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Testing Electronic Algorithms to Create Disease Registries in a Safety Net System

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Abstract

Electronic disease registries are a critical feature of the chronic disease management programs that are used to improve the care of individuals with chronic illnesses. These registries have been developed primarily in managed care settings; use in safety net institutions—organizations whose mission is to serve the uninsured and underserved—has not been described. We sought to assess the feasibility of developing disease registries from electronic data in a safety net institution, focusing on hypertension because of its importance in minority populations. We compared diagnoses obtained from algorithms utilizing electronic data, including laboratory and pharmacy records, against diagnoses derived from chart review. We found good concordance between diagnoses identified from electronic data and those identified by chart review, suggesting that registries of patients with chronic diseases can be developed outside the setting of closed panel managed care organizations.

Keywords

Hypertension; safety net; chronic disease; disease registries

The Chronic Care Model is a widely used approach to organizing care for individuals with chronic health conditions. Disease-specific patient registries are identified in the Chronic Care Model as prerequisites for improving the health outcomes of patients with chronic illnesses.^{1–3} In order to be feasible and sustainable, disease-specific patient registries must be built from information available solely through electronic records. To date, descriptions of the design and uses of disease registries have come almost exclusively from closed-panel managed care settings that have easily identifiable members and have often invested substantially in electronic data collection and electronic medical records.^{4,5} Safety net organizations, defined as urban public hospitals and community health centers whose mission is to care for the uninsured and underserved, provide a disproportionately large proportion of the care for racial and ethnic minority patients that historically suffer poor health outcomes.⁶ The use of disease-specific patient registries in safety net organizations might therefore play a critical role in reducing health disparities, but these organizations face substantial barriers to developing registries, including a tendency to have poorer financial and information technology resources, greater flux of patients in and out of their systems, and diminished opportunity to realize financial benefit from the decreased utilization resulting from improved chronic care.

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We sought to assess the feasibility of using existing electronic data to develop a hypertension registry at Denver Health, a safety net institution consisting of an acute care hospital and a network of community-based clinics providing primary care in Denver, Colorado. We chose hypertension as a prototypical chronic disease because of its importance to the health of minority populations.^{7,8} Our goal was to develop and test a methodology for building a hypertension registry that could be used for other disease states and in other safety net health organizations.

We tested an array of case-finding algorithms, defined as combinations of electronically obtained pharmacy data, laboratory data, and principal or secondary diagnosis codes (ICD-9CM), against gold standard diagnoses derived from chart review to determine the sensitivity and specificity of electronically obtained information. In addition to hypertension, we tested cardiovascular conditions (including diabetes, coronary artery disease, cerebrovascular disease, peripheral artery disease, congestive heart failure, chronic kidney disease, and dyslipidemia) and psychiatric and substance abuse conditions (depression, schizophrenia/psychotic disorders, bipolar disorder, alcohol abuse, and substance abuse). Psychiatric and substance abuse conditions were included because of their high prevalence in safety net institutions and because of their association with poorer health outcomes.^{9–12}

Methods

Setting

Denver Health is a highly integrated safety net health system serving the city of Denver, Colorado.⁶ It comprises a 349-bed hospital, 10 community health centers, 13 school-based clinics, and the county public health department. It provides 42% of the indigent care in the Denver metropolitan area and 30% of the indigent care for the entire state of Colorado. A system-wide electronic medical record has been in place at Denver Health since the mid 1990s, using the same patient identifier as the pharmacy and laboratory databases, which allows linking of electronically stored medical information. Historically, over half of Denver Health patients participate in the Colorado Indigent Care Program (CICP), the state-funded indigent care program. This program includes uninsured patients and low-income patients with Medicare who otherwise do not have prescription coverage. These individuals can receive their medications for minimal co-payments from the Denver Health pharmacy system, creating a substantial financial incentive to use the system for all medications for chronic health conditions.

Patients

We identified all patients who had at least 3 visits to Denver Health between January 1, 2002 and December 31, 2004. We used a stratified random sampling strategy to review charts of adult patients (age 21 years or older) until by our estimates there would be at least 250 patients from each of four age strata: 21–49 years, 50–59 years, 60–69 years and 70 years or older. In view of the relatively young population served by Denver Health, this sampling strategy was designed to obtain an adequate number of older individuals who were more likely to have hypertension and other chronic health conditions. We excluded visits at which blood pressure was not routinely recorded (public health clinics, mental health services, the alcohol detoxification center, podiatry, radiology or laboratory only), obstetrics visits (in order to exclude patients with pregnancy-related hypertension), and Department of Corrections appointments (for which Denver Health has limited information).

Electronic data

The following data elements were extracted from electronic records for each subject: primary and secondary diagnosis codes from both inpatient and outpatient encounters; selected

laboratory values (creatinine, hemoglobin A1C, blood alcohol levels, urine toxicology results); and medication data (medications filled, dosage instructions, number of doses dispensed and date dispensed).

Chart review

Three professional abstractors performed the chart review. Twenty-five charts were reviewed during a training period by all 3 abstractors and results were compared for agreement. Discrepancies were reviewed and corrected in weekly quality control meetings. After the initial 25, charts were randomly assigned to 1 of 3 abstractors. In order for the researchers to be able to calculate inter-rater reliability estimates, a random start point was identified within the next set of cases and all 3 reviewers then received a common chart every 20th chart (5% of their total charts) until the chart reviews were completed.

Sociodemographic data were captured from the electronic registration system. Gender, race, language preference, and country of origin were captured at the first contact between the patient and the hospital system and were all self-reported. Race and ethnicity were aggregated into a single variable, for which only one value could be selected in each case (these include African American, American/Alaskan Native, Asian, Hispanic/Latino/Spanish, Native Hawaiian, Other Pacific Islander, White, and Unknown). Insurance status and an indicator for homelessness were updated at least annually.

The abstractors reviewed the three most recent outpatient primary care visits and hospitalizations. For hospitalizations, they reviewed the inpatient history and physical and discharge summary. When a patient had fewer than three primary care visits, the reviewer reviewed subspecialty clinic notes to bring the total to three outpatient encounters. Operative notes and radiology studies were reviewed to identify procedures of interest. The variables that were abstracted from the charts were presence of hypertension, presence of pre-specified comorbid diseases (cardiovascular comorbid conditions: diabetes, coronary artery disease, cerebrovascular disease, peripheral artery disease, congestive heart failure, chronic kidney disease, dyslipidemia; and psychiatric and substance abuse conditions: depression, schizophrenia/psychotic disorders, bipolar disorder, alcohol abuse, substance abuse) listed in clinic notes or hospital admission or discharge notes; lists of medications taken; blood pressure; tobacco use; electrocardiographic data (presence or absence of left ventricular hypertrophy); echocardiographic data (left ventricular ejection fraction, presence of valvular abnormalities); radiographic data (presence or absence of cardiomegaly or pulmonary edema on chest x-rays).

In addition, reports of cardiac stress testing, cerebral imaging, and peripheral vascular studies were reviewed by a panel of physicians to determine if the patient had a diagnosis of coronary heart disease, cerebrovascular disease, or peripheral arterial disease.

Gold standard diagnoses

Definitions for hypertension and comorbid diseases were taken from definitions used previously in literature on chart review,^{8,13–17} or from consensus of the investigators when definitions were not available in the literature. We created these *gold standard* diagnoses from chart review data supplemented by electronic laboratory data. The gold standard definition for hypertension based on chart review was: two or more recordings of elevated blood pressures using JNC-VII criteria, or two or more listings of hypertension diagnoses, or a single diagnosis of hypertension plus at least one blood pressure medication or a single diagnosis of hypertension and one elevated blood pressure recording. Case finding algorithms were then tested against these gold standard diagnoses for sensitivity and specificity derived from electronic records.

Analysis

Descriptive statistics for the sample were recorded using chi-square tests for categorical variables and Student's t-test for continuous variables. Sensitivity, specificity, likelihood ratios (both positive ($LR+ = \text{sensitivity}/(1-\text{specificity})$) and negative ($LR- = 1-\text{sensitivity}/\text{specificity}$)) and proportion of cases with missing data were determined for the case finding algorithms in comparison with the chart review gold standard. We first identified all the algorithms with a specificity of at least 80% and from those algorithms we then identified those with the greatest sensitivity. We felt that for registries whose purpose is to evaluate the quality of care delivered and to implement strategies to improve care, specificity should be favored over sensitivity, since high specificity improves the positive predictive value of an algorithm and helps assure that individuals with an administrative claim for a disease are likely to have that diagnosis. It in turn improves the efficiency with which the registry can be used for quality assessment or clinical interventions. *A priori*, we determined that the simplest algorithm with the least missing data would be selected from high performing algorithms as the working registry definition.

Inter-rater reliability among the three abstractors was assessed using the kappa statistic. Although interpretations of kappa vary, we considered above 0.80 to be excellent, 0.61–0.80 good, and 0.41–0.60 moderate agreement. The value of the kappa statistic is a function of the prevalence of the disease in the sample, and tends to be much lower for prevalence close to 0% or 100% than in the middle of this range.¹⁸ This is because the kappa statistic measures agreement beyond that expected by chance alone and when chance agreement is expected to occur at a very high rate (i.e., in very high or low prevalence conditions), there is less room for agreement beyond chance than in conditions where chance agreement is expected at a lower rate (moderately prevalent conditions).¹⁸ Because it can be misleading to compare kappas of conditions with greatly different prevalences and because several of the conditions of interest in this study were expected to be present in less than 10% of the sample, we report kappa adjusted for prevalence and bias (PABAK) using the method of Byrt et al.¹⁸ Because the gold standard diagnosis for chronic kidney disease was based entirely on laboratory data (which was directly imported from the laboratory database) a kappa was not calculated for this diagnosis.

Once the prevalence of the conditions was determined for each stratum in the chart review sample, these rates were applied to the Denver Health population of adult persistent users (defined as at least three visits to Denver Health during the study period) using weights based on the sampling rates to adjust estimates to reflect the composition of the Denver Health population (SAS Proc SURVEYMEANS). All statistical analyses were performed in SAS, version 9.1 (SAS Institute, Cary, NC).

Results

Chart review

A total of 1,169 charts were reviewed (243 of the patients were 21–49 years old, 289 were 50–59 years old, 309 were 60–69 years old, and 328 were 70 years old or older). The characteristics of the patients are shown in Table 1. Of the total, 37.8% were male, 24.3% were Black, 52.4% were Latino, and 19.8% were White. Of the total, 30.4% were uninsured, 43.5% participated in the CICP program, and the mean age was 60.1 years. Rates of homelessness and uninsured status were higher in younger patients than older patients. For language preference and country of origin, the rates are only reported for those cases for which this information was known. Of the 1,169 patients in the chart review, 385 patients had hospital records, with increasing frequency by age (16% in the youngest age group, 35% in the oldest age group) (data not shown).

Inter-rater reliability assessment

The overall inter-rater reliability assessments for the three chart abstractors are presented in Table 2. There were too few shared charts with a diagnosis of peripheral arterial disease, substance abuse, or bipolar disorder for the kappa estimates to be stable, and they are therefore not reported. For the remainder of the diagnoses, the prevalence and bias-adjusted kappa values for inter-rater reliability were in the good to excellent range, ranging from 0.690 to 1.0.

Quality of electronic data

All of the patients had billing data, 87.9% had at least one pharmacy record, 60.9% had at least one creatinine measurement, 60.2% had at least one lipid profile, 3.0% had a blood alcohol test, and 8.0% had a urine toxicology screen performed. (data not shown)

Defining hypertension

The best performing algorithm for defining hypertension from electronic data was two or more diagnoses from either inpatient or outpatient claims (Table 3), which had a sensitivity of 81.4% and a specificity of 84.4%. Algorithms that incorporated pharmacy data had higher specificity (ranging from 85.0–95.2%) but lower sensitivity (31.0–71.1%), perhaps due to a relatively high rate of unavailable pharmacy data (13.4%) due to prescriptions that were filled outside the Denver Health system.

Defining comorbid conditions

As shown in Table 4, the best performing definitions for the comorbid conditions had high specificities (83.0–100%), but variable sensitivities (43.1%–91.6%). For chronic kidney disease, the gold standard definition used only laboratory data, and thus was identical to the case finding algorithm. For the majority of diagnoses, a single inpatient or outpatient visit with a relevant ICD-9CM code for the diagnoses performed best. As Table 4 also shows, algorithms with acceptable sensitivity and specificity could be defined for most mental health and substance abuse conditions.

Estimated prevalence in the Denver Health population

Estimated prevalence rates for hypertension and potentially comorbid cardiovascular, mental health, and substance abuse diagnoses in the population of adults served by Denver Health are shown in Table 5. When applied to the Denver Health population as a whole, the rates of cardiovascular diseases decreased while the rates of depression, bipolar disorder, alcohol abuse, and substance abuse increased. The rate of schizophrenia and psychotic disorders was unchanged.

Discussion

We sought to demonstrate the feasibility of developing a registry of patients with hypertension in a safety net hospital system. Our results indicate good concordance between diagnoses identified by chart review and those identified from claims data supplemented by laboratory data, suggesting that registries of patients with chronic diseases can be developed outside the setting of closed panel managed care organizations. The exceptions were cerebrovascular disease and peripheral arterial disease, for which sensitivities were less than 50%. In general, incorporation of pharmacy data did not improve algorithm performance, likely because too many patients obtained medications from pharmacies other than those at Denver Health. Algorithms with a specificity of greater than 89% were identified for all conditions except depression, for which the best performing algorithm had a specificity of 83%. The sensitivities for these conditions showed more variability. is lower sensitivity may be attributable to bias in coding, since conditions for which there are more ongoing treatment or diagnostic changes

are more likely to be coded than conditions that are either asymptomatic or not directly affecting the reason for visit, or to limitations in the gold standard definition itself. For example, the gold standard definition for cerebrovascular disease included computed tomography (CT) evidence of white matter disease, which may have identified some patients with clinically inapparent cerebrovascular disease in whom the CT scan was performed for other reasons.

Previous studies that identified patients with hypertension by algorithms using claims data report a sensitivity of 52–78% and a specificity of 91–98% compared with either chart review or patient self-report.^{19–22} These studies were performed in HMO settings or the Canadian health system or utilized Medicare databases to identify patients. Our best algorithm for hypertension, which had a sensitivity of 81.4% and a specificity of 84.4% performed similarly. Claims-based approaches to identify diabetes with or without laboratory data have been reported to have a sensitivity of 72–98% and a specificity of 93–99%.^{19–25} Our results are comparable (91.6% sensitivity and 95.8% specificity). Similarly, for congestive heart failure, cerebrovascular disease, coronary artery disease, peripheral vascular disease, and hyperlipidemia our claims based algorithms performed as well as prior studies in other settings.^{19–22} Few systems have assessed algorithms that can identify patients with psychiatric diseases or substance abuse. These conditions are particularly important in safety net institutions due to their higher prevalence and their impact on chronic disease management.^{9–12} Surprisingly, these algorithms also performed well. The relative accuracy of claims based data is very important in being able efficiently and inexpensively to identify patients for incorporation into disease specific registries. The fact that this methodology performs as well in a safety net institution as it does utilizing Medicare databases or in managed care settings is a first step in being able to apply the chronic care model in these organizations to evaluate and improve the quality of care.

An abundance of data demonstrates that racial and ethnic minorities suffer from a disproportionate burden of disease, and from disparities in the quality of care and access to medical care.^{7,26,27} Safety net hospitals and clinics provide care for many members of ethnic and racial minorities and are therefore a logical target for efforts to reduce disparities. In order to address the concern that the context of care in the safety net is itself a source of disparities,²⁷ one must be able to identify broadly patients with a disease of interest so that care might be improved. Electronic disease registries are an important component of this effort. Identifying patients by electronic means allows an organization to identify patients without having to rely on providers or patient self-identification to do so, and without having the expense associated with chart review. In addition, because the medical claim is submitted at the time of visit, patients can be enrolled into disease registries on an ongoing basis. This is particularly important in the safety net, since the rapid flux of patients in and out of the system may necessitate that programs to improve quality of care be able to identify patients for intervention quickly.

The main limitation of our study is the imperfect nature of our gold standard definitions. These chronic conditions had to be identified via retrospective chart review, which is subject to the inherent limitations of variability in documentation, lack of consistent problem lists, and difficulty in reading handwriting. Any limitation in the gold standard definition of the disease of interest could affect the sensitivity and specificity of the algorithms tested against it. In addition, only the three most recent encounters of each type were reviewed, while the claims-based algorithms relied on claims submitted during the entire study period. This asymmetry could have accounted for lower specificity of the electronic algorithms, but since the specificities for the majority of diagnoses were over 90%, this was likely a very small problem. The limitations of claims-based identification of patients for disease registries include the inherent variability in physician coding patterns, ambiguity of the ICD-9CM codes, and the error of coding for a condition that is being tested for before the condition has been established. Another limitation of our study is that the race and ethnicity categories in the Denver Health registration database

are mutually exclusive, and although they are supposed to be self-reported, the actual approach to entering this information by registration clerks may vary across clinics within Denver Health.

In conclusion, we were able to validate a methodology for creating disease registries previously used predominantly in managed care organizations to identify individuals with hypertension and other chronic health conditions, including common mental health and substance abuse conditions, in a large safety net hospital system. We found that no features inherent to our safety net organization precluded the application of this portion of the chronic care model, suggesting that population management may be applied to efforts to reduce health care disparities based on socioeconomic status.

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Notes

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Appendix

The following are investigators for the LUCAR study: Sheana Bull, PhD; Art Davidson, MD; Mori Krantz, MD; Carlin Long, MD; omas MacKenzie, MD; Frederick Masoudi, MD; Ricardo Padilla, MD; and Pamela Peterson, MD.

Table 1
DEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE^a

Demographic	Stratum 1 21–49 years	Stratum 2 50–59 years	Stratum 3 60–69 years	Stratum 4 70+ years	Overall	p-value
Mean age ± SD	37.9 (8.4)	54.4 (3.1)	64.3 (2.8)	77.6 (5.9)	60.1 (15.2) 21.3–104.4	N/A
Range, yrs					37.8	
Male sex (%)	34.6	42.9	43.4	30.5		.0012
Race/ethnicity (%)						.0003
African-American	27.6	19.7	25.6	23.5	24.3	
Hispanic/Latino	49.8	55.0	50.8	45.7	52.4	
White	18.5	20.4	20.1	18.6	19.8	
Other	4.1	4.9	3.5	12.2	3.4	
English language preference ^b (%)	91.6	95.5	92.6	89.8	92.2	.0954
Non-U.S. country of origin ^c (%)	8.3	6.8	7.5	8.6	7.8	.8551
Homeless (%)	7.4	4.5	1.3	.3	3.3	<.001
Uninsured (%)	49.0	46.7	23.6	8.5	30.4	<.001
CICP program (%)	46.1	50.9	47.6	31.4	43.5	<.001

^a N=1,169 unless noted.

^b n=1,018.

^c n=1,105.

Table 2

INTER-RATER RELIABILITY ASSESSMENTS OF CHART REVIEWERS (KAPPA) BASED ON GOLD STANDARD DIAGNOSIS FOR A RANDOM SAMPLE OF CHARTS THAT WERE REVIEWED BY MORE THAN ONE ABTRACTOR^a

Diagnosis	Average adjusted kappa ^b
Hypertension	.690
Diabetes	.936
Coronary artery disease	.871
Cerebrovascular disease	.950
Peripheral artery disease	—
Congestive heart failure	1.000
Chronic kidney disease	—
Dyslipidemia	.859
Depression	.936
Schizophrenia/psychotic disorders	.911
Bipolar disorder	—
Alcohol abuse	.897
Substance abuse	—

^a 80 common charts were reviewed by two reviewers with 37 of the common charts reviewed by a 3rd reviewer. Average kappas are weighted by the number of common charts reviewed by each pair of reviewers.

^b Prevalence and bias adjusted kappa (14).

Table 3
COMPARISON OF CASE FINDING ALGORITHMS VS. CHART REVIEW GOLD STANDARD FOR HYPERTENSION^a

Algorithm	Positives (%)	Missing data (%)	Sensitivity	Specificity	LR+	LR-
1 outpatient diagnosis	54.3	0	84.9	80.6	4.38	.187
1 diagnosis inpatient or outpatient	56.9	0	87.8	78.4	4.07	.156
2 or more diagnoses inpatient or outpatient	50.6	0	81.4	84.4	5.22	.220
3 or more diagnoses inpatient or outpatient	43.4	0	71.6	89.0	6.51	.319
1 fill of 1 antihypertensive medication	41.2	13.4	71.1	82.1	3.97	.352
2 or more fills of 1 antihypertensive medication	37.4	13.4	65.6	85.0	4.37	.405
1 fill each of 2 or more antihypertensive medications	19.5	13.4	34.8	92.9	4.90	.702
1 diagnosis and 1 fill of 1 antihypertensive medication	38.6	13.4	62.7	89.0	5.70	.419
1 diagnosis and 2 or more fills of 1 antihypertensive medication	35.4	13.4	58.1	90.5	6.12	.463
1 diagnosis and 1 fill each of 2 antihypertensive medications	18.7	13.4	31.0	95.2	6.46	.725
2 or more diagnoses and 1 fill of 1 antihypertensive medication	37.0	13.4	60.7	89.9	6.01	.437
2 or more diagnoses and 2 fills of 1 antihypertensive medication	34.2	13.4	56.7	91.4	6.59	.474
2 or more diagnoses and 1 fill each of 2 antihypertensive medications	18.5	13.4	30.5	95.2	6.35	.730

^aCharts abstracted = 1,169; gold standard positives = 623 (53.3%).

Table 4
BEST PERFORMING ALGORITHMS FOR COMORBID CONDITIONS

Condition	Algorithm	Positives (%)	Sensitivity	Specificity	LR+	LR-
Diabetes	1 diagnosis, any source	25.5	91.6	95.8	21.8	.088
Coronary artery disease	1 diagnosis, any source	11.2	84.4	90.9	9.2	.172
Cerebrovascular disease	1 diagnosis, any source	6.4	43.1	97.1	14.9	.590
Peripheral artery disease	1 diagnosis, any source	8.0	50.0	92.0	6.3	.543
Congestive heart failure	1 diagnosis, any source	7.9	72.9	96.3	19.5	.282
Chronic kidney disease	Same as gold standard	9.2	100	100	—	—
Dyslipidemia	Total cholesterol ≥ 240 or LDL ≥ 160	11.0	74.4	93.7	11.9	.273
Depression	1 diagnosis, any source	23.0	88.9	83.0	5.2	.134
Schizophrenia/psychotic disorders	1 diagnosis, any source	4.9	100	97.0	33.3	0
Bipolar disorder	1 diagnosis, any source	3.7	90.5	97.9	43.1	.097
Alcohol abuse	1 diagnosis or 1 lab	11.1	53.4	92.3	6.9	.505
Substance abuse	1 diagnosis or 1 lab	2.7	77.8	99.1	86.4	.224

Table 5

PREVALENCE OF COMORBID CONDITIONS IN CHART REVIEW SAMPLE AND ESTIMATED PREVALENCE IN THE ADULT DENVER HEALTH POPULATION

Diagnosis	Gold standard chart review N (%)	Estimated prevalence in Denver Health % (95% CI)
Hypertension	623 (53.3)	30.3 (26.6–34.1)
Diabetes	285 (24.4)	14.4 (11.6–17.3)
Coronary artery disease	32 (2.7)	1.3 (.5–2.2)
Cerebrovascular disease	102 (8.7)	2.4 (2.1–4.6)
Peripheral artery disease	2 (.17)	.05 (0–.13)
Congestive heart failure	70 (6.0)	2.6 (1.5–3.7)
Chronic kidney disease	107 (9.2)	3.1 (2.1–4.1)
Dyslipidemia	82 (7.0)	4.5 (2.8–6.2)
Depression	99 (8.5)	9.2 (6.5–12.0)
Schizophrenia/psychotic disorders	22 (1.9)	1.9 (.7–3.1)
Bipolar disorder	21 (1.8)	3.1 (1.4–4.8)
Alcohol abuse	88 (7.5)	11.4 (8.3–14.5)
Substance abuse	27 (2.3)	3.8 (1.9–5.6)