Patients with Diagnosed Diabetes Mellitus Can Be Accurately Identified in an Indian Health Service Patient Registration Database

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SYNOPSIS

Objective. The computerized patient registration databases maintained by the Indian Health Service (IHS) represent a potentially important source of data about the epidemic of diabetes among American Indian and Alaskan Native people. The purpose of this study is to determine the accuracy of this data source, and to identify the optimal search criteria to identify patients with a diagnosis of diabetes in an IHS patient registration database.

Methods. The authors compared the results of a series of computerized searches to a "gold standard" sample of 465 manually reviewed charts from a large IHS facility.

Results. Among patients ages 15 years and older, the best criterion for identifying patients diagnosed with diabetes was the presence of at least one purpose of visit narrative identified by a 250.00 to 250.93 ICD-9 code. The presence of a single computerized code for diabetes identified patients with diagnosed diabetes with a sensitivity of 92% (95% confidence interval [CI] 81, 97), a specificity of 99% (95% CI 98, 99), and a calculated positive predictive value of 94% (95% CI 85, 99). In a separate chart review of 462 charts of patients who had at least one 250.00 to 250.93 ICD-9 code recorded in the database, 435 had a diagnosis of diabetes for an observed positive predictive value of 94%. Because the prevalence of diabetes varies by age of the patient, the positive predictive value of the ability to identify patients with diabetes also varies by age.

Conclusion. A computerized search of an IHS patient database can identify patients with a diagnosis of diabetes with an accuracy that is similar to the reported accuracy from other health care system databases.

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INTRODUCTION

Diabetes is occurring in epidemic proportions among American Indian and Alaskan Native people.[1] As a major provider of health care for American Indian and Alaskan Native people, the Indian Health Service (IHS) has a responsibility to estimate the prevalence of diabetes and to assess the delivery of diabetes-related health care programs. To successfully meet this responsibility, the IHS must be able to accurately identify patients with a diagnosis of diabetes.[2]

Several large health maintenance organizations,[3–5] and government-affiliated health systems including Canada,[6] Scotland,[7] and the United States Veterans Administration,[8] have recognized the potential of using clinical and administrative databases for epidemiologic and performance improvement efforts. The patient registration databases maintained by the IHS therefore represent a potentially important source of data, but the validity of these IHS databases has not been systematically investigated. To assess the validity of information contained in one large IHS facility database, we performed a series of studies designed to ascertain the identity of patients with a diagnosis of diabetes and then describe a reproducible criterion that most accurately identifies those patients.

METHODS

We studied a sample of charts from among 40,479 patients ages 15 years or older who had at least one visit in a three-year period to the Phoenix Indian Medical Center. We chose these age and visit-frequency criteria to match the historical age and visit criteria used by the IHS to define an adult population of active medical users. Charts for the sample were selected using a random number generator program integral to the database, and we reviewed each randomly selected chart sequentially until 465 charts had been examined.

The medical record system of this and most IHS facilities consists of two main components. First is a typical paper-based chart for each patient. Second is an electronic medical record, the Resource and Patient Management System (RPMS), maintained in a searchable database at each facility. The RPMS record contains data manually transcribed from the paper chart and registration records and directly entered from pharmacy prescriptions, laboratory results, and radiology reports. To aid in transcribing data from the paper chart into the electronic medical record, a preprinted standardized patient care component (PCC) encounter form is used at each patient encounter to document the history, physical exam, and therapeutic interventions. At each encounter, one or more descriptive narratives are written in a specific section of the encounter form to identify the purpose of the visit. A copy of the encounter form is then used by trained medical coding and data entry staff to establish an *International Classification of Diseases, Ninth Revision* (ICD-9 code) for the purpose of that visit and to populate the electronic medical record. Because providers write directly in the paper chart, the paper chart has remained the legal record of the patient's clinical care. The electronic medical record, in contrast, has been used primarily for administrative purposes.

A physician, blinded to all computerized patient data, manually reviewed all paper charts selected for the study to create a "gold standard" sample of patients with and without a diagnosis of diabetes mellitus. A patient was classified as having diabetes if the reviewer identified any condition indicating the diagnosis of diabetes during the chart review. The 1997 American Diabetes Association diagnostic criteria[9] were used when data were available to confirm the diagnosis. When such documentation was not available, the reviewer accepted substantial written documentation by the attending clinical provider of a diagnosis of diabetes mellitus or a diabetes-specific complication such as diabetic retinopathy in the patient's history. A second reviewer re-evaluated 30 of the same charts. The classification of diabetes by the two reviewers was concordant for all 30 charts. This "gold standard" sample of patients was then used as a comparison for a series of computerized searches.

Separate from the manual chart review, we performed a series of queries of the electronic medical record database. As in the chart review, computerized queries were limited to patients ages 15 or older who had visited the facility in a three-year period. Various criteria were used to identify patients with a diagnosis of diabetes, including the identification of ICD-9 codes assigned to patient's purpose of visit narratives. One criterion defined diabetes by identifying all patients who had ever had at least one 250.00 to 250.93 ICD-9 code. Another query required patients to have at least two separate 250.00 to 250.93 ICD-9 codes. Another search identified patients with diabetes by the identification of a pharmacy prescription entry for sulfonylurea, metformin, acarbose, thiazolidindione, or insulin, as these medications have very little use except for the treatment of diabetes mellitus. Finally, a fourth query to identify patients with diabetes required patients to have had at least two separate glucose values $\geq$200 mg/dl. We chose this criterion because we could not be certain, by query criteria alone, whether a patient was fasting or not fasting at the time of a blood

Table 1. Identification of patients with diagnosed diabetes by different query criterion

Criterion	*N, Sensitivity, (95% CI)*	*N, Specificity, (95% CI)*	*N, Positive Predictive Value, (95% CI)*
One 250.00 to 250.93 ICD-9 code	56/61, 92%, (81%, 97%)	401/404, 99%, (98%, 99%)	56/59, 94% (85%, 99%)
Two 250.00 to 250.93 ICD-9 codes	39/61, 64% (50%, 75%)	402/404, 99% (98%, 99%)	39/41, 95% (82%, 99%)
Prescription[a]	36/61, 59% (46%, 71%)	402/404, 99% (98%, 99%)	36/38, 95% (80%, 99%)
Hyperglycemia[b]	16/61, 26% (16%, 39%)	402/404, 99% (98%, 99%)	16/18, 89% (64%, 98%)

[a]Any hypoglycemic medication
[b]Two blood glucose values greater than 200 mg/dl

glucose determination. While patients with diabetes may certainly have blood glucose values ≤200 mg/dl, patients with random blood glucose values ≥200 mg/dl on two separate occasions are very likely to have diabetes mellitus, regardless of feeding state.

We then tested the ability of the different query criteria to accurately classify the patients who had been independently classified in the "gold standard" sample. These comparisons were used to calculate the sensitivity, specificity, and positive and negative predictive values of each query criterion. To confirm the calculated predictive value of the optimal query criterion, we used the best performing criterion to select an additional sample of 462 charts of patients with diabetes as identified by this criterion. The observed predictive value was calculated as the percent of patients in this sample who had a diagnosis of diabetes confirmed by chart review using the same criterion used during the initial chart review. We used public domain software provided by the Centers for Disease Control and Prevention (Epi-Info, Version 6, Stone Mountain, Georgia) to determine statistical values and confidence intervals. This manuscript was reviewed and approved by the Institutional Review Board of the Phoenix Area Indian Health Service prior to submission.

RESULTS

In the "gold standard" sample, 61 patients (13%) had a diagnosis of diabetes and 404 patients (87%) did not have a diagnosis of diabetes. The query criterion of a single 250.00 to 250.93 ICD-9 code correctly identified 56 of these 61 patients, for a sensitivity of 92% (95% confidence interval [CI] 81, 97). This query criterion incorrectly classified three of 404 patients as having a diagnosis of diabetes, for a specificity of 99% (95% CI 98, 99). For this criterion, the calculated positive predictive value was 94% (95% CI 85, 99) and negative predictive value was 98% (95% CI 97, 99). When patients were required to have two separate 250.00 to 250.93 ICD-9 codes to be classified as having a diagnosis of diabetes, 39 of 61 patients were correctly classified, for a sensitivity of 64% (95% CI 50, 75). This query criterion resulted in two incorrect classifications among the 404 patients without a diagnosis of diabetes, for a specificity of 99% (95% CI 98, 99). The calculated positive predictive value was 95% (95% CI 82, 99) and the negative predictive value was 95% (95% CI 92, 96). A pharmacy prescription for a medication used to treat diabetes identified 36 of 61 diabetic patients, for a sensitivity of 59% (95% CI 46, 71). The query for the presence of two blood glucose values ≥200 mg/dl identified 16 of the 61 diabetic patients, for a sensitivity of 26% (95% CI 16, 39). Two patients each were incorrectly identified as having a diagnosis of diabetes by each of these criteria, for a specificity of 99% (95% CI 98, 99) each. The calculated positive predictive values were 95% (95% CI 80, 99) and 89% (95% CI 64, 98) and negative predictive values were 94% (95% CI 91, 96) and 90% (95% CI 87, 93) respectively. Table 1 displays the comparison of these sensitivity, specificity, and positive predictive value calculations from each of these different criteria.

Because the query criterion of a single 250.00 to 250.93 ICD-9 code appeared to be the optimum criterion for identifying patients with diagnosed diabetes, we used this criterion to select patients for a second chart review. From 6,870 patients identified by this query criterion, we randomly selected 500 patients and sequentially reviewed 462 of their charts to see if diabetes was identified as a diagnosis in the paper chart. As before, conditions indicating diabetes included American Diabetes Association diagnostic criteria[9] when available, or the finding of substantial written documentation by the attending provider of a diagnosis of diabetes mellitus or a diabetes-specific complication. Of these 462 patients, 435 (94%) had a diagnosis of diabetes confirmed by chart review. The observed positive predictive value is therefore 94%. In this second chart review, we also sought to understand the circumstances of the 27 false positive encounters when a diabetes code had been entered in the database without support for the diagnosis of diabetes on manual chart review. In 18 (67%) of these encounters, the words *diabetes, diabetic,* or the abbreviation diabetes mellitus (DM) was written as a purpose of visit by the attending provider. In seven of these 19 charts, the provider wrote "diabetes" (or similar notation) as the purpose of visit despite the fact that no other chart notation or evidence of diabetes existed. Since no other information could be identified in the chart suggesting a diagnosis of diabetes, the reason why the attending provider narrated diabetes on the purpose of visit is speculative. Other encounters when diabetes was written or narrated for the purpose of visit included: four to "rule out" diabetes, four with gestational diabetes, and three with a family history of diabetes. These circumstances appear to reflect imprecision in narrating a purpose of visit for the encounter by the provider. In the remaining 9 (33%) we found: two notations of foot ulcers, one diarrhea, one ketosis secondary to bulimia, one family planning, one hypertension, one otitis media, and one neurological problem of the upper extremity. In one instance, no paper record of an encounter existed for the day the code was assigned. Since no written or narrated notation of diabetes was identified in the paper chart, these circumstances appear to reflect imprecision in coding or in data entry for the encounter by the coding or data entry staff.

Because the prevalence of diabetes varies by age and because the prevalence of a condition affects the positive predictive value of a query, we sought to estimate the effect of the age of the patient on our results. Using the query criterion of at least one 250.00 to 250.93 ICD-9 code, we then estimated the age-specific rates of diabetes using 10-year age groupings. Of 40,479 patients ages 15 years and older with at least one visit in a three-year period, 6,870 (14.5%) were identified as having diabetes. The age-specific prevalence using these criteria ranged from 2% in the 15- to 24-year-old age group to 49% among patients in the 65- to 74-year-old age group (Figure 1). We then calculated the estimated positive and negative predictive values of this query criterion for diabetes by these different age groups, assuming a constant false positive rate. Figure 2 shows these calculated values by age group.

DISCUSSION

This study evaluated the ability to correctly identify patients with a diagnosis of diabetes using a computerized query of a patient registration database at an IHS health care facility. In addition to comparing the accuracy of different search criteria, this study estimated the effect of the age of the patient on the positive predictive value of the query result. Our findings validate the use of this IHS patient registration database as a source of epidemiologic data. Furthermore, because we quantified the factors that influence the accuracy of search criteria, our findings may have implications for other health care facilities using similar clinical and administrative patient databases for epidemiologic purposes.

The results of the present study are similar to those of two other published reports that assessed the ability of electronic databases to identify patients with diabetes. Morris and co-workers manually reviewed 636 records from eight general practices in Scotland.[7] The results of this manual review were compared to general practice diabetes case registries and to an electronic capture-recapture linkage of records from clinics, hospitals, prescription registries, regional laboratory databases, and a mobile unit used for eye screening. The general practice case registries had a sensitivity of 91% and a positive predictive value of 98%, while the electronic database registry had a sensitivity of 96% and a positive predictive value of 95% for the ascertainment of known diabetes. O'Connor et al. conducted a study of the sensitivity, specificity, and positive predictive value of identifying diagnosed diabetes among 3,186 members of a health maintenance organization by two different methods.[3] The authors compared the results of a telephone survey of members to the results obtained by a computerized database search. Their "gold standard" was created by reconciling disparities between the two methods using a manual chart review. The sensitivity of the telephone survey was 98%, and the sensitivity of the database search was 91%. The specificity of each method was >99%, and the positive predictive values were 83% for the telephone survey and 94% for the database method. While the methods of these previously reported studies were slightly different from ours, the findings were remarkably similar to the results in the present study.

In this IHS patient registration database, the most sensitive criterion to identify patients with diabetes was the identification of at least one 250.00 to 250.93 ICD-9 code assigned to one of the patient's purpose of visit narratives. Interestingly, the specificity of a single 250.00 to 250.93 ICD-9 code was nearly the same as the use of two 250.00 to 250.93 ICD-9 codes. The use of two 250.00 to 250.93 ICD-9 codes resulted in significant loss of sensitivity. Because specificity was already over 99%, the use of criteria that required multiple codes did not result in any appreciable gain in specificity. Robinson and colleagues reported a similar experience when attempting to identify patients with specific conditions from a large clinical database.[6] They compared the agreement in diagnosis between a provincial health insurance database and self-reported diagnoses from a survey of adults living in Manitoba, Canada. Increasing the number of required diagnoses in the insurance database to two decreased the number of cases ascertained in the survey by 16%, and three diagnoses decreased the number of cases by 29% compared to a single diagnosis. The best agreement between the two databases was achieved with the use of a single diagnosis. In our study this may be explained by the finding that a number of patients received mostly episodic acute care or specialty referral care at the study facility, while primary care was delivered at other IHS facilities. Patients receiving episodic acute care may be less likely to have chronic medical conditions such as diabetes documented as a purpose of visit. Similar to our study, Robinson and colleagues found a significant decrease in the accuracy of a diagnosis of diabetes among younger as compared to older groups of patients, although they did not speculate on the reason for this finding.[6]

As discussed by O'Connor, the measures of greatest practical importance when identifying patients from a large database are the sensitivity and the positive predictive value of the criteria.[3] In the present study, the sensitivity and the positive predictive value were above 90%. However, because diabetes prevalence varies by age, the positive predictive value of diabetes will vary with the age of the patient. This suggests that researchers consider the age-specific prevalence of diabetes when interpreting the results of searches of clinical databases.

Three issues about the present study deserve comment. First, IHS sites throughout the United States differ in size and provision of services. However, the data management procedures are similar in most facilities. While it is reasonable to assume that the present results are representative of other IHS facilities, similar studies are not available for comparison. Second, this study relied on the available clinical data from the medical chart to classify patients as being diagnosed with diabetes for the creation of a "gold standard." In the Strong Heart Study, there were clearly undiagnosed cases of diabetes in American Indian communities.[11] Thus, this "gold standard" reflects only the portion of people with diagnosed diabetes, and likely underestimates the true prevalence of the disease in this community. Third, the method used to define the "gold standard" classification was dependent on the accuracy of the clinical diagnosis. In a few instances, a classification of diabetes relied solely on the written documentation, albeit substantial, from referring providers from other IHS facilities. However, the IHS has a long record of using standards of care for diagnosis of diabetes that are consistent with the American Diabetes Association recommendations.[9] Therefore, a clinical diagnosis of diabetes is likely to be consistent throughout the agency.

In summary, we have shown that we can accurately identify patients who carry a diagnosis of diabetes from data collected in an IHS computerized patient registration database. We have defined the optimal criteria to identify those patients with a diagnosis of diabetes. Finally, we have improved the understanding of how situations, such as a variable age-specific prevalence of diabetes, may affect the positive predictive value of a query. The findings of this study can help guide the use of data for quality improvement projects and for epidemiologic purposes. This study also lays a foundation for future research. Because queries of this IHS database appear to have characteristics similar to queries of other health care system databases, it should be possible to analyze diabetes prevalence by comparing the databases maintained by different local or regional health care systems. Such analyses may provide a basis for the assessment of a number of public health efforts such as prevention, screening, and tracking programs.

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