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The Journal of Registry Management is indexed in the National Library of Medicine’s MEDLINE database. Citations from the articles indexed, the indexing terms (key words), and the English abstract printed in JRM are included and searchable using PubMed.

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Abstract: Background: Little is known about the effectiveness of a patient registry, an attribute within the patient-centered medical home (PCMH) model, as it relates to diabetes health outcomes. The purpose of this retrospective study was to compare hemoglobin A1c (HbA1c) values for patients (n = 713) from clinics with an established diabetes registry (n = 7) to patients (n = 325) at clinics without a diabetes registry (n = 15), and determine whether HbA1c levels improve significantly more over time at registry clinics compared to nonregistry clinics. Methods: Up to 3 most recent sequential HbA1c values, along with demographic variables of age, body mass index (BMI), gender, race, insurance type, marital status, and whether or not the patient lived in the local area around the medical center were extracted from the electronic medical record used throughout the primary health care system. Presence of comorbid conditions of lipid metabolism and hypertension disorders were also collected. Analysis of variance and propensity-score-matched 2-sample analyses were used to examine the association between diabetes registry status HbA1c, controlling for demographic variables. Results: Analyses indicated no evidence that patients in clinics with established diabetes registries had improved HbA1c levels significantly more than patients in clinics without diabetes registries. Discussion: Patients in clinics with diabetes registry did not have greater overall improvement in HbA1c values than patients in nondiabetes registry clinics. However, patients at all clinics had significantly reduced HbA1c values over time. More research is needed to determine if registries are effective PCMH tools to reduce diabetes morbidity and mortality.

Key words: diabetes, diabetes registry, patient-centered

Introduction

Diabetes mellitus II (DM II) is now an epidemic in the United States with 25.8 million Americans (8.3%) living with DM II.1 Approximately 1.9 million Americans aged 20 years or older were diagnosed with DM II in 2010.1 The impact that DM has on the economy in terms of direct and indirect costs is staggering, with estimated costs for diabetes care of $245 billion in 2012.2 Adults who have diabetes are at twice the risk of death compared to adults who do not have diabetes;3,4 heart disease and stroke are major risk factors in adults with diabetes, with a death rate 2 to 4 times higher than adults who do not have diabetes.3,5

The patient-centered medical home (PCMH) model is a collaborative approach to providing health care to improve health outcomes for patients living with chronic diseases like diabetes, and consists of 7 key principles: having a personal physician; embracing a medical team; appreciating the whole individual; providing integrated and coordinated care; obtaining access; maximizing health outcomes and safety systems; and creating multiple payment streams. Evidence now exists that implementing the PCMH model in primary care practices is effective.6 While there are ongoing efforts to implement the PCMH model within many primary care networks,6,9 it remains unclear which PCMH attributes are most effective in improving patients’ health. Disease registries,10 a system that allows the health care team to closely monitor patients’ health outcomes, seems like an efficient PCMH attribute to achieve optimum patient health. A patient registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves a predetermined scientific, clinical, or policy purpose(s).11 Thus, a diabetes registry is an organized system specifically focused on capturing patient information relative to diabetes. Theoretically, having a diabetes registry to closely monitor patients with chronic diseases, specifically DM II, may significantly control and reduce the risk of further complications. However, a 2014 study by Friedberg12 and colleagues found that while pilot practices receiving diabetes registries and technical assistance accumulated average bonuses of $92,000 per primary care physician during the 3-year intervention period, limited improvement were observed in health care
quality. Thus, we specifically examined the use of diabetes registries, which is an attribute within the PCMH model. The overall goal of this project was to test whether having a diabetes registry (a key attribute within the PCMH model) is significantly associated with improvement in patients’ HbA1c levels. The goal of this research report is to compare the improvement in diabetes outcomes as assessed by HbA1c in patients from clinics with and without a diabetes registry.

Methods

The Community Health and Family Medicine (CHFM) primary care clinical centers within this urban community consist of 22 clinics and over 80 physicians and nonphysician providers in Northeast Florida, serving more than 80,000 patients per year. At the beginning of this research, 7 primary care clinics had established an electronic medical record (EMR)-based diabetes registry, and 15 had not. Six of the 7 clinics used a Microsoft Access database, and 1 of the 7 used a Diabetes Masters Clinicians Program. At each of the 7 clinics with a diabetes registry, data gathered from the patient’s EMR were entered manually into the diabetes registry.

Source Population and Sampling Frame

The sampling frame for our study included all diabetic patients having a primary care visit and at least 1 recorded HbA1c lab value at 1 of the 22 primary clinics between January 1, 2010, and December 31, 2011. Primary care network data from 2008–2009 show that 127,000 patients had 654,000 patient visits with approximately 80% being adult patients (18–45 years old, 36%; 46–64 years old, 29%; ≥65 years old, 14%). Patients served by these primary care centers were ethnically/racially diverse (46% white, 37% black, 4% Hispanic/Latino, 2% Asian); resided in all geographic areas throughout Northeast Florida and beyond; and were more likely to be female (63%). Reviewing primary care network data revealed that the majority of care provided within this primary care network was for chronic diseases, such as hypertension, diabetes, and hyperlipidemia, regardless of patients’ ethnicity or race, geographic location, or gender.

Inclusion/Exclusion Criteria

All individuals with diabetes, aged 18 years or older and had 1 or more visits at 1 of the 22 primary care centers were given an equal chance of having their records randomly selected for inclusion. Diabetic patients who had type I or gestational diabetes were excluded since type II disease processes significantly differ from type I disease.

Sample Identification and Database Construction

A list of Community Health and Family Medicine (CHFM) clinic patients (n = 12,956) with International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) diagnoses codes of 250.00–250.99 was identified using billing services having at least 1 visit during January 1, 2010 through December 31, 2011, for each of the 22 clinics. The constructed list only included the medical record number (MRN) so that, if randomly selected, the chart was then reviewed. A random number generator was used to select the required number of patient records from each of the clinics.

Defining PCMH Status (Diabetes Registry)

The primary clinic variable of interest was whether or not each clinic used a diabetes registry. Features of having and maintaining a diabetes registry include, but are not limited to: all patients having diabetes will have their information included in secure database and patients’ information updated at each visit or encounter. Diabetes registries are also used to track patients’ compliance with visits and with taking medications. Diabetes registries can also be used to generate reminder letters as well as monitor patients’ health outcomes, including but not limited to HgbA1c levels. Lastly, it is ideal to have clinical staff and support specifically assigned to maintain the registry to increase effectiveness.

Electronic Medical Record

One aspect making this research feasible is the use of a universal EMR. Thus, while several primary care centers use a diabetes registry for closer monitoring of patients, all information, including patient visits, treatment plans, lab results as well as follow-up appointments were entered into the universal EMR, Allscripts which was used within this primary health care network.

Data Collection/Extraction

After institutional review board approval, trained team members (trained to review the medical record and abstract data in a consistent manner) collected data from existing sources to include separately asking medical directors, clinic administrators and medical support staff at each clinic about the use of diabetes registries in order to determine each primary care center’s diabetes registry status. Once confirmed that a diabetes registry was maintained, trained team members spoke with the clinic administrator and/or the persons in charge of maintaining the registry to understand what information was collected as well as the general process of how information was collected and used. Each primary care center was assigned a number from 1 to n, in order to maintain blinding.

Hemoglobin A1c (HbA1c) values are the primary patient variable. Up to the 3 most recent HbA1c values and testing dates noted in the EMR were recorded. Patient health outcomes and sociodemographics were collected from Allscripts for randomly selected charts only. No patient contact information (ie, address, telephone number) was collected. Up to 3 most recent sequential HbA1c values, along with demographic variables of age, body mass index (BMI), gender, race, insurance type, marital status, and whether or not the patient lived in the local area around the medical center were collected. Presence of comorbid conditions of lipid metabolism and hypertension disorders were also collected. While the MRN was used to accurately identify charts, it was not included in any database for analysis purposes. Moreover, a link was created with the MRN and
a number from 1 to \( n \) during the data collection phase for eventual data deidentification.

**Sample Size Justification**

Required sample size was estimated assuming a cluster-randomized design, although clusters were determined a priori and were not randomized. Assuming 7 diabetes registry clinics and 16 nondiabetes registry clinics, 80% power; a 5% 2-sided significance level, a clinically meaningful difference in the changes in HbA1c of 1% (meaning that the improvement in HbA1c would be greater by 1% in diabetes registry clinics than nondiabetes registry clinics), and an intraclass correlation coefficient (ICC)\(^{20} \) of 0.08, 119 patients were needed per diabetes registry clinic and 26 patients per nondiabetes registry clinic, thus requiring a total sample size of 1,249. Sample sizes were estimated using “sampsi” and “sampclus” modules in Stata/MP 11.2 for Windows.

**Data Analysis**

Summary statistics were calculated for baseline characteristics. Mean (standard deviations) were estimated for numeric variables and frequencies (percentages) for categorical variables. Demographic and baseline characteristics comparisons between diabetes registry versus nondiabetes registry patients were assessed using the nonparametric Wilcoxon Rank-Sum test for continuous data, and Pearson chi-squared test or Fisher’s exact test (when expected frequencies are small) for categorical data. Medians, first, and third quartiles (Q1, Q3) were used to describe the time (number of days) from first to second visit, and from second to third visit, respectively.

The primary analysis compared changes over time in diabetes registry versus nondiabetes registry patients using a mixed-model, repeated-measures analysis of variance (ANOVA) model. Factors in the ANOVA were diabetes registry clinic (yes/no), clinic nested in diabetes registry, visit (first, second, or third starting with the earliest), and the interactions of diabetes registry and visit and of clinic and visit (nested in diabetes registry) with the random effect of the mixed-model being clinic. Visit 1 refers to the patients’ first HbA1c reading during the study period. A patient might have 1, 2, or 3 visits with HbA1c readings during the study period. A significant diabetes registry by visit interaction would support the hypothesis that the diabetes registry clinics are improving care to a greater degree than are the nondiabetes registry clinics. The optimal covariance structure (compound symmetry for these data) was determined by fitting several covariance structures and determining the one with the lowest corrected Akaike information criterion (AIC).\(^{21} \)

Differences between levels of factors are estimated using least-square (LS) means, which are model-based predictions of the marginal means, often called *adjusted means*. For multiple comparisons among a set of differences in LS means, Tukey-Kramer adjusted \( P \) values were used to preserve an overall error rate of 5%.

Two approaches to control for potential confounding were employed in secondary analyses. First, each potential confounder (among age, BMI, gender, race [black/white/other], insurance [private/Medicare/limited], lipid disorder [yes/no], overweight [yes/no], hypertensive [yes/no], and residing in lower socioeconomic areas/urban core [yes/no]) was added to the previous ANOVA (1 variable per analysis) to determine if the potential confounder was statistically significant (and improved the AIC) and modified the visit by diabetes registry effect. All potential confounders were also simultaneously included in a separate model along with diabetes registry clinic (yes/no), clinic nested in diabetes registry, and the interactions of diabetes registry and visit and of clinic and visit (nested in diabetes registry).

The second approach to control potential confounding was a propensity-score matched analysis. The probability that each individual attended a diabetes registry clinic was estimated using a logistic regression model using all of the potential confounders listed above. These probabilities are called the propensity scores. Only patients with 2 or more visits were included in these analyses to allow for estimation of changes from the initial (baseline) visit. The distribution of propensity scores in the 2 diabetes registry clinic groups was graphed. The propensity scores were used with a “greedy-matching” approach\(^{22} \) to form matched pairs in which the propensity scores are as similar as possible. Wilcoxon signed-rank tests, McNemar’s tests and Bowker’s tests for symmetry were used to compare the matched groups. Paired-sample analyses were performed using the change in HbA1c from baseline to visit 2, to visit 3, and to the later of visits 2 and 3.

**Results**

Medical records were retrieved for 1,220 patients in 22 clinics (7 diabetes registry and 15 nondiabetes registry) since patients aged ≤17 years (\( n = 5 \)) or deceased (\( n = 24 \)) at the time of data extraction were removed from the original 1,249 dataset. One nondiabetes registry clinic was excluded due to only 1 patient having more than 1 clinic visit (14 total patients). Additionally, 168 patients were excluded due to no HbA1c values in Allscripts. Thus, the final study sample size is 1,038 patients. Table 1 summarizes the baseline characteristics of patients in diabetes registry (\( n = 713 \)) and nondiabetes registry (\( n = 325 \)) clinics. Patients in diabetes registry clinics had, on average, higher HbA1c values at the first visit, were younger, were more likely to reside in Jacksonville’s urban core, were more likely to be black, and were more likely to have Medicaid or limited insurance.

The median number of days between the first and second visit was 147 days (Q1 = 98 days, Q3 = 235 days), and between second and third visit was 141 days (Q1 = 103 days, Q3 = 208 days).

The mixed-model, repeated-measures ANOVA revealed that diabetes registry (\( P = .03 \), clinic (nested in diabetes registry) (\( P < .0001 \)), and visit (\( P = .001 \) were significant factors, while the interaction between visit and diabetes registry (\( P = .88 \)) and the interaction between visit and clinic (nested in registry) (\( P = .31 \)) were not significant. There are improvements with increasing visit numbers in both groups. Further, the differences between the diabetes registry and nondiabetes registry patients indicates diabetes registry patients have a higher mean HbA1c across all 3
### Table 1. Comparison of Baseline Characteristics among Patients from Registry and Nonregistry Clinics

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unmatched Sample (n = 1,038)</th>
<th>Matched-Pair Sample (n = 222)</th>
<th>P</th>
<th>Registry (n=111)</th>
<th>Non-registry (n=111)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>HgA1c a,b</td>
<td>7.88 ± 2.10 (63 ± 23)</td>
<td>7.43 ± 1.85 (58 ± 20.2)</td>
<td>.043</td>
<td>7.58 ± 1.69 (59 ± 18.5)</td>
<td>7.71 ± 2.14 (61 ± 23.4)</td>
<td>.782</td>
</tr>
<tr>
<td>Age</td>
<td>59.7 ± 2.6 (63 ± 23)</td>
<td>61.7 ± 13.6 (58 ± 20.2)</td>
<td>.007</td>
<td>61.4 ± 12.3 (59 ± 18.5)</td>
<td>62.4 ± 13.2 (61 ± 23.4)</td>
<td>.501</td>
</tr>
<tr>
<td>BMI</td>
<td>33.9 ± 8.1 (63 ± 23)</td>
<td>32.4 ± 7.6 (58 ± 20.2)</td>
<td>.014</td>
<td>34.8 ± 7.6 (59 ± 18.5)</td>
<td>33.7 ± 6.7 (61 ± 23.4)</td>
<td>.362</td>
</tr>
<tr>
<td>Location</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban Core</td>
<td>331 (50)</td>
<td>37 (12)</td>
<td>&lt;.0001</td>
<td>27 (24)</td>
<td>27 (24)</td>
<td>1.000</td>
</tr>
<tr>
<td>Other</td>
<td>326 (50)</td>
<td>284 (88)</td>
<td></td>
<td>84 (76)</td>
<td>84 (76)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>400 (56)</td>
<td>183 (56)</td>
<td>.954</td>
<td>59 (53)</td>
<td>59 (53)</td>
<td>1.000</td>
</tr>
<tr>
<td>Male</td>
<td>313 (44)</td>
<td>142 (44)</td>
<td></td>
<td>52 (47)</td>
<td>52 (47)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>427 (65)</td>
<td>92 (29)</td>
<td>&lt;.0001</td>
<td>54 (49)</td>
<td>53 (48)</td>
<td>.710</td>
</tr>
<tr>
<td>White</td>
<td>201 (31)</td>
<td>172 (54)</td>
<td></td>
<td>51 (46)</td>
<td>49 (44)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>29 (4)</td>
<td>57 (17)</td>
<td></td>
<td>6 (5)</td>
<td>9 (8)</td>
<td></td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid/Limited</td>
<td>287 (44)</td>
<td>53 (17)</td>
<td>&lt;.0001</td>
<td>21 (19)</td>
<td>25 (23)</td>
<td>.884</td>
</tr>
<tr>
<td>Medicare</td>
<td>277 (42)</td>
<td>165 (51)</td>
<td></td>
<td>65 (59)</td>
<td>60 (54)</td>
<td></td>
</tr>
<tr>
<td>Private</td>
<td>93 (14)</td>
<td>103 (32)</td>
<td></td>
<td>25 (23)</td>
<td>26 (23)</td>
<td></td>
</tr>
<tr>
<td>Lipid disorder</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>612 (86)</td>
<td>257 (79)</td>
<td>.006</td>
<td>94 (85)</td>
<td>92 (83)</td>
<td>.864</td>
</tr>
<tr>
<td>No</td>
<td>101 (14)</td>
<td>68 (21)</td>
<td></td>
<td>17 (15)</td>
<td>19 (17)</td>
<td></td>
</tr>
<tr>
<td>Overweight / obese</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>182 (26)</td>
<td>100 (31)</td>
<td>.078</td>
<td>39 (35)</td>
<td>37 (33)</td>
<td>.883</td>
</tr>
<tr>
<td>No</td>
<td>531 (74)</td>
<td>225 (69)</td>
<td></td>
<td>72 (65)</td>
<td>74 (37)</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>607 (85)</td>
<td>274 (84)</td>
<td>.731</td>
<td>98 (88)</td>
<td>97 (87)</td>
<td>1.000</td>
</tr>
<tr>
<td>No</td>
<td>106 (15)</td>
<td>51 (16)</td>
<td></td>
<td>13 (12)</td>
<td>14 (13)</td>
<td></td>
</tr>
</tbody>
</table>

Data are count (%) unless otherwise indicated.
aMean ± standard deviation.
bHgA1c values are presented as % NGSP, followed by the mmol/mol IFCC equivalent in parentheses.
cWilcoxon Rank Sum test; dPearson’s Chi-square; eWilcoxon Sign-Rank test; fMcNemar’s test; gBowker’s tests for symmetry.

### Table 2. Summary of Least-square (adjusted) Means HbA1c for Registry and Visit Factors in ANOVA Model

<table>
<thead>
<tr>
<th>Effect</th>
<th>Level</th>
<th>Mean HbA1c a,b</th>
<th>SE HbA1c a,b</th>
<th>Comparisons</th>
</tr>
</thead>
<tbody>
<tr>
<td>Registry</td>
<td>Yes</td>
<td>7.76 (61)</td>
<td>0.07 (0.8)</td>
<td>P = .029</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>7.49 (58)</td>
<td>0.10 (1.1)</td>
<td></td>
</tr>
<tr>
<td>Visit</td>
<td>1</td>
<td>7.76 (61)</td>
<td>0.07 (0.8)</td>
<td>1 vs. 2: P = .098</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>7.63 (60)</td>
<td>0.07 (0.8)</td>
<td>1 vs. 3: P = .0006</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>7.47 (58)</td>
<td>0.08 (0.9)</td>
<td>2 vs. 3: P = .031</td>
</tr>
</tbody>
</table>

aHbA1c values are presented as % NGSP, followed by the mmol/mol IFCC equivalent in parentheses.
bSE, Standard error.
cUsing Tukey-Kramer adjustments for multiple comparisons.
ANOVA, analysis of variance.
visits. The LS means are summarized in Table 2. Figure 1 shows the LS means between the diabetes-registry and nondiabetes-registry patients at each visit. The improvement over time in the diabetes-registry and nondiabetes-registry groups is similar over time, although the diabetes-registry patients started with a higher baseline HbA1c.

There was no evidence of confounding in any of the ANOVA models that adjusted for potential confounders, and the addition of confounders did not alter the associations cited above. In the propensity score analysis, there were 111 matched sets. After matching, no significant differences were found between the 2 groups with respect to the baseline characteristics used to calculate the propensity scores (Table 1). One analysis considered visit 2 in patients with only 2 visits (N = 111), a second considered visit 3 in patients with all 3 visits (N = 49), and a third considered the latter of visits 2 or 3 as available (N = 111). None of these was statistically significant (P = .94, .61, and .22, respectively).

**Discussion**

Our findings imply that patients in clinics with established diabetes registries have improved HbA1c levels that were similar to patients in clinics without diabetes registries. Additionally, diabetes registry clinics did not provide greater improvement in HbA1c values than nondiabetes registry clinics. However, all clinics were successful in reducing HbA1c values over time. One interpretation is that the diabetes registry clinic patients have higher HbA1c values at the first visit, and while all clinics are successful in reducing these values over time, the diabetes registry clinics do not provide greater improvement than did the nondiabetes registry clinics. However, if patients with higher baseline HbA1c values tend to not improve as much as patients with lower baseline values, then the equivalence of the improvement may suggest significant benefit after all.

Of note was the overall improvement in patients’ HbA1c values from all clinics. While it might be argued that clinics having diabetes registries started out with patients with more advanced disease conditions (ie, higher Hg1Ac values), our analyses attempted to control for demographic factors that might confound these relationships. One must then question what other inherent or traditionally nonmeasured variable influences patients’ diabetes status and outcomes. While it seems that multiple interventions made by both the patient and the physician/provider improve health outcomes, this study only evaluated 1 health outcome for 1 chronic disease. It is possible that the establishment of a diabetes registry may improve other health outcomes for other chronic diseases, such as weight loss in obesity or forced expiratory volume in 1 second (FEV1) improvement in patients with chronic obstructive pulmonary disease.

Another important issue is that outcomes were measured over the course of 2 years. Perhaps there would have been a significant difference in outcomes over a longer period of time. It was anticipated that there would be baseline differences between patients who attended diabetes registry clinics and patients who attended nondiabetes registry clinics. It was expected that these patients from diabetes registry clinics would have more severe diabetes, or have limited insurance than patients in nondiabetes registry clinics which was confirmed; one important difference in baseline characteristics was higher baseline HbA1c. Because of the potential confounding of these factors, a propensity-score matched analysis was undertaken to control for these differences.

**Discussion**

Relevant findings are that, while there was a significant improvement over time in both clinical groups, the change was constant over time in each group. The study is important since it contributes to the current body of knowledge regarding the usefulness of diabetes registries. When other endpoints such as smoking cessation were measured, a study by Roski and colleagues in 2003 concluded that patients visiting diabetes registry clinics accessed counseling programs statistically significantly more often (P < .001) than patients receiving care in the control condition.

Some of the strengths of the study include examining the association between diabetes registry use and HbA1c values in a large sample of patients living with diabetes as primary care practices transition into PCMH models of care. By focusing on the PCMH attribute of registries, we can determine whether the use of diabetes registries independently influence HbA1c values. Another strength is that a very specific end point measuring a relevant outcome for a common chronic disease such as diabetes was chosen for comparison and evaluation.

Some study limitations must be noted, however. For example, up to 3 HbA1c values were collected from patients’ EMR for a 2-year time period; if a longer study period was studied, greater differences over time and between diabetes registry/nondiabetes registry clinics may have been observed. Another potential limitation is missing information where fewer than 3 HbA1c values were available. However, missing information was not differential between clinics and we would expect that having more values would make patients more similar at baseline. Thus, missing information seems to underestimate any observed differences.
Another potential limitation is that time between patient visits or HbA1c values were not consistent; however, this represents actual, real-world practice and further reflects the potential generalizability of this study.

While we can consider only selecting patients in practices having at least 3 HbA1c values, which implies more visits and compliance, this also may produce an inherent bias since patients who are more compliant with medical visits are more willing to change their behavior to improve health.24,25 Another potential limitation is that prevalent, rather than incident disease status was measured; this is important since the trajectory for reducing HbA1c values may be different for patients newly diagnosed with diabetes compared to those who have been managing their diseases for some time. One may consider simply observing the effect on health outcomes using a diabetes registry consisting of newly diagnosed diabetes patients. However, our sample is a realistic example of what primary care physicians encounter, and how patients in diabetes registry or non-diabetes registry clinics are monitored, and thus would more likely represent the general population of diabetic patients.

Although we found that the use of diabetes registries, 1 PCMH attribute, is not significantly associated with greater improvement in HbA1c values, the combination of PCMH attributes may be more impactful to change health outcomes. Additional studies using a varied combination of PCMH attributes are needed to determine whether these results are consistent in similar patients as well as patients having other disease conditions. Another approach is to study HbA1c values within the same clinic before and after diabetes registry implementation, especially since many primary care centers are now implementing diabetes registries.

Conclusion

In summary, diabetes registries are being used in various PCMH settings. This observational study showed that patients getting care for their diabetes at a clinic with a diabetes registry did not have significantly lower HbA1c values than patients in clinics without a diabetes registry. As more practices begin to implement diabetes registries, careful evaluation should be given to understand what specific attributes of a diabetes registry directly influence and improve the monitoring of HbA1c values.

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Original Article

Chronic Myelogenous Leukemia in Eastern Pennsylvania: An Assessment of Registry Reporting

Kristen J. Mertz, MD, MPH; Jeanine M. Buchanich, MEd, PhD; Terri L. Washington; Elizabeth A. Irvin-Barnwell, PhD; Donald V. Woytowitz, MD; Roy E. Smith, MD

Abstract: Background: Chronic myelogenous leukemia (CML) has been reportable to the Pennsylvania Cancer Registry (PCR) since the 1980s, but the completeness of reporting is unknown. This study assessed CML reporting in eastern Pennsylvania where a cluster of another myeloproliferative neoplasm was previously identified. Methods: Cases were identified from 2 sources: 1) PCR case reports for residents of Carbon, Luzerne, or Schuylkill County with International Classification of Diseases for Oncology, Third Edition (ICD-O-3) codes 9875 (CML, BCR-ABL+), 9863 (CML, NOS), and 9860 (myeloid leukemia) and date of diagnosis 2001–2009, and 2) review of billing records at hematology practices. Participants were interviewed and their medical records were reviewed by board-certified hematologists. Results: PCR reports included 99 cases coded 9875 or 9863 and 9 cases coded 9860; 2 additional cases were identified by review of billing records. Of the 110 identified cases, 93 were mailed consent forms, 23 consented, and 12 medical records were reviewed. Hematologists confirmed 11 of 12 reviewed cases as CML cases; all 11 confirmed cases were BCR/ABL positive, but only 1 was coded as positive (code 9875). Conclusions: Very few unreported CML cases were identified, suggesting relatively complete reporting to the PCR. Cases reviewed were accurately diagnosed, but ICD-0-3 coding often did not reflect BCR-ABL-positive tests. Cancer registry abstracters should look for these test results and code accordingly.

Key words: chronic myelogenous leukemia, disease notification, environmental, exposure, international classification of diseases codes, risk factors

Introduction

Chronic myelogenous leukemia (CML) is a myeloproliferative neoplasm (MPN) characterized by unrestricted malignant proliferation of myeloid cells in the bone marrow. It is caused by an acquired genetic defect, a balanced translocation of chromosomes 9 and 22, which is characterized by the Philadelphia chromosome (shortened chromosome number 22) and the fusion of the ABL1 gene on chromosome 9 with the BCR gene on chromosome 22. The BCR-ABL protein associated with the BCR-ABL fusion gene has enhanced tyrosine kinase activity that leads to increased bone marrow production of hematopoietic cells.

CML accounts for 15% of leukemias in the United States, with an annual reported rate of CML of 1.6 to 2.0 per 100,000 and approximately 5,000 new cases per year. Recent studies, however, suggest that the incidence may be underestimated.

Since the 1980s, hospitals in Pennsylvania have been required by law to report all new cases of CML to the Pennsylvania Cancer Registry (PCR). Outpatient clinics and practices have been required to report since 2001. From 2001 through 2008, a statewide average of 177 CML cases per year were reported to the PCR (PA Department of Health, unpublished data). Previous to this investigation, evaluation of CML reporting to the PCR had not been conducted. The objectives of this study were to assess the completeness and accuracy of CML reporting and coding in a tri-county area of Eastern Pennsylvania. This investigation was conducted as part of a larger investigation of MPNs in an area with a known cluster of polycythemia vera and concern about environmental hazards.

Methods

The methodology for the larger investigation is described elsewhere. For the CML portion of the study, investigators received the names and addresses of all residents of Carbon, Luzerne, or Schuylkill County who were reported to the PCR with International Classification of Diseases for Oncology, Third Edition (ICD-O-3) codes 9875 (chronic myelogenous leukemia, BCR/ABL+), 9863 (chronic myelogenous leukemia, not otherwise specified) and 9860 (myeloid leukemia, not otherwise specified) with date of diagnosis from 2001 through 2009 or unknown. In general, cases are reported to the PCR by certified tumor registrars (CTRs) or health information management (HIM) staff in hospitals; doctors’ offices and other nonhospital facilities report by faxing medical records which are then abstracted by PCR staff.
PCR staff attempted to identify nonreported CML cases from outpatient facilities by requesting a billing report on all patients with a final International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code of 205.1 at hematology/oncology practices in the tri-county and surrounding areas. PCR staff then matched persons identified by the billing report with the PCR database. For cases listed on the billing report but not in the PCR, medical records were faxed to the PCR; they were reviewed and abstracted by PCR staff.

Current contact information for CML cases was accessed using standard commercial and noncommercial tracing services. Cases were mailed packets of information which included a description of the study and a consent form. For deceased cases, the next of kin listed on the death certificate was mailed a packet. Repeated attempts, both by phone and by mail, were made to contact cases or next of kin who did not respond.

All cases or next of kin were asked to consent to an interview and to a review of the medical records pertaining to their leukemia diagnosis. Medical records were requested from named hospitals or physicians’ offices, reviewed for relevance and completeness, arranged in chronologic order, and sent to an expert panel. Each case was reviewed by 3 of the 4 panel members, all of whom were board-certified hematologists. Cases were classified as confirmed cases if the patient met the 2008 WHO criteria for the accelerated or blast phase or the study criteria for chronic phase (BCR/ ABL+ and WBC>50,000) or if all of the reviewing panel members determined the case was “definitely” or “probably” CML according to conventional hematology practice standards at the time of diagnosis.

Data were entered into the REDCap data management system and exported into SAS for analysis. The study was approved by the institutional review boards at the University of Pittsburgh and the Pennsylvania Department of Health and conducted from May 2011 through November 2012.

Results
For tri-county residents, the PCR received 88 CML case reports with year of diagnosis from 2001 through 2009 and 11 CML case reports with no date of diagnosis specified but submitted during the same time period. Of these 99 cases, 18 (18%) were coded as 9875 (CML, BCR-ABL+) or both 9875 and 9863 (CML, NOS); 81 (82%) were coded only as 9863. An additional 9 cases with code 9860 (myeloid leukemia, NOS) were reported. Review of billing information at hematologist/oncologist offices by PCR staff led to the identification of 2 additional CML cases.

Of the 110 cases identified, 93 (85%) were successfully traced and were mailed consent forms. Of these 93 cases located, 23 (25%) consented, 4 (4%) refused, 1 (1%) was unable to consent, and 65 (70%) did not respond despite repeated attempts to contact them by phone and mail. Medical records were obtained for 12 (52%) of the 23 who consented. Of the 11 not obtained, facilities were unable to find them (n = 2), unwilling to send them (n = 3), or required proof of executorship (n = 6). The expert panel of hematologists confirmed 11 (92%) of the 12 cases reviewed as CML cases; 9 were labeled as “definitely CML” by all 3 reviewers and 2 were labeled as “definitely CML” or “probably CML” by all 3. The case not confirmed as CML had been reported as 9860 (myeloid leukemia, not otherwise specified) and was negative for the BCR-ABL mutation. All 11 confirmed cases were BCR-ABL+ according to their medical records, but only 1 case (8%) was coded as 9875 (CML, BCR-ABL+) in the PCR.

Discussion
To our knowledge, this is one of the few studies of CML reporting in the United States. Our findings suggest that completeness of CML reporting to the PCR in the tri-county area was high, given that review of billing information in outpatient settings revealed that only 2 additional cases may have been missed. These 2 patients did not respond to our request to participate in the study and thus were not assessed by our expert panel, so their true case status is unknown.

A previous study indicated possible underreporting of CML to the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute by as much as 70%, possibly because of a change in reporting requirements or because outpatient cases were missed. A recent comparison of claims data to registry data from outpatient clinics suggested that leukemia in general was underreported during the first year after diagnosis, but after allowing for time lags only about 4% of leukemia cases were missed. We found very little evidence of underreporting of CML to the PCR from hematology practices in the tri-county area.

In the tri-county area, the accuracy of PCR reporting was much higher for CML than for the other MPNs as determined by the larger study with almost all reported CML cases confirmed by the expert panel. The diagnosis of CML is relatively straightforward because of the availability of genetic testing for the Philadelphia chromosome and the BCR-ABL fusion gene, which has been standard practice for many years, whereas the diagnoses of other MPNs involves use of a newer genetic test and more complex diagnostic criteria.

Although almost all CML cases reported were confirmed as CML, the specific codes assigned to cases were not accurate: all of the 11 cases we confirmed were BCR-ABL positive, which means that all 11 should have been coded as 9875. Instead, most were coded as 9863. Statewide in 2001 through 2008, more than 3 times as many cases of CML coded as 9863 were reported to the PCR than cases coded as 9875 (Pennsylvania Department of Health, unpublished data). Because testing for the Philadelphia chromosome or the BCR-ABL fusion gene is normally part of the diagnostic tests for patients with suspected CML, cancer registry abstracters should look for these results and code accordingly.

This investigation was limited by its low response rate (25%), which may have been partly due to “study fatigue” among residents of the tri-county area, the site of many studies of MPNs following the report of a suspected cluster
of PV cases in 2005.8,9 We were only able to evaluate a small percentage of cases for accurate diagnoses and coding. The study may also have been limited by the scope of additional case-finding efforts at hematology practices; review of billing records was confined to practices within the tri-county and nearby areas.

**Conclusion**

In summary, our findings suggest that reporting of CML to the PCR is relatively complete, given that only 2 additional cases were identified by the billing record review at outpatient clinics. The subset of reported CML cases we reviewed were accurately diagnosed, reflecting use of BCR-ABL genetic tests, but inaccurately coded, reflecting inattention by coders to BCR-ABL test results.

**Acknowledgments**

We thank Wendy Aldinger, Robin Otto, and staff at the PA Cancer Registry for providing information from the PCR and for their review of billing records at hematology practices. We are also indebted to David Marchetto and James Logue at the Pennsylvania Department of Health for their facilitation of the study. We are grateful to Anthony Rizzardi of Hazelton General Hospital and the Pennsylvania Department of Health clinics in Wilkes Barre and Pottsville for sharing their clinic space with study interviewers. We appreciate the work of Dr. Emmanuel Besa as an expert panelist. We thank Brittany Eckberg for entering data and compiling copies of medical records for review. Finally, we thank the late Paul Roda for his assistance with this study as an expert panelist, advisor, and editor, and for his career-long work toward better detection and treatment of myeloproliferative disorders.

**References**

Acute Myocardial Infarction in Pregnancy: A Statewide Analysis

Zuber D. Mulla, PhD, CPH; Bailey Wilson, MD; Zainul Abedin, MD; Loretta L. Hernandez, MPH, MT(ASCP); Sanja Kupesic Plavsic, MD, PhD

Abstract: Objective: Acute myocardial infarction (AMI) during pregnancy and the puerperium is a rare but devastating event. The objective of this study was to describe the clinical and epidemiological features of pregnancy-related AMI. Methods: A retrospective study was conducted using Texas hospital inpatient data (years 2004–2007). Diagnoses and procedures had been coded using International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM). Adjusted odds ratios (OR) for hospital mortality and length of stay > 4 days (prolonged length of stay [PLOS]) were calculated using logistic regression with Firth’s bias correction and multiple imputation. Results: 103 women with pregnancy-related AMI were identified in the statewide hospital database (6.5 cases per 100,000 births). The prevalence of cardiomyopathy was 16.5%. Approximately 14% of the pregnancies were complicated by preeclampsia/eclampsia. A history of cocaine use was noted in 3 patients. Congestive heart failure was present in 18 patients (17.5%). Two patients had attempted suicide and 1 died in the hospital. The overall hospital mortality rate was 9.7%. Placement of coronary artery stents was the most common coronary revascularization procedure (11 patients or 10.7%). The adjusted hospital mortality OR for women 35–39 years old (versus 30–34 years old) was 6.29 (P = .07). Patients with preeclampsia were more likely to have PLOS than patients whose deliveries were not complicated by preeclampsia (OR, 3.84; P = .06). Conclusions: While AMI in pregnancy remains a rare occurrence, it is associated with significant morbidity and a high case-fatality rate.

Key words: acute myocardial infarction, epidemiology, pregnancy, statewide hospital inpatient discharge database

Introduction

Acute myocardial infarction (AMI) during pregnancy and the puerperium is a rare but devastating event that is a leading cause of maternal mortality in the developed world.1–3 A statewide analysis of California hospital discharge records linked to vital statistics databases found an incidence of 1 case of pregnancy-related AMI per 35,700 deliveries.2 James and colleagues examined the Nationwide Inpatient Sample and reported a rate of AMI of 6.2 per 100,000 deliveries.1 While the incidence of pregnancy-related AMI is low, the case fatality rate has been reported to be as high as 37%, making each individual case of death due to myocardial infarction in pregnancy a significant contribution towards maternal mortality.1

Population-based studies of AMI during pregnancy in Texas are lacking. Texas is a large state both in terms of population (25,145,561 residents in the year 2010) and land area (approximately 261,232 square miles in 2010).4 The objective of this analysis was to describe the demographic, clinical, and epidemiologic features of pregnancy-related AMI in patients found in the Texas Public Use Data File, a hospital inpatient discharge data set, with a focus on identifying predictors of hospital mortality and a prolonged length of stay.

Methods

The study protocol was reviewed by the Institutional Review Board for the Protection of Human Subjects of the Texas Tech University Health Sciences Center at El Paso and was deemed exempt from formal review.

Source of Data

A retrospective cohort study was conducted using hospital inpatient discharge data that were obtained from the Texas Department of State Health Services (Austin, Texas). The Texas database contained information from all state licensed hospitals except those that are exempt from reporting to the Texas Health Care Information Council (THCIC). According to the data user manual, “Exempt hospitals include those located in a county with a population of less than 35,000, or those located in a county with a population more than 35,000 and with fewer than 100 licensed hospital beds and not located in an area that is delineated as an urbanized area by the United States Bureau of the Census...” Hospitals that do not seek insurance payment or government reimbursement are also exempt from the reporting requirement.

The statewide data set contained clinical and demographic information for patients who were discharged in 2004 through 2007. The principal diagnosis and up to 24
secondary diagnoses were evaluated in our study. These variables were coded using the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM). Up to and including 25 procedures (a principal procedure field plus 24 secondary procedures) performed during the hospital stay could have been recorded by the reporting facility using ICD-9-CM codes. These fields were also evaluated in our investigation.

### Inclusion Criteria

Records were included in our study if any of the discharge diagnosis fields contained an ICD-9-CM code for AMI (codes beginning with 410) and the discharge record also contained 1 or more of the following ICD-9-CM codes indicating that the patient was either pregnant or receiving postpartum care during her hospital stay: V23*, V24*, V27*, 630*, 631*, 632*, 633*, 634*, 635*, 636*, 637*, 638*, 639*, 640*, 641*, 642*, 643*, 644*, 645*, 646*, 647*, or 648*.

A total of 103 records were identified that fit the search criteria noted above. Ninety-seven of these patients were classified as female while 1 was classified as a male and 5 had missing values for the sex variable. The records of these 6 patients who fell into the latter 2 categories were retained in our analysis as all of them contained multiple maternal/obstetric ICD-9-CM condition codes.

### Coronary Revascularization Procedures

The insertion of non–drug-eluting and drug-eluting coronary artery stents were defined as the presence of ICD-9-CM procedure codes 36.06 and 36.07, respectively, in any of the ICD-9 procedure fields (Table 1). Coronary angioplasty not otherwise specified (code 36.09) was combined with percutaneous transluminal coronary angioplasty (code 00.66). Bypass anastomosis for heart revascularization was defined as codes 36.10, 36.11, 36.12, 36.13, 36.14, 36.15, 36.16, 36.17, or 36.19. Injection or infusion of a thrombolytic agent was identified using ICD-9-CM procedure code 99.10.

### Definition of Outcomes

Two dichotomous outcomes were evaluated during multivariable analyses. The first outcome was hospital mortality. The second was a prolonged length of stay (yes vs no). A prolonged length of stay (PLOS) was defined as a stay longer than the median length of stay of the sample (which was 4 days).

### Definition of Predictors

Several independent variables (predictors) were studied including maternal age, race, Hispanic ethnicity, insurance status, and selected comorbidities including diabetes (combined with gestational diabetes), hypertension, preeclampsia/eclampsia, tobacco use, and peripartum cardiomyopathy (see Table 1 for definitions).

### Statistical Analysis

Data were analyzed using SAS 9.3 software (SAS Institute, Inc). Descriptive analyses preceded multivariable modeling. The number of hospitalized cases of pregnancy-related AMI was divided by the number of births in Texas for the years 2004 through 2007 to arrive at an estimate of the statewide incidence.5

Logistic regression was used to calculate odds ratios (OR) for the dichotomous outcomes of PLOS and hospital mortality. The alpha was set at 0.05. ORs were reported with 95% confidence intervals (CI) and P values.

Due to the small number of in-hospital deaths (and the small number of episodes of PLOS) relative to the number of predictors in the logistic model, Firth’s likelihood penalty was used in both logistic regression models. An established technique known as multiple imputation was used to replace missing values for any predictor variable with plausible values.6,7 Patients who are found in this statewide

### Table 1. ICD-9-CM Codes of the Conditions, Diagnoses, and Procedures under Study

<table>
<thead>
<tr>
<th>Condition or Diagnosis</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cocaine abuse or dependence (unspecified, continuous, episodic, or in remission)</td>
<td>304.20–304.23, 305.60–305.63</td>
</tr>
<tr>
<td>Cardiomyopathy or peripartum cardiomyopathy</td>
<td>425, 674.5</td>
</tr>
<tr>
<td>Preeclampsia or eclampsia</td>
<td>642.4–642.7</td>
</tr>
<tr>
<td>Diabetes mellitus, or abnormal glucose tolerance of mother complicating pregnancy, childbirth or the puerperium complicating pregnancy, childbirth or the puerperium</td>
<td>250, 648.8</td>
</tr>
<tr>
<td>Supervision of high-risk pregnancy with insufficient prenatal care</td>
<td>V23.7</td>
</tr>
<tr>
<td>Overweight, obesity (unspecified), morbid obesity, or obesity complicating pregnancy, childbirth, or the puerperium</td>
<td>278.00–278.02, 649.1</td>
</tr>
<tr>
<td>Suicide and self-inflicted poisoning by analgesics, antipyretics, and antirheumatics</td>
<td>E950.0</td>
</tr>
<tr>
<td>Suicide and self-inflicted poisoning by other sedatives and hypnotics</td>
<td>E950.2</td>
</tr>
<tr>
<td>Tobacco use disorder, history of tobacco use, tobacco use disorder complicating pregnancy, childbirth, or the puerperium</td>
<td>305.1, 649.0, V15.82</td>
</tr>
<tr>
<td>Heart failure</td>
<td>428</td>
</tr>
<tr>
<td>Procedure</td>
<td></td>
</tr>
<tr>
<td>Insertion of non–drug-eluting or drug-eluting coronary artery stents(s)</td>
<td>36.06, 36.07</td>
</tr>
<tr>
<td>Percutaneous transluminal coronary angioplasty</td>
<td>0.66</td>
</tr>
<tr>
<td>Other removal of coronary artery obstruction/ coronary angioplasty not otherwise specified</td>
<td>36.09</td>
</tr>
<tr>
<td>Aortocoronary bypass, Abdominal-coronary artery bypass, or other bypass anastomosis for heart revascularization</td>
<td>36.10–36.19</td>
</tr>
<tr>
<td>Injection or infusion of thrombolytic agent</td>
<td>99.1</td>
</tr>
</tbody>
</table>

database who are infected with HIV and/or are drug users have their age classified in categories that are much broader (eg, age 18–44 years) than the remaining patients. Our study sample had 5 such patients. The age of these 5 patients was set to missing and the issue of missing data was addressed using multiple imputation.

Table 2. Clinical, Demographic, and Epidemiologic Characteristics of 103 Women Who Had an Acute Myocardial Infarction during Pregnancy or in the Peripartum Period and Were Hospitalized in Texas between 2004 and 2007

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
</tr>
<tr>
<td>≤24</td>
<td>12 (11.7)</td>
</tr>
<tr>
<td>25–29</td>
<td>14 (13.6)</td>
</tr>
<tr>
<td>30–34</td>
<td>33 (32.0)</td>
</tr>
<tr>
<td>35–39</td>
<td>24 (23.3)</td>
</tr>
<tr>
<td>40–44</td>
<td>12 (11.7)</td>
</tr>
<tr>
<td>45–49</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>50–54</td>
<td>2 (1.9)</td>
</tr>
<tr>
<td>Missing*</td>
<td>5 (4.9)</td>
</tr>
<tr>
<td>Race–ethnicity</td>
<td></td>
</tr>
<tr>
<td>Black non-Hispanic</td>
<td>21 (20.4)</td>
</tr>
<tr>
<td>White Hispanic</td>
<td>10 (9.7)</td>
</tr>
<tr>
<td>White non-Hispanic</td>
<td>29 (28.2)</td>
</tr>
<tr>
<td>Other (Asian, Native American, etc.)</td>
<td>42 (40.8)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (1.0)</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>41 (39.8)</td>
</tr>
<tr>
<td>Other (Medicare, commercial, etc.)</td>
<td>60 (58.3)</td>
</tr>
<tr>
<td>Missing</td>
<td>2 (1.9)</td>
</tr>
<tr>
<td>Obstetrical history and conditions</td>
<td></td>
</tr>
<tr>
<td>Cardiomyopathy/peripartum cardiomyopathy</td>
<td>17 (16.5)</td>
</tr>
<tr>
<td>Cesarean delivery</td>
<td>22 (21.4)</td>
</tr>
<tr>
<td>Diabetes/gestational diabetes</td>
<td>17 (16.5)</td>
</tr>
<tr>
<td>No prenatal care</td>
<td>2 (1.9)</td>
</tr>
<tr>
<td>Overweight or obese</td>
<td>8 (7.8)</td>
</tr>
<tr>
<td>Preeclampsia/eclampsia</td>
<td>14 (13.6)</td>
</tr>
<tr>
<td>Suicide or self-inflicted injury noted in current hospitalization</td>
<td>2* (1.9)</td>
</tr>
<tr>
<td>Social and behavioral factors</td>
<td></td>
</tr>
<tr>
<td>Cocaine user (current or former)</td>
<td>3 (2.9)</td>
</tr>
<tr>
<td>Tobacco use disorder, history of tobacco use</td>
<td>7 (6.8)</td>
</tr>
</tbody>
</table>

*Five patients were assigned to the broad age category of 18–44 years by the state health department (see Methods for details) and set to missing and then imputed.

†One of these patients died in the hospital.

Results

A total of 103 cases of pregnancy-related AMI were identified using Texas hospital inpatient data on women discharged during the years 2004 through 2007. The number of births in Texas during the same period was 1,573,740, resulting in an incidence estimate of 6.5 cases of AMI per 100,000 births.

Selected characteristics of the sample are reported in Table 2 (N = 103). Five patients had a missing value for age while 1 patient had a missing value for the race-ethnicity variable and 2 patients were missing information on health insurance status. The prevalence of diabetes was 16.5%. Approximately 14% of the patient records had ICD-9-CM codes indicating the presence of preeclampsia/eclampsia. Two of the 103 women were noted to have self-inflicted injuries.
The subendocardial region was the most common location of the AMI (Table 3). Approximately 15% of the cases experienced anterior wall infarctions. A significant proportion of the records (14.6%) contained a diagnosis code beginning with 410.9 which indicated an unspecified site of the AMI.

Coronary revascularization procedures as well as other in-hospital outcomes are noted in Table 4. Approximately 11% of the patients underwent coronary artery stenting. The hospital mortality rate was 9.7%.

Adjusted ORs for hospital mortality are presented in Table 5. The logistic regression model initially contained 13 predictors including cocaine use, coronary angioplasty, and stenting; however, the trace (time series) plots from the multiple imputation procedure indicated that convergence of the Markov chain was not likely (data not shown) and hence several predictor variables had to be removed from the model. The final model contained the following independent variables: age, race/ethnicity, Medicaid status, diabetes, preeclampsia/eclampsia, and hypertension. Trace and autocorrelation plots from the final model suggested that the Markov chain had converged. The adjusted OR for hospital death for women who were 35 to 39 years of age compared to women who were 30 to 34 years was 6.29 (95% CI, 0.84–46.96; \( P = .07 \)).

The length of stay ranged from 1 day to 72 days. PLOS was defined as a stay longer than the median length of stay of the sample (which was 4 days). Adjusted ORs for a PLOS are shown in Table 6. Hypertensive patients were over 5 times as likely to have a PLOS compared to normotensive patients (OR, 5.52; 95% CI, 1.17–25.89, \( P = .03 \)).

Discussion

Using a Texas hospital inpatient discharge data set, we identified cases of pregnancy-related AMI during a 4-year period. Our estimate of the incidence of pregnancy-related AMI, 6.5 per 100,000 births is similar to the frequency reported by James and colleagues, 6.2 per 100,000 deliveries.\(^1\) A strength of our study is the use of a statewide hospital discharge database obtained from the THCIC, rather than the use of data from a single institution or a limited geographical area. In 2007, quarterly figures indicated that, on average, 80% of the state licensed hospitals in Texas were required to report their data to the THCIC and, of this group, 99% did report (personal communication, THCIC staff, Austin, Texas).

We observed a hospital mortality of 9.7% while Ladner and colleagues reported an estimate of 7.3%.\(^2\) James and colleagues noted a case-fatality rate of 5.1% for women with pregnancy-related AMI.\(^1\) Neither of these 2 previous investigations cited suicide or attempted suicide as a possible risk factor for AMI. The records of 2 of the patients in our series had ICD-9-CM external (E) injury codes for self-inflicted poisoning by certain medications (Table 1, codes E950.0 and E950.2). One of these 2 patients died in the hospital and had a principal discharge diagnosis of a mental disorder.
Table 6. Adjusted* Odds Ratios for a Prolonged Length of Stay (>4 Days) from a Logistic Regression Model using Firth Bias Correction in 103 Women Who Had an Acute Myocardial Infarction during Pregnancy or in the Peripartum Period and Were Hospitalized in Texas between 2004 and 2007 (49 patients Had a Prolonged Length of Stay)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Demographic</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤24</td>
<td>1.01</td>
<td>0.19–5.34</td>
<td>.99</td>
</tr>
<tr>
<td>25–29</td>
<td>1.81</td>
<td>0.42–7.88</td>
<td>.43</td>
</tr>
<tr>
<td>30-34</td>
<td>1.00</td>
<td>(Referent)</td>
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</tr>
<tr>
<td>35–39</td>
<td>2.21</td>
<td>0.64–7.65</td>
<td>.21</td>
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<tr>
<td>≥40</td>
<td>0.87</td>
<td>0.20–3.81</td>
<td>.86</td>
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<tr>
<td><strong>Race–ethnicity</strong></td>
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<td></td>
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<tr>
<td>Black non-Hispanic</td>
<td>0.83</td>
<td>0.21–3.29</td>
<td>.79</td>
</tr>
<tr>
<td>White Hispanic</td>
<td>1.58</td>
<td>0.29–8.64</td>
<td>.6</td>
</tr>
<tr>
<td>White non-Hispanic</td>
<td>1.00</td>
<td>(Referent)</td>
<td>–</td>
</tr>
<tr>
<td>Other (Asian, Native American, etc)</td>
<td>2.00</td>
<td>0.63–6.32</td>
<td>.24</td>
</tr>
<tr>
<td>Medicaid (vs other payer or no payer)</td>
<td>0.56</td>
<td>0.19–1.66</td>
<td>.3</td>
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<tr>
<td><strong>Clinical</strong></td>
<td></td>
<td></td>
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<tr>
<td>Preeclampsia/eclampsia (present vs absent)</td>
<td>3.84</td>
<td>0.92–15.99</td>
<td>.06</td>
</tr>
<tr>
<td>Underwent bypass anastomosis for heart revascularization (yes vs no)</td>
<td>21.54</td>
<td>0.92–504.85</td>
<td>.06</td>
</tr>
<tr>
<td>Diabetes (present vs absent)</td>
<td>1.12</td>
<td>0.27–4.69</td>
<td>.88</td>
</tr>
<tr>
<td>Hypertension (present vs absent)</td>
<td>5.52</td>
<td>1.17–25.89</td>
<td>.03</td>
</tr>
</tbody>
</table>

Multiple imputation was used to address missing covariate values.
*Each odds ratio is adjusted for the remaining variables in the table.

complicating pregnancy, childbirth, or the puerperium classifiable to opioid abuse. The second patient did not die in the hospital and had a principal discharge diagnosis of poisoning by a sedative or hypnotic. Both of these patients had a secondary discharge diagnosis code indicating the occurrence of a spontaneous abortion. Future analyses of statewide data sets or registries should include a search for diagnosis codes indicating the presence of concomitant mental illness and/or a recent history of injury when investigating pregnancy-related AMI.

Approximately 60% of the patient records in our sample contained an ICD-9 discharge diagnosis code beginning with 410.7, subendocardial infarction (Table 3). Subendocardial infarction in current clinical nomenclature is referred to as a non-ST segment elevation myocardial infarction (NSTEMI).9 ICD-9 codes for AMI that do not begin with 410.7 or 410.9 (unspecified site) identify patients with ST elevation myocardial infarction (STEMI).9 It has been reported that the ratio of the number of NSTEMI cases to STEMI cases is at least 2 to 1.9 We note a similar NSTEMI:STEMI ratio in our series of patients after excluding the 15 cases who had an unknown myocardial infarction type (code 410.9): 62/26 = 2.4 to 1 (Table 3). From a clinical perspective, NSTEMI tends to be less severe than STEMI.10 While the management of patients with STEMI includes invasive procedures such as angioplasty, the standard of care for NSTEMI is medical management with antiplatelet and anticoagulant medications.9

Hospital discharge data sets may suffer from miscoding. Fisher and colleagues studied the accuracy of Medicare hospital claims data.11 They analyzed data from the 1985 National Diagnosis Related Group Validation Study, which reabstracted and reassigned ICD-9-CM diagnosis and procedure codes from a US national sample of 7,050 medical records. The ICD-9-CM coding of AMI was found to be accurate with a sensitivity of 90% and positive predictive value of 87% when code 410 was found in any of the patient’s discharge diagnosis fields. The sensitivity increased to 94% and the positive predictive value increased to 92% when code 410 was in the principal discharge diagnosis field.

Kiyota and colleagues examined the accuracy of discharge diagnosis codes and diagnosis related groups for AMI in a sample of individuals who were Medicare beneficiaries in Pennsylvania in the years 1999 or 2000 or both.12 Hospital records were reviewed by trained abstractors who used World Health Organization criteria for diagnosing AMI. The authors found a positive predictive value for a primary Medicare claims-based definition of 94.1% (95% CI, 93.0%–95.2%).

Our investigation has several limitations. The Public Use Data File does not contain a unique patient identifier
and hence we were unable to determine if a patient was hospitalized more than once during her pregnancy or the postpartum period with a discharge diagnosis of AMI. Nonetheless, the majority of the patients (98 of the 103 cases) had an ICD-9-CM AMI code that ended in the fifth digit of 1 which indicates an initial episode of care. The fifth-digit of 1 is used regardless of the number of times a patient may be transferred during the initial episode of care. Eight (7.8%) of the cases in our sample were discharged to another short-term general hospital.

Another limitation of our study was the inability to link the mother’s discharge record with her infant’s record. The linkage of maternal and infant hospital discharge summaries and further linkage with birth certificate data would allow for richer analyses. However, the standard data use agreement offered by the THCIC prohibits the user from linking the Texas Public Use Data File with personally identifiable records from any other source.

References

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How We Organized a Regional Meeting: Cancer Registrars Association of Central Ohio and Michigan Cancer Registrars Association

Gretchen Booth, BS, CTR

Abstract: Due to the cost of sending staff to a national meeting, it is sometimes difficult for hospitals to fulfill Cancer Program Standard 1.11 if they desire a commendation. The Cancer Registrars Association of Central Ohio teamed up with the Michigan Cancer Registrars Association to organize a regional meeting. The goal for the planning committee was to keep costs to a minimum. The meeting was a success with nearly 190 attendees from 5 states.

Key words: cancer registrar education, commendation, regional meeting

Introduction

Standard 1.11 of the Cancer Program Standards states: “Each year, all members of the cancer registry staff participate in 1 cancer-related educational activity other than cancer conferences.” For commendation, “All CTR staff attend a national or regional cancer-related meeting once during the 3-year survey cycle.”

Methods

In these days of cutbacks, hospitals are looking for inexpensive methods of educating their staff. Sending all cancer registry staff members to a national meeting is very expensive when totaling airfare, hotel and registration fees. A less expensive solution for a commendation is participating in a regional meeting.

In 2012, the Cancer Registrars Association of Central Ohio (CRACO) was working on a spring workshop to offer to registrars in Ohio. In a brainstorming session, the organization discussed having a regional meeting to fulfill the commendation for Standard 1.11.

The group had the idea to extend an invitation to the Michigan Cancer Registrars Association (MiCRA) to participate in the planning process. The definition, according to the standards, for a regional meeting is it “involves more than one state organization working collaboratively to develop the workshop. Agendas and meeting notices indicate the collaborative effort (regional activity).” We verified the definition with the Commission on Cancer to assure we were correctly interpreting the standard. MiCRA board members agreed to participate in the planning process with us. We had several telephone meetings with MiCRA to plan the meeting and divided the planning duties among members of both organizations.

Since we were inviting registrars from multiple states, the planning members decided to hire a national speaker. We invited April Fritz to speak, as she is knowledgeable and a popular speaker. At the Ohio Cancer Registrars Association (OCRA) annual meetings, participants comment that they want topics that would aid the registrars in their daily work. April had ideas for topics on her website and the planning members also brainstormed for possible topics. The decision was made for discussions regarding coding issues for surgery, radiation, grading, complex morphologies, and collaborative staging. We also had a 45-minute question and answer session where questions were submitted ahead of time and forwarded to April.

Discussion was held regarding what time of year was best to hold the event. Since we were asking registrars from various states, weather was a factor in planning the date. Also, we did not want to interfere with those attending any other meetings. The decision was made to hold the event in the month of April as a 1-day session. The meeting would end mid-afternoon to avoid rush hour and facilitate the drive home.

As for location, we decided a city centrally located would be easiest. We also needed a facility that could hold up to 200 people. We chose Mount Carmel Health Center East in Columbus, Ohio, as Columbus is in the middle of Ohio and most convenient for all the states that were invited. Mount Carmel is also conveniently located near the freeway for easy access.

Discussion was held whether we should record and/or videoconference the event. It was proposed that cancer registry staff members could view the DVD or watch via videoconference to obtain credit. The group decided that it would be too difficult to control the location of DVDs and the number of staff viewing it, whether by DVD or videoconference. We made the decision that staff members would need to attend the session in person in order to obtain continuing education credit for the regional meeting.

As for registration, the planning members wanted the registration fee to be minimal so that attending the meeting was more affordable. The fact that it was a 1-day meeting kept hotel costs low, even though some attendees did stay the night before if they had a long drive. We calculated all costs that would be accrued (food, travel costs for the
speaker, and supplies). We provided a continental breakfast and box lunch. In addition, we emailed the handouts to attendees to avoid any printing costs.

For publicity, we sent invitations to the presidents of the cancer registry organizations of the neighboring states of Pennsylvania, Kentucky, and Indiana. We also publicized the event on the National Cancer Registrars Association (NCRA), Ohio Health Information Management Association, and OCRA websites. Attendees accrued 6 continuing education credits approved by NCRA.

Results
The response was overwhelming. We had 189 attendees from Ohio, Michigan, Pennsylvania, Indiana, and Kentucky. We provided evaluation forms and the comments were overwhelmingly positive. The speaker and topics, facility, and location worked together to make for a great meeting. Of course, there were problems typical of a large meeting (eg, parking, room temperature, someone didn’t like the food).

Discussion
Due to the overwhelming success of the regional meeting planned by CRACO and MiCRA, the decision was made by the planning committee to hold another regional meeting in April 2015. We will be holding the meeting in Michigan for ease of travel for the Michigan members. Members are currently in the planning process. The meeting will be held in Livonia, Michigan.

Reference
Special Feature

Raising the Bar: Never High-Five a Porcupine

Michele Webb, CTR

Porcupine sightings in Central California are somewhat rare these days, but recently while travelling through a rural part of the valley I came upon a porcupine slowly waddling across a country road. He did not seem to be too concerned that I was rocketing down the rough and bumpy road at high speed or that he was directly in my path. It seemed to me, as I practiced my sudden stop maneuver, that he rather enjoyed taking a break while he watched me bring my vehicle to a shuddering stop. After a few moments of mutual admiration, he slowly made his way over to the shoulder of the road and climbed up an almond tree that was in full bloom in the orchard that bordered the road. He made it about halfway up the tree where he settled down onto a large branch and began munching away on the blossoms.

After I returned home, I was curious about the type of porcupine I had seen and their prevalence in the Central California valley so I went online and researched the prickly facts and fiction. I found some interesting information about my pointy road buddy that parallels our work as cancer registrars.

Here are 4 facts about porcupines:

1. Porcupine quills are premedicated.

Porcupines are solitary creatures and there is no really no one for them to chat with. When they do communicate, it is usually with a lot of loud squabbling. Some wild porcupines will use teeth clacking to warn predators, while others will use a rhythmic singing to put their babies to sleep. Male porcupines may use a high-pitched, angry howl to send other males away.

All cancer registrars have encountered individuals who are poor communicators. And some may have encountered folks who shriek, howl, or squabble! But, before you start pointing at others, be honest and do a self-check. Have you ever used one or more of these tactics?

All health care professionals must be effective communicators. Do not let your emotions, shyness, a preference for working alone, or negative thoughts such as “I am not good at talking,” or “Why can’t they do that themselves?” keep you from doing your work or being your best self. We should not resort to destructive behaviors that do not offer positive solutions and outcomes. Look for learning and growth opportunities in personal communications. Practice

2. Porcupine munchies trigger growth.

Some porcupines are lightweight animals with big appetites. They can strip a tree of its fruit and seeds very quickly. Some tropical trees defend themselves against this type of predator by flowering and fruiting in one big burst. Fortunately, even the most voracious vegetarians are not able to eat all the flora, so some seeds escape and germinate. Because different trees flower at different times, the porcupine can always find a food source.

Without too much effort, you may be able to think of 1 or 2 predators you have come into contact in the past few years. Human predators can strip another individual of his or her ability to be productive and grow just as easily as a porcupine strips a fruit tree. Just keep in mind that no single individual can possibly destroy everyone or everything in its path. Choose to be the survivor!

Find creative ways in which to protect yourself to prevent total destruction. Encourage growth, creativity, and practical, commonsense management of all problems. Never let another person destroy you, or a member of your work or personal family. Look for the hidden gems in the bad situations and find ways to continually grow new skills and capabilities.

3. Porcupines are horrible at conversation.

The quills of the North American porcupine have a topical antibiotic on them, so even though getting stuck is painful, it will not cause an infection. Bear in mind that the porcupines do not medicate their quills as a courtesy to those they come in contact with. Rather, it is a defense against self-quilling or those pesky selfie-sticks that can happen if they tumble out of a tree or are bounced off the road by moving vehicle.

Cancer registrars are familiar with situations where self-defense is necessary. We frequently come into contact with patients, family members, health care providers, or even our own weary peers or office staff. It is inevitable that we will take a tumble here or there and fall on our own quills. By premedicating our quills, so to speak, by taking advantage of frequent and routine training in all areas of our profession such as scientific, clinical, informatics, and professional development, we can turn those ugly selfie-sticks into positive, collaborative experiences.

One author said this so well, “If you prepare for the worst but hope for the best, you will rarely be disappointed.”
new and creative ways to talk about our work and about the patients from whom we gather data in order to illustrate the value and importance of our work.

4. Porcupines are odiferous.

When a porcupine is threatened, it uses an olfactory signal to tell the potential predator that it has raised its quills and is not afraid to use them. This pungent odor is unique to porcupines and has been categorized as “indescribable.”

We all want to be recognized for our uniqueness, and many would consider being called “indescribable” a compliment. But consider this: when was the last time you raised your quills and were ready to use them? When we are criticized or challenged, it is easy to signal others by raising our quills or sending some sort of signal (perhaps even a stinky one) that we are getting ready to launch a defense or attack. For the most part, this type of behavior only serves to irritate others and detract from our work. Learn how to deal with prickly situations without unleashing a stinky response on those around you.

You may think that comparing people to porcupines is silly or perhaps even unprofessional. But is it really? Every day that we drive the freeways to work and back, walk the hallways of our organizations, stop by the local grocery store, or take your children to or from school or sporting events, we encounter people who have porcupine-like characteristics. Often the only difference between a 4-legged pointy critter and a human is its species. Behaviors may be identical.

Take a few minutes and reflect on the past 30 days. At any time, did you exhibit the same behaviors as a porcupine? If you did, then consider the circumstances and situation behind the behavior. Identify an alternative response that you could have given to get to the desired result. Replaying the negative situation over and over in your mind will only bring about more negative behavior. Instead, envision how you would have responded in a positive manner. Practice telling yourself that you are willing and capable of doing better. It is only through practice that our behaviors can change. Your positive interactions will assure others, through your verbal, nonverbal, and physical signals, that you are a member of the health care team that can be trusted to deliver value in the middle of a storm or in any situation.

In summary, before you high-five a porcupine, look to see if he or she is poised to deliver a stinky, painful slap to your hand. Neutralize people and situations that challenge you with calm, rational behavior. Before long, you will have them eating out of your hand instead of sending you off in search of a pair of pliers to start yanking out those painful quills.

The North American Association of Central Cancer Registries (NAACCR) edits metafile, NAACCR v15_Beta (version 15), was posted in January and can be downloaded from the NAACCR website. This is a beta test release of the v15 metafile and provides registrars and software vendors a chance to test the edits on converted data. The final, or production, version is expected to have been released by the time of this publication. Edits are based on updated standards in the NAACCR Standards for Cancer Registries, Volume II, Data Standards and Data Dictionary, Nineteenth Edition, Record Layout Version 15 and the Hematopoietic and Lymphoid Coding Manual and Database. Many edits have been added or modified to support requirements for American Joint Committee on Cancer (AJCC)-TNM staging for cases diagnosed 2015 and later. Collaborative Stage, Version 02.05 remains in use for 2015 cases. To download metafiles, go to http://www.naaccr.org/StandardsandRegistryOperations/VolumeIV.aspx. In addition to the metafile, a spreadsheet listing the changes, Edit Detail Report (PDF file with descriptions of all edits), and a spreadsheet of edits included in each edit set are available for download.

Because some new/revised edits could impact old cases, it is recommended that a registry run the edits on existing cases as well as new incoming abstracts. If any of the new or changed edits generate a large number of errors, please notify your software vendor and ask them to notify the NAACCR Edits Metafile Administrator or notify NAACCR.

**Highlights of Edit Changes**

**Edit Name: Histology ICDO3, Grade, Date of DX (SEER)**
- Histology code 9714 must be coded to grade 5 or 6 for diagnosis years 2010 and later
- Histology codes 9659, 9761, 9826 must be coded to grade 6 for diagnosis years 2010 and later
- Histology codes 9670, 9728, 9805, and 9836 removed; obsolete codes
- Histology code 9756 must be coded to grade 9 for diagnosis years 2010 and later
- Added list of histologies for which grade must not be 1–4

**Edit Name: Obsolete Histology ICDO3, Date of DX (SEER)**
- Histology code 8157 is obsolete for all years and should be replaced by 8152
- Histology code 9752 added as obsolete
- Added column of current codes to be used in place of the obsolete codes

**Hematopoietic Conversions for 2015**

As part of the Hematopoietic and Lymphoid project update for 2015, a conversion program has been written to convert some of the Hematopoietic data. Two documents have been posted on the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute website, http://seer.cancer.gov/tools/heme/conversions.html, that outline the specifics and rationale for these conversions. The Hematopoietic Conversion Document provides details and rationale for the changes. The companion spreadsheet shows what the computer conversion will do.
- Obsolete histologies will be converted to current histologies
- When needed, grade will be reassigned to histologies that don’t agree with the grade instructions in the Hematopoietic Manual & Databases
- When needed, primary site will be reassigned to histologies that don’t agree with the primary site instructions in the Hematopoietic Manual & Database

**Primary Site, Heme Morph, DateDX, Override (SEER)**

This edit validates the coding of primary site by histology based on the Hematopoietic and Lymphoid Neoplasm Coding Manual and Database. For cases diagnosed 2010 and later, specific histology codes are allowed only for specified sites. An over-ride flag can be set for the histology/primary site combinations included in this edit after review of supporting documentation confirms that the coded site is correct.
Prostate Grade Conversion

Coding instructions for Grade [440] were modified for cases diagnosed in 2014 and later. Under those instructions, and according to an edit added to the v15 metafile, the Grade code for prostate cancers should be consistent with the codes for Gleason score as coded in Collaborative Stage (CS) site-specific factors 8 and 10. A conversion has been implemented to save registries the task of correcting grade errors manually. The conversion for prostate grade applies only to cases meeting the CS schema definition of prostate and diagnosed in 2014 and later.

<table>
<thead>
<tr>
<th>Histology</th>
<th>“Preferred” Primary Sites</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hodgkin lymphomas (9650, 9651, 9652, 9653, 9655, 9659, 9663)</td>
<td>Lymph nodes (C770–C779)</td>
</tr>
<tr>
<td>T-cell rich histiocyte lymphoma (9688)</td>
<td>Lymph nodes (C770–C779)</td>
</tr>
<tr>
<td>Cutaneous lymphomas (9597, 9700, 9701, 9709, 9718, 9725)</td>
<td>Skin (C440–C449, C510–C512, C518–C519, C600–C602, C608–C609, C632)</td>
</tr>
<tr>
<td>Cutaneous, subcutaneous lymphomas (9708, 9726)</td>
<td>Skin and soft tissue (C440–C449, C490–C499, C510–C512, C518–C519, C600–C602, C608–C609, C632)</td>
</tr>
<tr>
<td>Extranodal T-cell lymphoma, nasal-type</td>
<td>Primarily in the aerodigestive (C050–C059, C110–C119, C300–C301, C310–C319)</td>
</tr>
<tr>
<td>Langerhans (9751)</td>
<td>Lungs, bones, bone marrow, skin, lymph nodes (C340–C349, C400–C419, C421, C440–C449, C770–C779)</td>
</tr>
</tbody>
</table>

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Established by Congress through the Cancer Registries Amendment Act in 1992, and administered by the Centers for Disease Control and Prevention (CDC), the National Program of Cancer Registries (NPCR) collects data on cancer occurrence (including the type, extent, and location of the cancer) and the type of initial treatment.

Before NPCR was established, 10 states had no registry, and most states with registries lacked the resources and legislative support they needed to gather complete data. Today, through NPCR, CDC supports central cancer registries in 45 states, the District of Columbia, Puerto Rico, and the US Pacific Island Jurisdictions. These data represent 96% of the US population.

Together, CDC’s NPCR and the National Cancer Institute’s (NCI’s) Surveillance, Epidemiology and End Results (SEER) Program collect data for the entire US population. This national coverage enables researchers, clinicians, policy makers, public health professionals, and members of the public to monitor the burden of cancer, evaluate the success of programs, and identify additional needs for cancer prevention and control efforts at national, state, and more local levels.

Medical facilities such as hospitals, doctor’s offices, and pathology laboratories send information about cancer cases to their cancer registries. Most information comes from hospitals, where highly trained cancer registrars transfer the information from the patient’s medical record to the registry’s computer software using standardized codes. The data are then sent to the central cancer registry.

Every year, the central cancer registries electronically submit incidence, demographic, and clinical data to NPCR or SEER. None of the information submitted to CDC contains identifying information about individual patients. The cancer registry data are used to monitor cancer trends over time; show cancer patterns in various populations; identify high-risk groups; guide planning and evaluation of cancer control programs; help set priorities for allocating health resources; and advance clinical, epidemiologic, and health services research.

The following NPCR case studies highlight how the data are used to inform public health programs and initiatives. Visit the website at http://www.cdc.gov/cancer/npcr/success/index.htm to read more case studies on important data-driven projects happening across the United States.
Public Health Problem
Reporting of melanoma skin cancer has been underreported by physicians, affecting accurate recording of incidence rates in Arizona.

Use of Surveillance
Prior to 2003, the Arizona Cancer Registry data showed melanoma incidence in Arizona was on a steady trend upward. And, in 2003, Arizona melanoma rates were above the US national average. However, in more recent years, Arizona melanoma incidence has been declining and dropping below the national average. Figure 1 compares Arizona to the rest of the US. It was suspected that underreporting of melanoma incidence might be the cause for the decline.

Collaboration
Starting in 2011, a group that included the Arizona Cancer Registry, community dermatologists, and dermatopathologists from the Tucson and Phoenix Dermatology Societies, and the Arizona Skin Cancer Institute at the Arizona Cancer Center, formed to determine whether the decrease in Arizona melanoma incidence rates was real or due to underreported cases. Known as the Arizona Melanoma Task Force (AMTF), this group conducted a pilot study that reviewed 15 dermatology practices in the Phoenix and Tucson areas. The AMTF’s review showed that 72% of the study cases examined in these practices were not reported to the Arizona Cancer Registry.

The AMTF continued to identify barriers and develop strategies to improve melanoma reporting by physicians in Arizona. Since the original pilot study was performed, several critical ongoing activities have been conducted by the task force:
- Statewide survey of dermatology practices regarding cancer reporting
- Educational presentations at society meetings
- Assessment of the root causes of underreporting
- Revision of the physician reporting form for melanoma cases
- Letters distributed to physicians through the societies regarding the importance of reporting
- Physician email distribution list obtained for direct communication
- Development of a melanoma report
- Ongoing monthly teleconferences

Public Health Outcome
Figure 2 shows the number of melanoma cases reported to the Arizona Cancer Registry by physicians from 2006–2013. The increase in the 2009 diagnosis year is a result of the pilot study done in 2011–2012 that reviewed all melanoma cases from just 15 dermatology practices in the Phoenix and Tucson areas. An additional 349 new cases (or 33% of all 2009 case reports) were received from physician offices as a result of the study of 15 practices. Furthermore, the registry has seen an increase in newly reported cases by physicians for the 2011–2012 diagnosis year. This shows an increased awareness of reporting requirements due to the leadership of the AMTF.

Figure 2. Physician Case Reports*, Invasive and In Situ Melanoma Cases, Arizona Resident Diagnosis Years 2006–2013

*Physician case reports are cases reported by a physician. More than 1 case report may be received for each new melanoma case.
**2011, 2012, and 2013 physician-reported cases are preliminary.
Figure 3 demonstrates the important role physicians play in reporting melanoma to the Arizona Cancer Registry. Prior to the pilot study, most melanoma case reports to the Arizona Cancer Registry were received from reporting sources other than physicians. The 2009 diagnosis year shows the initial increase in physician reported cases due to reporting generated from the pilot study. In the 2011 diagnosis year, there is a transition to more melanoma cases reported by physicians than from other sources. Reports from physicians are crucial for accurately tracking melanoma in Arizona.

As AMTF leader Dr. Nancy Silvis stated in a letter to physicians receiving its report, “It has been exciting to see the community of dermatologists and dermatopathologists respond to this public health issue. With your continued efforts, we anticipate even further improvement in accurately determining Arizona’s burden of melanoma.”

Figure 4 shows that with the implementation of the Arizona Melanoma Task Force initiatives, the melanoma age-adjusted rate in 2011 increased 13% over the melanoma age-adjusted rate in 2008; this rate is projected to increase based on preliminary data collection.
Cancer Data Registry of Idaho: Using Area-Based Measures to Target Disparities and Guide Policy Initiatives

Public Health Problem
While social determinants have a great impact on health, population-based cancer registries, including the Cancer Data Registry of Idaho (CDRI), do not collect individual-level socioeconomic status (SES) data for cancer patients. An overarching goal of Healthy People 2020 is to “achieve health equity, eliminate disparities, and improve the health of all groups.” By geocoding cancer registry data and using area-based socioeconomic measures, it is possible for registries to calculate incidence rates and other measures of cancer burden by area-based SES, and quantify disparities. Cancer registries can use this information to help guide policy initiatives and measure progress towards eliminating disparities.

Use of Surveillance
In April 2014, the Comprehensive Cancer Alliance for Idaho (CCAI) convened a meeting of key stakeholders to develop a cancer policy action agenda. Based on burden measures and the ability to address specific cancers through policy interventions, the CCAI board of directors identified 4 areas for detailed analysis: tobacco-related cancers, colorectal cancer, breast cancer, and melanoma. Using data for 2007–2011 and methods derived from the Public Health Geocoding Project, CDRI presented cancer incidence rates stratified by area-based SES.

CDRI showed that colorectal and lung cancer incidence rates were significantly higher in the census tracts with a higher proportion of uninsured. Colorectal cancer incidence was also significantly higher in the census tracts with a higher proportion of persons with incomes below federal poverty guidelines, and 5-year relative survival from colorectal cancer was significantly lower among persons living in high poverty areas. For breast cancer and melanoma of the skin, the direction of the area-based SES gradients in incidence was reversed.

Collaboration
Participants of the Idaho Cancer Policy Action Agenda Meeting included oncologists; directors of cancer treatment facilities and other health care delivery systems; insurance company executives; public health officials; experts in health care quality improvement; representatives from the American Cancer Society (ACS), ACS Cancer Action Network, and other cancer-affiliated groups (eg, Komen, Leukemia and Lymphoma Society); a state legislator; and cancer survivors. The charge to the meeting participants was delivered by the director of research for the largest cancer treatment center in Idaho, and the meeting was professionally facilitated to arrive at consensus around policy approaches to critical issues in Idaho.

Public Health Outcome
The facilitated process used the CDRI data presentation to guide directions for policy initiatives. The presentation created supporting evidence that CCAI could make an impact in Idaho by targeting specific health disparities. Three focal areas were selected for pursuing policy initiatives: decreasing the numbers of uninsured in Idaho through Medicaid redesign or other means, supporting proposed legislation to restrict tanning bed access among minors, and addressing parity in coverage for oral cancer drugs. Strategies for furthering these policy initiatives are being developed now, and CDRI data will be used for messaging.

Lessons Learned
The methods used to measure disparities via area-based SES are technical, and these details can overwhelm the message from the analysis. It may also be challenging to explain that these are ecologic analyses, and that there may be additional mediator variables (such as smoking in the causal chain between low SES and higher rates of lung cancer). Nonetheless, it is important to understand the characteristics of those most at risk in order to tailor interventions.

References
Nebraska Cancer Registry: Using a Linked Cancer Registry-Hospital Discharge Database for Treatment-Related Research

Public Health Problem
Like cancer registries in other states, the Nebraska Cancer Registry (NCR) uses its data primarily for the calculation and analysis of incidence rates and incidence-related statistics. Although treatment information is also collected by the NCR, treatment-related research questions have rarely been addressed using registry data. During the past year, however, an opportunity arose for the NCR to collaborate on an investigation that focused on the surgical treatment of colon cancer patients. Specifically, the research question of interest was: are there any differences in the demographic and clinical characteristics, and outcomes of colon cancer patients treated with the recently-introduced laparoscopic colectomy procedure compared to those treated with the traditional open colectomy method?

Use of Surveillance
Since the treatment data collected by the registry are not specific enough to identify colon cancer patients by the type of surgery that they have received, surgically-treated cases were first identified in the state inpatient hospital discharge database using International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) procedure codes. These discharges were then linked with colon cancer cases reported to the NCR. This linked database included 1,062 colon cancer cases diagnosed between 2008 and 2011; 302 (28.4%) were treated with laparoscopic colectomy and 760 (71.6%) were treated with open colectomy. More than 80 variables were selected from the cancer registry and the hospital discharge databases for inclusion in the linked database.

Collaboration
This research was conducted as part of a capstone project by an epidemiology graduate student at the University of Nebraska Medical Center-College of Public Health (UNMC-CPH). Collaborators in the design and analysis of the study included the NCR, UNMC-CPH, and the Nebraska Cancer Coalition. The NCR itself is a collaborative operation: data collection and editing are handled by the Nebraska Methodist Hospital of Omaha, while data analysis and overall registry management are the responsibility of the Nebraska Department of Health and Human Services.

Public Health Outcome
Analysis of the linked database showed that colon cancer patients treated with laparoscopic colectomy were significantly younger (mean 67.8 vs 70.4 years) than those treated with open colectomy, and that residents of urban areas were more likely to have had the laparoscopic procedure than were rural residents. Laparoscopically-treated patients were also significantly more likely to have been diagnosed at an early stage (in situ or local) than open colectomy patients (54.0% vs 41.2%), and to have significantly smaller tumors. A logistic regression model included all of these factors as significant predictors of treatment type. Laparoscopic surgical treatment also resulted in significantly shorter length of hospital stay (mean 6.0 vs 8.5 days) and lower total hospital charges (mean $45,888 vs $55,132) compared to treatment with open colectomy, although the difference in total hospital charges disappeared entirely when the median values were examined.

Lessons Learned
With effective collaboration, opportunities do exist for state cancer registries to do more than calculate incidence statistics. This research also demonstrates how a linkage with hospital discharge data can expand the analytical capabilities of cancer registry data specific to treatment.
New Jersey State Cancer Registry: Implementing CDC’s Registry Plus™ Web Plus for Ambulatory Centers and Physicians’ Offices

Special Feature

Operational Challenge
In 2011, New Jersey State Cancer Registry (NJSCR) staff manually entered incidence data for over 7,000 paper-based reports. At this same time, the NJSCR experienced a significant staffing reduction, thus limiting human resources to perform this task. To maximize production and increase efficiency in handling cases, the NJSCR needed to provide an electronic reporting method for physicians’ offices, radiation centers, surgery centers, and ambulatory centers, promoting case reporting in a paperless format.

Intervention
The NJSCR worked collaboratively with bioinformatics experts at the Rutgers Cancer Institute of New Jersey to conduct a needs assessment with NJSCR staff and nonhospital reporters. After speaking with other registries, the Centers for Disease Control and Prevention’s Registry Plus™ Web Plus reporting tool was identified as the optimal software to use for electronic reporting by ambulatory facilities and physician offices. Key factors that were considered included Web Plus’s ability to enable facilities to submit standardized data securely via the internet. NJSCR also developed and implemented an onboarding process that included remote support, screens tailored to the individual needs of each type of reporting facility, and a customized instructional manual that was designed in-house to ensure continuity and efficiency in the implementation process across facilities.

Collaborations
NJSCR staff (past and present) were vital to the success of this project: Jamal Johnson, CTR; Henry Lewis; Karen Robinson, CTR (formerly of NJSCR); John Kerrigan, Director; Anasuya Shukla, Senior Database Architect; and Michael Tumblety, Content Specialist, at the Rutgers Cancer Institute of New Jersey, Biomedical Informatics Core; for their invaluable guidance, expertise, and commitment to the successful implementation of Web Plus. The NJSCR is a participant in the Centers for Disease Control and Prevention’s National Program of Cancer Registries (NPCR) and is a National Cancer Institute Surveillance, Epidemiology, and End Results Program (SEER) Expansion Registry.

Operational Impact
Each facility reporting electronically through Web Plus eliminates the need for manual entry; promotes environmental sustainability by reducing paper; cuts costs for postage, fax or scanning supplies; and, most importantly, improves the timeliness of case reports entering the workflow. This project continues to grow as more facilities are being added every month. NJSCR currently has 51 users in 31 facilities, and has exported 365 cases from ambulatory surgery centers and physician offices since October 2013; and, currently has 273 exported cases from radiation facilities since January 2014.

Lessons Learned
During this process, NJSCR staff learned about the burgeoning informatics and information systems industry. Our migration from paper-based ambulatory and physician reporting to electronic, Web-based reporting systems coupled with our transition from the Rocky Mountain Cancer Data System (RMCDS) to the National Cancer Institute’s SEER*DMS system facilitated a powerful paradigm shift in the cancer surveillance operations to enhance electronic reporting of more than 53,000 new cases of cancer and more than 100,000 records reported to the NJSCR.

The NJSCR also learned that outreach to facilities will be the key to ensuring the uptake of electronic reporting. As a result, we set up a link on the NJSCR website to enable physicians to register for access and onboarding for Web Plus (www.state.nj.us/health/ces/webplus.shtml).

We have further identified more than 200 more facilities to target outreach efforts, acknowledging that there will be a few facilities that will be unable to send electronic data due to the lack of computers or Internet access.
Special Feature

Washington State Cancer Registry: Using Cancer Registry Data to Identify Disparities in Late-Stage Female Breast Cancers

Public Health Problem

Breast cancer is the most frequently diagnosed cancer, and the second leading cause of cancer death among Washington State (WA) women. In its 2011 Community Profile Report, the Puget Sound affiliate of the Susan G. Komen Foundation (PS Komen) WA revealed that nationally, WA ranked twelfth highest in female breast cancer incidence and 35th highest in breast cancer mortality. They found that disparities were leading to higher rates of late stage breast cancer among specific groups of women.

Use of Surveillance Data

The PS Komen prepares a Community Profile Report every 3 to 5 years. These reports rely on qualitative data gathered from community input. They also depend upon quantitative data from the Washington State Cancer Registry (WSCR), and the Cancer Surveillance System (CSS)—the Surveillance, Epidemiology and End Results (SEER) central registry at the Fred Hutchinson Cancer Research Center. The CSS provided female breast cancer incidence and survival rates for 13 of the 16 counties serviced by the PS Komen. WSCR provided female breast cancer incidence data for the remaining 3 counties.

PS Komen identified that a greater proportion of late stage breast cancer cases occur in specific geographic and racial–ethnic communities in the 16 counties they serve. Specifically Lewis and Pacific counties were highest at 32 percent. The highest rates among racial–ethnic groups were African American (37.4%), Hispanic white (35.7%), and American Indian/Alaska native (32.5%) women. They believed this was occurring in low income women due to low participation in breast cancer screening, and poor access to breast cancer screening, information resources and/or care.

Collaboration

Puget Sound Affiliate of Susan G. Komen: Used WSCR data to prepare its Community Profile report. These reports profile the female breast cancer burden and disparities in their 16-county service area in northwest Washington State.

Washington State Cancer Registry (WSCR): Provided data on female breast cancer incidence for the 3 counties that are part of the local Komen Foundation service area, but outside the Puget Sound/SEER data capture area.

Fred Hutchinson/Cancer Surveillance System (SEER): Provided data on female breast cancer incidence and survival rates in the 13 counties that are part of the Washington State Komen Foundation affiliate service area.

Public Health Outcome

Based on their analysis, PS Komen distributed more than $6.6 million to reduce the number of late stage breast cancer cases in the priority communities. The funds were used to support breast cancer screening, education, and patient navigation services. There appears to be a noticeable, if not statistically significant, reduction in late stage breast cancers. Additional improvements have been noted in survival rates among breast cancer patients in these priority counties and communities.

Lessons Learned

- Cancer registry data can help organizations to identify and address cancer-related disparities in specific communities.
- Cancer data can help communities and organizations to secure and distribute scarce funds in ways that achieve maximum impact.
- Partnerships draw on the diverse strengths of its members and increase the positive impact on public health.
Special Compilation of Collaborative Stage Data Collection System Coding Instructions
(For 2015 CTR Exam Candidates Only)
NCRA has compiled the specific sites of the Collaborative Stage Data Collection System Coding Instructions to be used during the open-book portion of the exam. This easy-to-use special edition includes the five specific sites: bladder, breast, colon, lung, and prostate. NCRA member price: $50; non-member price: $75.

NCRA revised its popular study guide for the 2015 exam. There are five new case studies that include answers with rationales. Companion CD contains additional study resources. NCRA member price: $85; non-member price: $105.

CTR Exam Prep Online Workshop
NCRA has created a CTR Exam Prep Online Workshop consisting of nine, 90-minute live webinars on critical exam topics. Workshop member price: $365; non-member price: $485: Individual webinars can be purchased separately. Member price: $45; non-member price: $60.

Go to www.ncra-usa.org/CTRPrep to learn more and order!
Continuing Education Quiz—SPRING 2015

DIABETES REGISTRIES IN PATIENT-CENTERED MEDICAL HOMES

Quiz Instructions: The multiple choice or true/false quiz below is provided as an alternative method of earning CE credit hours. Refer to the article for the ONE best answer to each question. The questions are based solely on the content of the article. Answer the questions and send the original quiz answer sheet and fee to the NCRA Executive Office before the processing date listed on the answer sheet. Quizzes may not be retaken nor can NCRA staff respond to questions regarding answers. Allow 4–6 weeks for processing following the submission deadline to receive return notification of your completion of the CE process. The CE hour will be dated when it is submitted for grading; that date will determine the CE cycle year.

After reading this article and taking the quiz, the participants will be able to:
• Evaluate the effectiveness of patient registries in terms of diabetes health outcomes
• Explain the impact diabetes has on the economy
• Describe the patient-centered medical home (PCMH) model

1. Key principles associated with the patient-centered medical home (PCMH) model include:

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<th>having a personal physician</th>
<th>obtaining access</th>
<th>eliminating multiple payment streams</th>
<th>maximizing health outcomes</th>
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2. A patient registry is an organized system that uses observational study methods to:

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<th>collect uniform data</th>
<th>evaluate outcomes</th>
<th>serve a predetermined purpose</th>
<th>control home health care costs</th>
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3. A 2014 study by Friedberg and colleagues found that pilot practices receiving diabetes registries and technical assistance resulted in:

a) marked improvement in healthcare quality
b) marked decrease in healthcare quality
c) bonuses averaging $92,000 per primary care physician
d) decreases in primary care physician income

4. The overall goal of this project was to test whether having a diabetes registry is associated with improvement in:

a) weight control
b) exercise frequency
c) hypertension
d) HbA1c levels

5. This study includes diabetic patients:

a) representing all age groups
b) who are at least 18 years old
c) with gestational diabetes
d) with type 1 diabetes

6. Diabetes registries are used to:

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<th>track compliance with medication</th>
<th>update information annually</th>
<th>generate reminder letters</th>
<th>monitor HgbA1c levels</th>
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7. According to Figure 1, Plot of Adjusted Means and 95% Confidence Intervals for HgbA1c levels by Visit and Clinic Group (Registry and Nonregistry):

a) registry patients had overall lower HgbA1c levels
b) non-registry patients had overall higher HgbA1c levels
c) HgbA1c levels for both groups increased over time
d) HgbA1c levels for both groups decreased over time

8. On average, patients in diabetes registry clinics were younger, and more likely to:

a) reside in suburban areas
b) be Caucasian
c) have Medicaid or limited insurance
d) have lower HgbA1c values at the first visit

9. The study findings imply that, compared to nondiabetes registry clinics, diabetes registry clinics:

a) provided greater improvement in HgbA1c values
b) provided similar improvement in HgbA1c values
c) were unsuccessful in reducing HgbA1c values
d) treat patients with lower initial HgbA1c values

10. According to the authors, the limitations of this study include:

a) a longer study period may have shown fewer differences over time
b) time between patient visits or HgbA1c values were consistent
c) prevalent, rather than incident disease status was measured
d) compliant patients are less willing to change behavior to improve health

The JRM Quiz and answers are now available through NCRA’s Center for Cancer Registry Education (CCRE). For your convenience, the JRM article and quiz can be accessed online at www.CancerRegistryEducation.org/jrm-quizzes. Download the article, complete the quiz and claim CE credit all online.

The Journal of Registry Management 2015 Volume 42 Number 1
### Instructions
Mark your answers clearly by filling in the correct answer, like this ■ not like this □. Passing score of 70% entitles one (1) CE clock hour per quiz.

*Please use black ballpoint pen.*

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Submit the original quiz answer sheet only! No photocopies will be accepted.

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This original quiz answer sheet will not be graded, no CE credit will be awarded, and the processing fee will be forfeited unless postmarked by:

**June 30, 2017**

**Quiz Identification Number:**

**4201.01**

**JRM Quiz Article:**

**DIABETES REGISTRIES IN PATIENT-CENTERED MEDICAL HOMES**

- Please check one:
  - [ ] Processing Fee: **Member $25**  **Nonmember $35**
  - [ ] Payment is due with submission of answer sheet. Make check or money order payable to NCRA. US currency only. Do not send cash. No refund under any circumstances. Please allow 4–6 weeks following the submission deadline for processing.

**For Internal Use Only**

Date Received: ____________

Amount Received: ____________

Notification Mailed: ____________

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**Mail to:** NCRA Executive Office
JRM CE Quiz
1330 Braddock Place
#520
Alexandria, VA 22314
National Cancer Registrars Association
CALL FOR PAPERS

Vonetta L. Williams, PhD, MPH, CTR | EDITOR-IN-CHIEF, JRM

The Journal of Registry Management, official journal of the National Cancer Registrars Association (NCRA), announces a call for original manuscripts on registry methodology or research findings related to the 5 subjects listed below and related topics.

Topics:
1. Birth Defects Registries
2. Cancer Registries
   - AJCC TNM Stage
   - Cancer and Socioeconomic Status
   - History
3. Trauma Registries
4. Recruitment, Training, and Retention
5. Public Relations

Contributed manuscripts are peer-reviewed prior to publication.

Manuscripts of the following types may be submitted for publication:
1. Methodology Articles addressing topics of broad interest and appeal to the readership, including methodological aspects of registry organization and operation.
2. Research articles reporting findings of original, reviewed, data-based research.
3. Primers providing basic and comprehensive tutorials on relevant subjects.
4. “How I Do It” Articles describe tips, techniques, or procedures for an aspect of registry operations that the author does particularly well. The “How I Do It” feature in the Journal provides registrars with an informal forum for sharing strategies with colleagues in all types of registries.
5. Opinion papers/editorials including position papers, commentaries, essays, and interviews that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management.
6. Bibliographies which are specifically targeted and of significant interest will be considered.
7. Letters to the Editor are also invited.

Address all manuscripts to: Vonetta L. Williams, PhD, MPH, CTR, Editor-in-Chief, Journal of Registry Management, (813) 745-1783, JRMEditor@ncra-usa.org.

Manuscript submission requirements are given in “Information for Authors” found on the inside back cover of each Journal and on the NCRA Web site at http://www.ncra-usa.org/jrm.
Manuscripts may be submitted for publication in the following categories: Articles addressing topics of broad interest and appeal to the readership, including Methodology papers about registry organization and operation; Research papers reporting findings of original, reviewed, data-based research; Primers providing tutorials on relevant subjects; and “How I Do It” papers are also solicited. Opinion papers/editorials including position papers, commentaries, and essays that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management; Letters to the Editor; and specifically-targeted Bibliographies of significant interest are invited.

The following guidelines are provided to assist prospective authors in preparing manuscripts for the journal, and to facilitate technical processing of submissions. Failure to follow the guidelines may delay consideration of your manuscript. Authors who are unfamiliar with preparation and submission of manuscripts for publication are encouraged to contact the Editor for clarification or additional assistance.

Submission Requirements

Manuscripts. The terms manuscripts, articles, and papers are used synonymously herein. E-mail only submission of manuscripts is encouraged. If not feasible, submit the original manuscript and 4 copies to the Editor. Manuscripts should be double-spaced on white 8-1/2” x 11” paper, with margins of at least 1 inch. Use only letter-quality printers; poor quality copies will not be considered. Number the manuscript pages consecutively with the (first) title page as page one, followed by the abstract, text, references, and visuals. The accompanying cover letter should include the name, mailing address, e-mail address, and telephone number of the corresponding author. For electronic submission, files should be IBM-compatible format in Corel WordPerfect®, Microsoft® Word for Windows®, or converted to ASCII code.

Manuscripts (Research Articles). Articles should follow the standard format for research reporting (Introduction, Methods, Results, Discussion, References), and the submission instructions outlined above. The introduction will normally include background information, and a rationale/justification as to why the subject matter is of interest. The discussion often includes a conclusion subsection. Comprehensive references are encouraged, as are an appropriate combination of tables and figures (graphs).

Manuscripts (Methodology/Process Papers). Methodology papers should follow the standard format for research reporting (Introduction, Methods, Results, Discussion), or for explanatory papers not reporting results (Introduction, Methods, Discussion), as well as the submission instructions outlined above.

Manuscripts (“How I Do It” articles). The “How I Do It” feature in the journal provides registrars with a forum for sharing strategies with colleagues in all types of registries. These articles describe tips, techniques, or procedures for an aspect of registry operations that the author does particularly well. When shared, these innovations can help registry professionals improve their skills, enhance registry operations, or increase efficiency.

“How I Do It” articles should be 1,500 words or less (excluding references) and can contain up to 2 tables or figures. To the extent possible, the standard headings (Introduction, Methods, Results, Discussion) should be used. If results are not presented, that section may be omitted. Authors should describe the problem or issue, their solution, advantages (and disadvantages) to the suggested approach, and their conclusion. All submitted “How I Do It” articles will have the benefit of peer/editorial review.

Authors. Each author’s name, degrees, certifications, title, professional affiliation, and e-mail address must be noted on the title page exactly as it is to appear in publication. The corresponding author should be noted, with mailing address included. Joint authors should be listed in the order of their contribution to the work. Generally, a maximum of 6 authors for each article will be listed.

Title. Authors are urged to choose a title that accurately and concisely describes the content of the manuscript. Every effort will be made to use the title as submitted, however, Journal of Registry Management reserves the right to select a title that is consistent with editorial and production requirements.

Abstract. A brief abstract must accompany each article or research paper. The abstract should summarize the main point(s) and quickly give the reader an understanding of the manuscript’s content. It should be placed on a page by itself, immediately following the title page.

Length. Authors are invited to contact the Editor regarding submission of markedly longer manuscripts.


Visuals. Use visuals selectively to supplement the text. Visual elements—charts, graphs, tables, diagrams, and figures—will be reproduced exactly as received. Copies must be clear and properly identified, and preferably e-mailed. Each visual must have a brief, self-explanatory title. Submit each visual on a separately numbered page at the end of the manuscript, following the references.

Attribution. Authors are to provide appropriate acknowledgment of products, activities, and support especially for those articles based on, or utilizing, registry data (including acknowledgment of hospital and central registrars). Appropriate attribution is also to be provided to acknowledge federal funding sources of registries from which the data are obtained.

References. References should be carefully selected, and relevant. References must be numbered in order of their appearance in the text. At the end of the manuscript, list the references as they are cited; do not list references alphabetically. Journal citations should include author, title, journal, year, volume, issue, and pages. Book citations should include author, title, city, publisher, year, and pages. Authors are responsible for the accuracy of all references. Examples:


Key words. Authors are requested to provide up to 5, alphabetized key words or phrases which will be used in compiling the Annual Subject Index.

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Originality. Articles are reviewed for publication assuming that they have not been accepted or published previously and are not under simultaneous consideration for publication elsewhere. If the article has been previously published or significantly distributed, this should be noted in the submission for consideration.

Editing

Journal of Registry Management reserves the right to edit all contributions for clarity and length. Minor changes (punctuation, spelling, grammar, syntax) will be made at the discretion of the editorial staff. Substantive changes will be verified with the author(s) prior to publication.

Peer Review

Contributed manuscripts are peer-reviewed prior to publication, generally by 3 reviewers. The Journal Editor makes the final decision regarding acceptance of manuscripts. Receipt of manuscripts will be acknowledged promptly, and corresponding authors will be advised of the status of their submission as soon as possible.

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www.CancerRegistryEducation.org

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Questions? Call 703-299-6640 Ext. 317 or e-mail ccre@ncra-usa.org

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