Accuracy of Administrative Coding for Type 2 Diabetes in Children, Adolescents, and Young Adults

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Administrative data are used with increasing frequency in research. However, validity of such data, including International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM) codes (1), varies across diseases and settings (2–12). The ICD-9-CM coding for diabetes in youth may be especially susceptible to errors. While most diagnoses of diabetes in American youth are type 1 diabetes (13), incidence of type 2 diabetes is increasing (14). Rising prevalence of pediatric obesity (15) makes distinguishing between type 1 and type 2 diabetes at diagnosis difficult, and type 2 diabetes ICD-9-CM codes (250.X0/X2) include "unspecified" diabetes (1). Our aim was to evaluate the positive predictive value (PPV) of type 2 diabetes ICD-9-CM codes in children, adolescents, and young adults.

RESEARCH DESIGN AND METHODS

— In a retrospective chart review, we evaluated 432 patients aged <26 years as of 31 January 2005 with at least one visit to the Endocrine/Diabetes or Obesity Programs at Children's Hospital Boston in Boston, Massachusetts, from 1 July 2003 to 31 January 2005 and at least one type 2 diabetes ICD-9-CM code (250.X0/X2, X = 0–9) from inpatient/outpatient sites before 5 April 2005. We identified 455 patients utilizing scheduling and billing information, and excluded 23 patients without completed visits.

To contrast the accuracy of type 2 diabetes ICD-9-CM codes with type 1 diabetes ICD-9-CM codes, we reviewed charts of patients <26 years as of 31 January 2005 with at least one visit to the Endocrine/Diabetes Program from 1 July 2003 to 31 January 2005 with a type 1 diabetes ICD-9-CM code (250.X1/X3, X = 0–9) at that visit. We randomly sampled 100 of 932 patients identified utilizing scheduling and billing information and excluded 1 patient without completed visits. Children's Hospital Boston Institutional Review Board approved the study.

Chart review

A research assistant reviewed up to three records from Endocrine/Diabetes or Obesity Programs in reverse chronological order from 31 January 2005 using an algorithm. The algorithm assigned one diagnosis in the following order of priority based on provider-documented diagnoses in the records: any type of diabetes, impaired glucose tolerance, hyperglycemia, insulin resistance, hyperinsulinism/hyperinsulinemia, obesity, or diabetes insipidus. If more than one type of diabetes or if none of these diagnoses were documented, diagnosis was deferred to reviewers who were pediatric endocrinologists blinded to the study aim. After review, patients without these diagnoses were categorized as "other."

Statistical analysis

Results are presented as proportions with PPV defined as the proportion with a type 2 diabetes ICD-9-CM code that had a clinical diagnosis of type 2 diabetes: [PPV = true positives/(true positives + false positives)]. Proportions were compared with χ^2 test (SAS version 9.0).

RESULTS

— Among 432 patients with a type 2 diabetes ICD-9-CM code, the average age as of 31 January 2005 was 15.5 ± 4.8 years (range 1.8–25.9). Average time between first and last encounter reviewed for patients with more than one visit was 0.78 ± 0.8 years (range 0.01–6.66). Diagnoses were assigned to 283 participants (66%) by algorithm and 149 (34%) by reviewers. Results are summarized in Table 1. Sixty-nine patients had type 2 diabetes (PPV 16.0%), and most others had type 1 diabetes. PPV was higher for the type 2 diabetes ICD-9-CM codes originating from Endocrine/Diabetes or Obesity Programs (19.9 vs. 7.7%, χ^2 test, $P = 0.001$), and patients with ICD-9-CM codes originating from other hospital sites more often had cystic fibrosis–related diabetes, steroid-induced diabetes, or "other" diagnoses.

In contrast to type 2 diabetes codes, PPV for type 1 diabetes ICD-9-CM codes was higher. Among 99 patients assigned a type 1 diabetes ICD-9-CM code, 96 had type 1 diabetes (PPV 97.0%).

CONCLUSIONS

— Administrative data provide useful information for researchers. However, disease and coding methods threaten validity. In a large children's hospital, PPV of type 2 diabetes ICD-9-CM codes was low, whereas type 1 diabetes codes were highly accurate.

Several issues may explain these findings. First, type 2 diabetes ICD-9-CM codes include "unspecified" diabetes. Given the rising prevalence of pediatric obesity (15), differentiating type 1 and type 2 diabetes at diagnosis may be difficult. Patients with phenotypic characteristics of type 2 diabetes may have pancreatic autoimmunity (16), and African Americans may present with nonautoimmune (idiopathic) type 1b diabetes

Table 1—*Clinical diagnosis of pediatric patients with an ICD-9-CM code for type 2 diabetes*

Clinical diagnosis (ICD-9-CM code)*	All sites combined	Origin of type 2 diabetes ICD-9-CM code†	
		Endocrine/Diabetes or Obesity Programs‡	Other inpatient or outpatient sites
n	432	286	143
Type 1 diabetes (250.X1 or 250.X3 with X = 0–9)	251 (58.1)	178 (62.2)	73 (51.0)
Type 2 diabetes (250.X0 or 250.X2 with X = 0–9)§	69 (16.0)	57 (19.9)	11 (7.7)
Insulin resistance (277.7 or 251)‖	28 (6.5)	19 (6.6)	9 (6.3)
Cystic fibrosis–related diabetes (251.8 and 277.0)	19 (4.4)	6 (2.1)	13 (9.1)
Other§	19 (4.4)	0 (0)	18 (12.6)
Obesity (278.0X with X = 0–2)	18 (4.2)	13 (4.5)	5 (3.5)
Steroid-induced diabetes (251.8 and E932.0)	11 (2.5)	2 (0.7)	9 (6.3)
Impaired glucose tolerance (790.22)	8 (1.9)	5 (1.7)	3 (2.1)
Diabetes insipidus (253.5 or 588.1)	3 (0.7)	1 (0.3)	2 (1.4)
Maturity-onset diabetes of the young (251.8)	2 (0.5)	2 (0.7)	0 (0)
Hyperinsulinism/hyperinsulinemia (277.7 or 251)§‖	2 (0.5)	1 (0.3)	0 (0)
Diabetes secondary to pancreatectomy (251.3)	1 (0.2)	1 (0.3)	0 (0)
Hyperglycemia (790.6)	1 (0.2)	1 (0.3)	0 (0)

Data are *n* (%). *ICD-9-CM code appropriately corresponding with clinical diagnoses. †A single visit was chosen at random in cases where a patient had multiple visits with a type 2 diabetes ICD-9-CM code. ‡For the purposes of coding assignment, we included satellite Endocrine/Diabetes Programs and the inpatient Endocrine/Diabetes Service in this category. §One patient with this diagnosis did not have an available assignment for the source of the ICD-9-CM code. ‖A specific ICD-9-CM code for insulin resistance or hyperinsulinemia is not currently available. Options include 277.7 (dysmetabolic syndrome X) or 251 (other disorders of pancreatic internal secretion).

(17). These patients might be classified as unspecified with type 2 diabetes ICD-9-CM codes until the diagnosis is clarified. Second, type 2 diabetes codes may be utilized instead of more accurate but less familiar codes for other forms of diabetes, such as steroid-induced diabetes (codes 251.8 and E932.0). Third, many patients in our study without diabetes had type 2 diabetes risk factors, such as insulin resistance, suggesting inaccurate assignment of type 2 diabetes codes during diagnostic evaluation. A similar issue has been noted with ICD-9-CM coding for acute myocardial infarction (10,11). Finally, coding methods may influence accuracy. If patients only have "diabetes" written on billing forms, coders may utilize "unspecified" type 2 diabetes codes. In contrast, ICD-10-CM codes will separate the "unspecified" category (18).

While, to our knowledge, validity of type 2 diabetes ICD-9-CM coding in youth has not been evaluated, adult studies have examined accuracy of administrative data for identification of diabetes and its complications (7–10). Among 23,657 Medicare beneficiaries, PPV of diabetes ICD-9-CM code 250.x was 98%

(9). Similarly, among 1,976 adults, PPV of two ICD-9-CM codes for diabetes (code 250) was 94% (7). Two codes were used because using one identified many patients without diabetes (7), consistent with our findings. In these studies, however, focus was on diabetes in general, and therefore the PPV cannot be directly compared with our findings.

Several limitations should be noted. First, we evaluated PPV of one type 2 diabetes ICD-9-CM code. This likely highlighted the worst-case scenario but underscores limitations of administrative coding for distinguishing between type 1 and type 2 diabetes. Alternative approaches including additional type 2 diabetes codes or excluding type 1 diabetes codes should be explored. Second, we could not evaluate sensitivity of type 2 diabetes codes, as alternative methods of identifying type 2 diabetic patients were lacking. Third, our analysis was conducted in one hospital. As PPV is influenced by prevalence of type 2 diabetes, our findings may not generalize to locations with higher rates of type 2 diabetes in youth. Institutional coding practices may also influence outcomes. Lastly, dia-

betes diagnoses were based on provider assessments, which could differ from diagnoses based on laboratory or other standardized criteria. However, the algorithm and reviewer blinding guarded against bias in assignment of diagnoses with respect to ICD-9-CM codes. Overall, our findings argue for clinical corroboration of these codes before widely applying them to pediatric diabetes research.

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