, and 671.5 because we do not know the true prevalence of sinovenous thrombosis at our hospital. We cannot use Canadian estimates because the genetic and ethnic composition of Indiana is quite different from that in Canada. *ICD*-9 codes 325, 437.6, and 671.5 may miss children with cerebral sinovenous thrombosis, so we may have undercounted the total number of cases. For example, children with intracranial hemorrhage secondary to sinovenous thrombosis may have been coded as having intracranial hemorrhage but not sinovenous thrombosis. We are attempting to determine how many children with sinovenous thrombosis are missed with *ICD*-9 searches using codes 325, 437.6, and 671.5. Several studies of children with stroke using multiple strategies for case identification are ongoing at our institution; in the future, when we know the true number of children with these diagnoses, we may be able to identify the positive and negative predictive values of these codes. We decided not to search back more years because our colleagues had already used sinovenous thrombosis *ICD*-9 codes to search years 1986 to 1999 in a previous study on childhood sinovenous thrombosis.[9] They found that many medical charts had missing elements, making it difficult to confirm the diagnosis (personal communication, K. Carvalho, 2005). Since then, our hospital has computerized most medical records and improved maintenance of charts, making it easier to confirm the diagnosis.

At our hospital, *ICD*-9 code 325 reliably identifies children who are likely to have sinovenous thrombosis, but 87% of cases are not pyogenic, and in 23.1%, the diagnosis is not definite. It is important to screen for *ICD*-9 code 325 in any position, as limiting it to the primary position will result in missing more than 85% of cases. *ICD*-9 code 437.6 misses many nonpyogenic cases of cerebral sinvenous thrombosis. It is unclear how many cases of sinovenous thrombosis are missed by searches using these codes in any position. We suspect the National Hospital Discharge database has similar limitations. Further studies

of the accuracy of *ICD*-9 codes at other institutions are needed to identify the true accuracy of regional and national medical databases.

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