NCRA Launches the New Center for Cancer Registry Education!

www.CancerRegistryEducation.org

The Center for Cancer Registry Education (CCRE) provides easy access to high-quality educational programming to support both seasoned professionals and those new to the cancer registry field. The website offers a variety of products and services, allowing you to tailor your training and manage CE credits.

Use your NCRA Website member log-in and password!

Questions? Call 703-299-0640 Ext. 317 or e-mail ccre@ncra-usa.org

The CCRE Website is partially funded by the Centers for Disease Control and Prevention, Cooperative Agreement U50 DP000342.
Contents

Original Articles
Feasibility of Using Central Registry Data to Assess Timeliness of Breast Cancer Care in Delaware
Stephanie H. Belinske, MPH; Marjorie Shannon, MS; Lisa Henry, MS; James Spellman, MD; Allison Shevock, MS, PhD

Construction of a Comorbidity Index for Prostate Cancer Patients
Linking State Cancer Registry with Inpatient and Outpatient Data
Hong Xiao, PhD; Fei Tan, PhD; Pierre Goovaerts, PhD; Askal Ayalew Ali, MA; Georges Adunlin, MA; Youjie Huang, MD, DrPH; Clement K. Gwede, PhD, MPH, RN

Registry Data Quality Improvement by Identifying Discrepancies between Assigned Codes and Text Descriptions of Birth Defects
Sandra D. Richardson, RN, MS; Deborah J. Fox, MPH; Brooke Wittman, BS

Using Cancer Registries to Assess the Accuracy of Primary Liver or Intrahepatic Bile Duct Cancer as the Underlying Cause of Death, 1999–2010
Anthony P. Polednak, PhD

Enhancement and Validation of an Arab Surname Database
Kendra Schwartz, MD, MSPH; Ganj Beebani; Mai Sedki; Mamon Tahhan, MD; Julie J. Ruterbusch, MPH

Impact of Race/Ethnicity and Socioeconomic Status on Adjuvant Chemotherapy Use among Elderly Patients with Stage III Colon Cancer
Mi-Chin Hsieh, MSPH, CTR; Yu-Wen Chiu, DrPH; Cruz Velasco, PhD; Xiao-Cheng Wu, MD, MPH, CTR; Mary B. O’Flarity, MN; Vivien W. Chen, PhD

Using the Cancer Registry to Meet the Commission on Cancer Clinical Trials Accrual Standard

Features and Other Journal Departments:
Raising the Bar: Working Under Frigid Conditions
Michele Webb, CTR

The Journey from Office to Home
Melissa Riddle, CTR

How I Do It: “Down and Dirty” Texting—A Template for Documenting Text in the Abstract
Pamela S. Warren, PhD, CTR

Winter 2013 Continuing Education Quiz
Deborah C. Roberson, MSM, CTR; Denise Harrison, BS, CTR

Correction to “ICD-O-3 Terminology Approved for Use with Cases Diagnosed January 1, 2014 and After” in the Fall 2013 Journal of Registry Management

Index

Call for Papers

Information for Authors
Editors
Vicki Nelson, MPH, RHIT, CTR, Editor-in-Chief
Vonetta Williams, MPH, CTR, Associate Editor
Reda J. Wilson, MPH, RHIT, CTR, Editor Emeritus
Ginger Yarger, Copy Editor
Janice Ford, Production Editor

Contributing Editors
Faith G. Davis, PhD—Epidemiology
April Fritz, BA, RHIT, CTR—Cancer Registry
Denise Harrison, BS, CTR—CE Credits
Deborah C. Roberson, MSM, CTR—CE Credits
Michele A. Webb, CTR

NCRA 2012-2013 Board of Directors
President: Shirley Jordan Seay, PhD, OCN, CTR
President Elect/Secretary: Therese M. Richardson, RHIA, CTR
Immediate Past President: Sarah Burton, CTR
Treasurer Senior: Dianna L. Wilson CTR, RHIA
Treasurer Junior: Janet Reynolds, CTR
Educational Director: Paulette Zinkann, CTR
Professional Development Director: Deidre M. Watson, CTR
Public Relations Director & Liaison to JRM: Theresa M. Vallerand, CTR, BGS
Recruitment & Retention Director: Linda Corrigan, MHE, RHIT, CTR

ATP Director—East: Pamela Moats, RHIT, CTR
ATP Director—Midwest: Mindy Young, CTR
ATP Director—West: Kendra Hayes, RHIA, CTR

2012-2013 JRM Editorial Advisory Board
Tim Aldrich, PhD
Tammy Berryhill, MA, RHIA
Betty Gentry, BS, CTR
Robert German, PhD
Donna Gress, BS, CTR
Alison Hennig, BS, CTR
Monique Hernandez, PhD
Amy Kahn, MS, CTR
Leah Kiesow, MBA, CTR
Herman Menck, MBA, CDP
Kathleen Thoburn, CTR
Kevin Ward, PhD, MPH, CTR
Pamela Warren, PhD, CTR
Reda Wilson, MPH, RHIT, CTR (Editor Emeritus)
Vonetta Williams, MPH, CTR (Associate Editor)

Production and Printing
The Goetz Printing Company

Indexing
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.

For your convenience, the Journal of Registry Management is indexed in the 4th issue of each year and on the Web (under “Resources” at http://www.ncra-usa.org/jrm). The 4th issue indexes all articles for that particular year. The Web index is a cumulative index of all JRM articles ever published.
Feasibility of Using Central Registry Data to Assess Timeliness of Breast Cancer Care in Delaware

Stephanie H. Belinske, MPH; Marjorie Shannon, MS; Lisa Henry, MS; James Spellman, MD; Allison Shevock, MS, PhD

Abstract: Studies have shown that timely screening, diagnosis, and treatment of breast cancer reduces mortality rates. The objective of this study was to determine if data collected by the Delaware Cancer Registry (DCR) could be used to assess the timeliness of diagnosis and treatment for breast cancer patients, using the Centers for Disease Control and Prevention (CDC) recommendations of 60 days maximum for screening to diagnosis and 60 days maximum for diagnosis to treatment. This study analyzed DCR data for female Delawarean breast cancer patients diagnosed in 2004; data were included that had a valid screening, diagnosis, and treatment date. Calculations of 3 time intervals were performed: screening to diagnosis (time interval A), diagnosis to treatment (time interval B), and screening to treatment (time interval C). Results of this study show that, while not captured as an independent variable, screening dates could be extracted from text fields to calculate appropriate time intervals. The mean and median for time intervals A (23.2 days, 20.0 days), B (2.1 days, 0.0 days), and C (40.1 days, 37.0 days) met CDC recommendations. This study shows that it is possible to utilize DCR data to conduct a timeliness of breast cancer treatment providing the ability to benchmark Delaware breast cancer treatment timelines to national recommendations.

Key words: breast cancer, follow-up, mammogram, screening, time to treatment

Introduction

Breast cancer screening followed by timely follow-up and appropriate treatment reduces mortality rates. Studies have shown that women who wait longer than 6 to 12 months for diagnostic workup have a poorer prognosis. Limited data are available on the optimal diagnostic and treatment intervals that might increase survival time from breast cancer detected by mammography. Some investigators have found that follow-up intervals of up to 3 months may not impact overall survival, whereas others have shown that women who waited more than 30 days for evaluation after breast cancer detection were more likely to experience breast cancer recurrence or death. The Centers for Disease Control and Prevention (CDC) has established quality standards of having a diagnosis within 60 days of an abnormal screening test result and initiation of treatment within 60 days of diagnosis. These standards ensure timely diagnosis and treatment initiation for women screened through its National Breast and Cervical Cancer Early Detection Program (NBCCEDP) program.

Breast cancer screening rates have risen across the country in recent years. Reports of an incomplete or delayed clinical follow-up after an abnormal cancer screening may be a significant public health concern. The Delaware Cancer Consortium (DCC) and the Delaware Division of Public Health (DPH) initiated an investigation into the average length of time between screening, diagnosis, and treatment initiation among female breast cancer patients. The DCC elected to use breast cancer data from a single diagnosis year (2004) to develop a standardized protocol for investigating cancer time-to-treatment patterns in Delaware. Results from this investigation will enable the DCC to expand future time-to-treatment analyses to include additional diagnosis years and cancer types, and serve as a baseline for studying cancer-related time-to-treatment trends statewide.

The Delaware Cancer Registry (DCR) is managed by DPH and serves as the state’s central cancer registry. Thirty-three facilities submit data to the DCR; these facilities include 7 hospitals, 10 diagnostic laboratories, 15 free-standing ambulatory surgery centers, and dozens of physician offices. DCR has met the highest rating (Gold Standard for Registry Certification) given by the North American Association of Central Cancer Registries (NAACCR) for diagnosis years 1999 and 2003 through 2009. DCR met Silver certification in 1998 and 2002.

Methods

Design and Participants

This was a retrospective cohort study of breast cancer patients with a primary residence in Delaware and diagnosed from January 1, 2004 through December 31, 2004. Patients with breast cancer had to meet the following eligibility criteria to be retained in the analyses (Figure 1): 1) diagnosed with breast cancer during calendar year 2004; 2) female; 3) classified as Class of Case 1 (ie, her diagnosis and all or part of her first course of treatment were performed at the facility that ultimately reported the case to the DCR); and 4) had a unique identification number with valid date data. The study population used for analyses included 311 cases.

Address correspondence to Stephanie H. Belinske, MPH, Chronic Disease Epidemiologist, 540 S. DuPont Highway Suite 10, Dover, DE 19901. Telephone: (302) 744-1036. Email: Stephanie.Belinske@state.de.us.
Figure 1. Inclusion Criteria Flow Diagram

Breast Cancer Patients with Primary Residence in Delaware Diagnosis Year 2004 (N=705)

Females Only (N=698)

Class of Case 1 Diagnosis and all or part of first course of treatment performed at reporting facility (N=604)

Unique patients with valid date data for at least one abnormal mammogram, diagnostic procedure, and first course treatment (N=311)

Measures

For this study, the DCR provided complete records for all breast cancer patients diagnosed in the state between January 1, 2004 and December 31, 2004. Breast cancer patients were identified using the Surveillance, Epidemiology, and End Results (SEER) case definition: ICD-O-3 site C500–509, excluding histologies 9050–9055, 9590–9989, and 9140. For most cancer surveillance activities, a data request is submitted to the DCR to obtain a file of cancer patients and selected variables that would be used for analysis. The DCR fulfills requests by providing an encrypted file, but is unable to export text fields using this data exchange method. To facilitate exportation of text fields, the DCR provided a complete NAACCR format file including 385 variables for all breast cancer cases diagnosed in 2004. All variables collected in association with each patient were determined and coded according to NAACCR guidelines.10

Date Identification for Key Time Interval Variables

Preliminary analyses identified the text fields most often containing key dates of interest. A subset of these text variables was created and each field was manually probed, extracting dates of abnormal mammogram, diagnosis, and initiation of treatment. For cases with multiple dates of mammogram screening and diagnostic procedures, all dates were extracted for later analyses and stored in a separate file. Extracted date data were used to create a new file. This new file was merged with the NAACCR format file, using patient identification (ID) as the merging variable. The National Comprehensive Cancer Network (NCCN) Guidelines11 for breast cancer screening and diagnosis provided guidance for determining dates for analysis for cases that had multiple dates for screening or diagnosis. A mammogram result was taken as abnormal if described as suspicious or abnormal in the text field of the NAACCR variable “DxProc-XRay/scan.” Date of diagnosis was listed as the NAACCR variable “Date of Diagnosis.” Two dates of treatment were described in the NAACCR file: “Date of Initial RX—SEER” and “Date of 1st Crs RX—CoC.” We chose to use “Date of 1st Crs RX—CoC” as the treatment variable in this study because it contained useful information not available in the “Date of Initial RX—SEER” variable:

• Per the Commission on Cancer (CoC) definition, the date of nontreatment (if applicable) was recorded in this field.
• In contrast, the SEER-defined variable “Date of Initial RX—SEER” is left blank if no treatment was administered.

Further, we cross-checked and recorded the earliest of the following dates as the date of treatment initiation: “Date of First Surgical Procedure,” “Date Radiation Started,” “Date Systemic Therapy Started,” and “Date Other Treatment Started.”

Conceptual Model and Statistical Analyses

The initial conceptual model for this study (Figure 2) was composed of 3 time intervals of particular interest (see A, B, and C). Time interval A represents the time period between the date on which a woman receives a mammogram that yields abnormal results and the date of breast cancer diagnosis. Time interval B represents the time period between the date on which a woman receives a diagnosis confirming cancer and the date which she begins her cancer treatment. Time interval C represents the overall time period between date of abnormal mammogram and date of treatment initiation.

For women with multiple dates of mammogram screening and diagnostic procedures, variations were made in calculating the time intervals proposed in the initial conceptual model (Figure 2). For women with 2 dates of abnormal mammogram, the second mammogram date was used for analyses (Figure 3a). Additionally, the first diagnostic procedure was used when calculating time interval A and the last diagnostic procedure was used when calculating time interval B. Finally, a fourth time interval was calculated to determine the time it took for the 2 or more diagnostic procedures and labeled it as time interval D (Figure 3b). The final model took into account only a single mammogram date but multiple diagnosis dates. Therefore, calculations for time interval A were made using date of first diagnostic procedure and time interval B using date of last diagnostic procedure. Again, a fourth time interval was calculated to determine the time it took for the 2 or more diagnostic procedures and labeled it as time interval D (Figure 4).

Analyses were performed on all above-mentioned time intervals for each model. Time intervals A through D for Model 2 and Model 2 Alternative were combined due to the small sample size. Time periods were analyzed for statistically significant differences among the various models. Selected demographic characteristics were summarized for each model and the entire sample. Additionally, analyses were performed to determine if there were any statistically significant differences for each of the demographic characteristics among the different models.
Results

Baseline Characteristics

A total of 705 cases of breast cancer were identified between January 1, 2004 and December 31, 2004. Out of the original sample, 7 were male cases and were excluded from analyses. Further, 94 cases were dropped from the analyses because the diagnosis and all or parts of the treatment were not performed at the facility that ultimately reported the case to the DCR (ie, the cases dropped were not of Class of Case 1). In addition, 293 cases did not have a valid date for at least 1 abnormal mammogram, diagnostic procedure, and/or first course treatment (Figure 1). The study population group was comprised of 311 breast cancer cases.

Table 1 describes the mean and standard deviation for continuous variables and number and frequency for categorical variables for the entire sample (n = 705), study population (n = 311), and excluded cases (n = 394). For the entire sample, the average age was almost 61 years, primarily white (80.9%), from New Castle County (59.7%), had local stage breast cancer (47.5%), and were either using a private insurance (53.1%) or were on Medicare (41.2%). In addition to descriptive analysis, we compared the study population to the excluded cases to determine if there were any statistically significant differences between the 2 populations. New Castle County was underrepresented in the study population. Only 48.9% of the study population was from New Castle County while 59.7% of the original cases were from New Castle County.
### Table 1. Comparison of the Cases Included in the Study Population to Those Who Were Excluded

<table>
<thead>
<tr>
<th>Variable</th>
<th>Entire Sample n = 705</th>
<th>Study Population n = 311</th>
<th>Excluded from Study Population n = 394</th>
<th>Independent t-test (P-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>60.7 (13.8)</td>
<td>60.6 (13.1)</td>
<td>60.9 (14.4)</td>
<td>-0.26 (.7941)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td>1.8674 (.3931)</td>
</tr>
<tr>
<td>White</td>
<td>570 (80.9)</td>
<td>252 (81.0)</td>
<td>318 (80.7)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>122 (16.4)</td>
<td>51 (16.4)</td>
<td>71 (18.0)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>13 (1.8)</td>
<td>8 (2.6)</td>
<td>5 (1.3)</td>
<td></td>
</tr>
<tr>
<td>County</td>
<td></td>
<td></td>
<td></td>
<td>37.0010 (&lt;.0001)*</td>
</tr>
<tr>
<td>Kent</td>
<td>101 (14.3)</td>
<td>44 (14.2)</td>
<td>57 (14.5)</td>
<td></td>
</tr>
<tr>
<td>New Castle</td>
<td>421 (59.7)</td>
<td>152 (48.9)</td>
<td>269 (68.3)</td>
<td></td>
</tr>
<tr>
<td>Sussex</td>
<td>183 (26.0)</td>
<td>115 (37.0)</td>
<td>68 (17.3)</td>
<td></td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
<td></td>
<td>16.5974 (.0023)*</td>
</tr>
<tr>
<td>In situ</td>
<td>165 (23.4)</td>
<td>80 (25.7)</td>
<td>85 (21.6)</td>
<td></td>
</tr>
<tr>
<td>Local</td>
<td>335 (47.5)</td>
<td>158 (50.8)</td>
<td>177 (44.9)</td>
<td></td>
</tr>
<tr>
<td>Regional</td>
<td>174 (24.7)</td>
<td>69 (22.2)</td>
<td>105 (26.7)</td>
<td></td>
</tr>
<tr>
<td>Distant</td>
<td>26 (3.7)</td>
<td>4 (1.3)</td>
<td>22 (5.6)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>5 (0.7)</td>
<td>0 (0.0)</td>
<td>5 (1.3)</td>
<td></td>
</tr>
<tr>
<td>Primary Payer</td>
<td>n = 680</td>
<td>n = 300</td>
<td>n = 380</td>
<td>3.0188 (.5547)</td>
</tr>
<tr>
<td>Private</td>
<td>361 (53.1)</td>
<td>155 (51.7)</td>
<td>206 (54.2)</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>25 (3.7)</td>
<td>14 (4.7)</td>
<td>11 (2.9)</td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>280 (41.2)</td>
<td>124 (41.3)</td>
<td>156 (41.1)</td>
<td></td>
</tr>
<tr>
<td>Not Insured</td>
<td>8 (1.2)</td>
<td>5 (1.7)</td>
<td>3 (0.8)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>6 (0.9)</td>
<td>2 (0.7)</td>
<td>4 (1.1)</td>
<td></td>
</tr>
</tbody>
</table>

*P-value <.05.

### Table 2. Comparison of Selected Demographic Characteristics to 2004 Delaware Female Population

<table>
<thead>
<tr>
<th>Variable</th>
<th>Expected</th>
<th>Observed</th>
<th>$\chi^2$ (P-value) or % Difference</th>
<th>Expected</th>
<th>Observed</th>
<th>$\chi^2$ (P-value) or % Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>521</td>
<td>565</td>
<td>20.19 (&lt;.0001)*</td>
<td>232</td>
<td>252</td>
<td>7.31 (.0258)*</td>
</tr>
<tr>
<td>White</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>145</td>
<td>121</td>
<td>-16.6</td>
<td>65</td>
<td>51</td>
<td>-21.5</td>
</tr>
<tr>
<td>Other</td>
<td>32</td>
<td>12</td>
<td>-62.5</td>
<td>14</td>
<td>8</td>
<td>-42.9</td>
</tr>
<tr>
<td>County</td>
<td></td>
<td></td>
<td>13.26 (.0013)*</td>
<td>51.26 (&lt;.0001)*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kent</td>
<td>117</td>
<td>101</td>
<td>-5.0</td>
<td>53</td>
<td>44</td>
<td>-21.6</td>
</tr>
<tr>
<td>New Castle</td>
<td>436</td>
<td>414</td>
<td>-13.7</td>
<td>194</td>
<td>152</td>
<td>-17.0</td>
</tr>
<tr>
<td>Sussex</td>
<td>145</td>
<td>183</td>
<td>26.2</td>
<td>64</td>
<td>115</td>
<td>79.7</td>
</tr>
</tbody>
</table>

*P-value <.05.
resided in New Castle County. Sussex County was overrepresented, with 37.0% of cases represented in the study population, while only 26.0% of the entire sample resided in Sussex County. In the study population, in situ (25.7%) and local (50.8%) stage cancers were overrepresented where all others were underrepresented. Additionally, all cancers had a stage assigned for those included in the study population.

To further strengthen the study, we compared the entire sample to the female Delaware population estimates for 2004 provided by the Delaware Population Consortium. As our study was concerned with female breast cancer, only women (n = 698) from the entire sample were included in the comparison. The inclusion of males in this comparison would skew the observed and expected observations since the incidence of male breast cancer is 94 times lower than female breast cancer (1.73 per 100,000 males vs 163.3 per 100,000 females). Expected values are the number of cases we would expect to see for each demographic group and observed values are the number of cases that were diagnosed among the 2004 female breast cancer patients. As illustrated in Table 2, the proportions among racial groups were not representative and statistically different from the 2004 Delaware population estimates for both the entire sample of women ($\chi^2 = 20.19$, df = 2, $P < .0001$) and the study population ($\chi^2 = 7.31$, df = 2, $P = .0258$). Additionally, both the entire sample of women and the study population were not consistent and significantly different in distribution among counties compared to the 2004 Delaware population estimates ($\chi^2 = 13.26$, df = 2, $P = .0013$; $\chi^2 = 51.26$, df = 2, $P < .0001$).

A 1-sample Z-test was not calculated to compare the differences in mean age among the 2004 Delaware population, entire sample of women, and study population since age is a known confounder and not expected to be the same as the population.

### Statistical Analyses

Univariate analyses were used for descriptive summarization of time intervals A, B, C, and D. All analyses were performed using SAS 9.2 (SAS Institute, Car, NC) except for $\chi^2$ and $P$-values in Table 2 which were calculated using a chi-square goodness-of-fit interactive calculator.

Baseline characteristics of cases within Models 1, 2, and 3 are shown in Table 3. The mean age at diagnosis was 60.7 years (range, 29–92 years). Among the 311 cases, the majority of the women were white (81.0%) and lived in New Castle County (48.9%). Most of the women were insured:

### Table 3. Demographic Characteristics for the Study Population, Model 1, Model 2, and Model 3

<table>
<thead>
<tr>
<th>Variable</th>
<th>Study Population</th>
<th>Model 1</th>
<th>Model 2</th>
<th>Model 3</th>
<th>One-Way ANOVA</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$n = 311$</td>
<td>$n = 108$</td>
<td>$n = 16$</td>
<td>$n = 187$</td>
<td>(P-value)</td>
</tr>
<tr>
<td>Age</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>0.85 (.7572)</td>
</tr>
<tr>
<td></td>
<td>60.6 (13.1)</td>
<td>61.2 (13.3)</td>
<td>60.4 (11.6)</td>
<td>60.3 (13.1)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>$\chi^2$ (P-value)</td>
</tr>
<tr>
<td>White</td>
<td>252 (81.0)</td>
<td>87 (80.6)</td>
<td>14 (87.5)</td>
<td>151 (80.8)</td>
<td>2.2566 (.6887)</td>
</tr>
<tr>
<td>Black</td>
<td>51 (16.4)</td>
<td>19 (17.6)</td>
<td>1 (6.3)</td>
<td>31 (16.6)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8 (2.6)</td>
<td>2 (1.9)</td>
<td>1 (6.3)</td>
<td>5 (2.7)</td>
<td></td>
</tr>
<tr>
<td>County</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>31.6482 (&lt;.0001)*</td>
</tr>
<tr>
<td>Kent</td>
<td>44 (14.2)</td>
<td>11 (10.2)</td>
<td>0 (0.0)</td>
<td>33 (17.7)</td>
<td></td>
</tr>
<tr>
<td>New Castle</td>
<td>152 (48.9)</td>
<td>73 (67.6)</td>
<td>4 (25.0)</td>
<td>75 (40.1)</td>
<td></td>
</tr>
<tr>
<td>Sussex</td>
<td>115 (37.0)</td>
<td>24 (22.2)</td>
<td>12 (75.0)</td>
<td>79 (42.3)</td>
<td></td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>20.0710 (.0027)*</td>
</tr>
<tr>
<td>In situ</td>
<td>80 (25.8)</td>
<td>27 (25.0)</td>
<td>9 (56.3)</td>
<td>44 (23.5)</td>
<td></td>
</tr>
<tr>
<td>Local</td>
<td>158 (50.8)</td>
<td>47 (43.5)</td>
<td>6 (37.5)</td>
<td>105 (56.2)</td>
<td></td>
</tr>
<tr>
<td>Regional</td>
<td>69 (22.2)</td>
<td>30 (27.8)</td>
<td>1 (6.3)</td>
<td>38 (20.3)</td>
<td></td>
</tr>
<tr>
<td>Distant</td>
<td>4 (1.3)</td>
<td>4 (3.7)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>Primary Payer†</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.77 (.9873)</td>
</tr>
<tr>
<td>Private</td>
<td>155 (51.7)</td>
<td>50 (49.0)</td>
<td>8 (57.1)</td>
<td>97 (52.7)</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>14 (4.7)</td>
<td>6 (5.9)</td>
<td>0 (0.0)</td>
<td>8 (4.4)</td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>124 (41.3)</td>
<td>43 (42.2)</td>
<td>6 (42.9)</td>
<td>75 (40.8)</td>
<td></td>
</tr>
<tr>
<td>Not Insured</td>
<td>5 (1.7)</td>
<td>2 (2.0)</td>
<td>0 (0.0)</td>
<td>3 (1.6)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (0.7)</td>
<td>1 (1.0)</td>
<td>0 (0.0)</td>
<td>1 (0.5)</td>
<td></td>
</tr>
</tbody>
</table>

†11 observations missing values for Primary Payer: entire sample = 300; Model 1 = 102; Model 2 = 14; Model 3 = 184.

*P-value <.05.
### Table 4. Descriptive Analysis of Time Intervals A, B, and C for the Study Population, Model 1, Model 2, Model 3

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Mean (SD)</th>
<th>Median (Q1, Q3)</th>
<th>IQR</th>
<th>Range (Min, Max)</th>
<th>One-Way ANOVA (P-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study Population</td>
<td>23.2 (19.4)</td>
<td>20.0 (9.0, 32.0)</td>
<td>23</td>
<td>120.0 (0.0, 120.0)</td>
<td>1.23 (.1356)</td>
</tr>
<tr>
<td>Model 1</td>
<td>26.5 (22.4)</td>
<td>22.5 (12.0, 37.0)</td>
<td>25</td>
<td>120.0 (0.0, 120.0)</td>
<td></td>
</tr>
<tr>
<td>Model 2</td>
<td>22.1 (10.1)</td>
<td>22.5 (15.0, 30.0)</td>
<td>15</td>
<td>35.0 (7.0, 42.0)</td>
<td></td>
</tr>
<tr>
<td>Model 3</td>
<td>21.4 (17.8)</td>
<td>18.0 (8.0, 31.0)</td>
<td>23</td>
<td>107.0 (0.0, 107.0)</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study Population</td>
<td>2.1 (11.6)</td>
<td>0.0 (0.0, 0.0)</td>
<td>0</td>
<td>145.0 (0.0, 145.0)</td>
<td></td>
</tr>
<tr>
<td>Model 1</td>
<td>4.6 (16.6)</td>
<td>0.0 (0.0, 0.0)</td>
<td>0</td>
<td>145.0 (0.0, 145.0)</td>
<td></td>
</tr>
<tr>
<td>Model 2</td>
<td>0.0 (0.0)</td>
<td>0.0 (0.0, 0.0)</td>
<td>0</td>
<td>0.0 (0.0, 0.0)</td>
<td></td>
</tr>
<tr>
<td>Model 3</td>
<td>0.9 (7.8)</td>
<td>0.0 (0.0, 0.0)</td>
<td>0</td>
<td>0.0 (0.0, 88.0)</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study Population</td>
<td>40.1 (26.2)</td>
<td>37.0 (22.0, 50.0)</td>
<td>28</td>
<td>211.0 (0.0, 211.0)</td>
<td></td>
</tr>
<tr>
<td>Model 1</td>
<td>31.2 (24.4)</td>
<td>28.0 (14.5, 40.0)</td>
<td>25.5</td>
<td>147.0 (0.0, 147.0)</td>
<td></td>
</tr>
<tr>
<td>Model 2</td>
<td>39.9 (11.7)</td>
<td>39.0 (36.0, 48.5)</td>
<td>12.5</td>
<td>39.0 (18.0, 57.0)</td>
<td></td>
</tr>
<tr>
<td>Model 3</td>
<td>45.2 (26.8)</td>
<td>40.0 (28.0, 58.0)</td>
<td>29.5</td>
<td>209.0 (2.0, 211.0)</td>
<td></td>
</tr>
</tbody>
</table>

Time interval D

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Study Population n = 311</th>
<th>Model 1 n = 108</th>
<th>Model 2 n = 15</th>
<th>Model 3 n = 187</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>4.5658 (.1020)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60 days</td>
<td>298 (95.8)</td>
<td>100 (92.6)</td>
<td>16 (100.0)</td>
<td>182 (97.3)</td>
</tr>
<tr>
<td>61 days – 120 days</td>
<td>13 (4.2)</td>
<td>8 (7.4)</td>
<td>0 (0.0)</td>
<td>5 (2.7)</td>
</tr>
<tr>
<td>≥120 days</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

### Table 5. Comparison of Time Intervals A, B, and C for the Study Population, Model 1, Model 2, and Model 3

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Study Population n = 311 n (%)</th>
<th>Model 1 n = 108 n (%)</th>
<th>Model 2 n = 15 n (%)</th>
<th>Model 3 n = 187 n (%)</th>
<th>χ² (P-value)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60 days</td>
<td>298 (95.8)</td>
<td>100 (92.6)</td>
<td>16 (100.0)</td>
<td>182 (97.3)</td>
<td>4.5658 (.1020)</td>
</tr>
<tr>
<td>61 days – 120 days</td>
<td>13 (4.2)</td>
<td>8 (7.4)</td>
<td>0 (0.0)</td>
<td>5 (2.7)</td>
<td></td>
</tr>
<tr>
<td>≥120 days</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Study Population n = 311</th>
<th>Model 1 n = 108</th>
<th>Model 2 n = 15</th>
<th>Model 3 n = 187</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>2.5445 (.6367)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60 days</td>
<td>309 (99.4)</td>
<td>107 (99.1)</td>
<td>16 (100.0)</td>
<td>186 (99.5)</td>
</tr>
<tr>
<td>61 days – 120 days</td>
<td>1 (0.3)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>1 (0.5)</td>
</tr>
<tr>
<td>≥120 days</td>
<td>1 (0.3)</td>
<td>1 (0.9)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Study Population n = 311</th>
<th>Model 1 n = 108</th>
<th>Model 2 n = 15</th>
<th>Model 3 n = 187</th>
</tr>
</thead>
<tbody>
<tr>
<td>C</td>
<td>13.2659 (.0100)*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60 days</td>
<td>257 (82.6)</td>
<td>98 (90.7)</td>
<td>16 (100.0)</td>
<td>143 (76.5)</td>
</tr>
<tr>
<td>61 days – 120 days</td>
<td>49 (15.8)</td>
<td>9 (8.3)</td>
<td>0 (0.0)</td>
<td>40 (21.4)</td>
</tr>
<tr>
<td>≥120 days</td>
<td>5 (1.6)</td>
<td>1 (0.9)</td>
<td>0 (0.0)</td>
<td>4 (2.1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time Interval</th>
<th>Study Population n = 311</th>
<th>Model 1 n = 108</th>
<th>Model 2 n = 15</th>
<th>Model 3 n = 187</th>
</tr>
</thead>
<tbody>
<tr>
<td>D</td>
<td>2.0087 (.7342)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤60 days</td>
<td>308 (99.0)</td>
<td>108 (100.0)</td>
<td>16 (100.0)</td>
<td>184 (98.4)</td>
</tr>
<tr>
<td>61 days – 120 days</td>
<td>2 (0.6)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>2 (1.1)</td>
</tr>
<tr>
<td>≥120 days</td>
<td>1 (1.3)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>1 (0.5)</td>
</tr>
</tbody>
</table>

Study Population n = 311; Model 1, n = 108; Model 2, n = 16; Model 3, n = 187.

*P-value <0.05.
private payer (51.7%), Medicare (41.3%), or Medicaid (4.7%). Additionally, the majority of breast cancer cases were in situ (25.8%) or local (50.8%) stage.

Statistical Analyses of Time Intervals

Table 4 summarizes the time intervals for each of the models as well as the study population. Table 5 illustrates the number of cases in each model and the study population whose diagnostic and treatment course met CDC’s recommendations (≤60 days) or exceeded recommendations. For those exceeding recommendations, we characterized the exceeded time into 2 groups: 61–120 days and greater than 120 days. It is important to note that time interval C is the combination of time interval A and time interval B, both of which independently have a recommendation of ≤60 days.

Time Interval A. For the study population, analysis shows a mean of 23.2 days (median of 20 days) from screening mammogram to first diagnostic procedure. Range varies from 0 to 120 days. No significant differences were noted among the entire sample or the 3 models used to calculate time intervals (Table 4). There were only 13 cases for the study population whose time exceeded 60 days: 8 cases from Model 1 and 5 cases from Model 3. No cases exceeded 120 days (Table 5).

Time Interval B. Analysis revealed a mean of 2.1 days (median of 0 days) from diagnosis to treatment for the entire sample and the range was from 0 to 145 days. However, Model 1 showed a mean of 4.6 days with a median of 0 days. This difference between mean and median is due to a single case where navigating the screening to diagnosis protocol took 145 days (Table 4). There was a statistically significant difference between the mean of Model 1 and other models (Table 4). Only 1 case from Model 3 took between 61 and 120 days (Table 5).

Time Interval C. As noted in Table 4, the mean number of days from screening mammogram to treatment was 40.1 days with a median of 37.0 days; the range was 0 to 211 days. There were significant differences among the means of Model 1 (31.2 days), Model 2 (39.9 days) and Model 3 (45.2 days). Forty-nine cases had more than 61 days between screening and first course of treatment. Additionally, 5 cases exceeded 120 days (Table 5).

Time Interval D. The study population had a mean of 14.7 days with a median of 13 days and a range from 0 of 137 days between first and last diagnostic procedure. There were statistically significant differences among the models. Of the total study population of 311 women, 203 had more than 1 diagnostic procedure. Model 1 did not include more than 1 diagnostic date, accounting for the average and median of 0 days. Model 2 had a mean of 17.9 days with a median of 13.5 days. Model 3 had a mean 22.9 days with a median of 21.0 days (Table 4). Only 3 cases exceeded 60 days, and 1 case exceeded 120 days (Table 5).

Discussion

This is a feasibility study to determine if DCR data can be used to calculate the time it takes a patient to navigate through the process of screening, diagnosis, and commencement of treatment. The CDC’s NBCCEDP standard recommends that a woman should receive a diagnosis within 60 days of being screened (time interval A). Our study results show a mean of 23.2 days and a median of 20 days for women who have had a screening mammography to complete an initial diagnostic procedure. Of the study population, only 13 cases (4.2%) exceeded the 60 days recommendation. The CDC also recommends commencement of first course of treatment within 60 days of diagnosis (time interval B). Our study shows a mean of 2.1 days with a median of 0 days for this time interval. Only 2 (0.6%) women exceeded this recommendation. Additionally, for the entire time interval investigated (screening to first course of treatment, ie, time interval C), only 5 women (1.6%) exceeded 120 days.

Variations on the number of screening mammograms and number of diagnostic procedures among women were noted and alternatives to the original conceptual model were included. These variations suggested a number of different pathways a woman may take through screening to diagnosis and then to first course of treatment. As we were assessing the providers’ ability to meet the CDC’s recommended benchmarks, we were careful to include models which took into account different decision-making points. As this was a feasibility study, we did not conduct a validation study and did not penalize a provider for variances from the recommended time intervals. Preliminary analyses suggest the number of screening mammograms and diagnostic procedures may affect the length of time from screening to treatment but further investigation is needed.

Limitations and Strengths

Our study was specifically designed as a pilot project to determine if we could use DCR data to study the average length of time between screening, diagnosis, and treatment initiation among Delaware women diagnosed with breast cancer. Because of the length of time that has elapsed since the 2004 diagnoses, our results may not reflect current practices. As this was a preliminary feasibility study; no data validation was undertaken. Validation, which may enable us to retain additional women in our study population and to better understand the reasons for observed variations, will be an important part of a planned follow-up study. Additionally, while the DCR maintains a NAACCR Gold certification, due to the submission processes and timelines from hospital registries, all data fields may not be complete. No attempt was made to obtain additional dates if not found in the registry text fields.

Additionally, we elected to limit the study to only those cases who met Class of Case 1 criteria. We took this approach to assure that any aberrations found could not have resulted from factors related to multiprovider care delivery, such as a need for additional authorizations. By limiting this study to Class of Case 1, we are unable to generalize back to the entire sample. Our study population also only included those who had a valid screening procedure date, diagnosis date, and treatment initiation date. Therefore, the study population included only 44.1% of the original sample. When the study population was compared to the excluded cases, differences in both county and stage of cancer were noted. These
differences could have created bias in our study population. A number of variables of interest are not collected by DCR as they are not required by NAACCR. A key variable, mammography date, was manually abstracted from text fields. When multiple mammography dates were found, the second mammography date was used which shortened the length of time interval A. Additionally, the only variable to indicate socioeconomic status (SES) was primary payer. Due to the average age of our study population, Medicare, which is not indicative of SES, was the insurance payer for over 40% of our study population. Therefore, in future studies, methodology to calculate SES should be included so this social indicator can be used in analyses and controlled for in any multivariate analyses.

In follow up studies, we would like to investigate these timeliness of treatment benchmarks with a larger sample size. Because Delaware has a small population, it may be necessary to look at these benchmarks across several years to create a larger sample. In addition, caution should be exercised when interpreting differences among models due to the small sample size noted in Model 2.

Our study is the first in Delaware to systematically explore the timeliness of breast cancer diagnosis and initiation of treatment. This study will contribute to the development of a standardized protocol for investigating timeliness of cancer treatment trends in Delaware.

Conclusions

The DCR is an important source of data for investigating cancer and cancer treatment trends in Delaware. We have illustrated that it is possible to use DCR data when investigating Delaware timeliness of cancer treatment. Our results show that most of the follow-up occurred within 60 days of diagnosis. However, further investigation that includes a validation study needs to be conducted with a larger population. Bias may have been created due to the sampling methods when eliminating the majority (55.9%) of the original sample.

In summary, this study has shown that it is possible to utilize DCR data to conduct a timeliness of cancer treatment study focused on breast cancer. Adding a validation study to this methodology will be an essential component to future studies. Identifying disparities in race, ethnicity, or socioeconomic status may be important to identify at-risk populations can be identified for targeted public health interventions. Additionally, future research needs to focus on identifying the barriers to follow-up so that effective interventions may be implemented.

Acknowledgements

The authors gratefully acknowledge the collaborators at the Delaware Cancer Registry who provided data for analysis. The Delaware Cancer Registry is funded by the National Program for Cancer Registries (CDC), and the State of Delaware, Tobacco Master Settlement Funds and General Funds. We also would like to acknowledge the members of the Delaware Cancer Consortium Data Committee.

References

Construction of a Comorbidity Index for Prostate Cancer Patients Linking State Cancer Registry with Inpatient and Outpatient Data

Hong Xiao, PhD; Fei Tan, PhD; Pierre Goovaerts, PhD; Askal Ayalew Ali, MA; Georges Adunlin, MA; Youjie Huang, MD, DrPH; Clement K. Gwede, PhD, MPH, RN

Abstract: Introduction: Identifying clinically relevant comorbid conditions might lead to effective control of prostate cancer–specific risk factors and provide opportunities to improve patient care and outcomes. There are challenges in assessing comorbidity using linked databases such as statewide hospital administrative data and state cancer registry. The objective was to compile a comprehensive list of clinically relevant comorbid conditions for patients with prostate cancer using registry and statewide diagnosis databases. Methods: Florida Cancer Data System cases were linked with the inpatient/outpatient diagnosis information. The Elixhauser Comorbidity Index was used as a reference. Conditions not captured by Elixhauser were identified, and grouped into clinically meaningful categories. Descriptive analysis was performed on comorbidity conditions and major study population variables. Associations of comorbidity with selected demographic and disease characteristics were examined. Results: Twenty-nine Elixhauser and 16 additional categories were examined within the 1 record per patient data set. Statistically significant association was found between comorbidity with race, stage, and age. Blacks had a higher mean number of conditions compared to whites. A higher proportion of blacks had at least 1 comorbid condition compared to whites. Additional conditions identified by this research capture more comorbidities for white men. Distinct trends towards larger number of comorbidities with older age at diagnosis and advanced disease stage were observed. Conclusions: The Elixhauser Comorbidity Index captured the majority of comorbidities in the study population while the additional conditions identified by this research add more information. This study offers important insights into the challenges and process to identify relevant comorbidities for prostate cancer patients.

Key words: administrative data, cancer registry, comorbidity, Elixhauser, prostate cancer

Introduction

Different approaches have been used to capture comorbidity, depending on the outcome measure, clinical setting, and source of data. Comorbidity has been defined as the co-occurrence of 1 or more diseases or disorders in an individual. Comorbidity reflects the aggregate effect of all clinical conditions a patient might have, excluding the disease of primary interest.

The elderly population (those aged 65 years or older) in the United States is expected to double from approximately 35 million in 2013 to more than 70 million by 2030. The increased prevalence of cancer and comorbid conditions is associated with aging; however, there are unanswered questions on the relationship between comorbidity and cancer screening in the elderly. This aging American population, with a concomitant rise in the number of people living with chronic diseases, has major implications for health care services.

Effective management of chronic diseases such as prostate cancer often presents enormous challenges. Studies have shown that prostate cancer patients with high comorbidity and short life expectancy are less likely to receive aggressive therapy. These patients are also more likely to participate in active surveillance initiatives. Clinicians and patients alike can be overwhelmed by the need to address comorbid chronic conditions in addition to patients’ prostate cancer–specific treatment goals. Suboptimal management of concurrent disease, however, can lead to ineffective control of prostate cancer–specific risk factors and may miss opportunities to improve patients’ functioning and quality of life, and to decrease mortality risk.

The complexity of comorbidity data and its potential for creating unwieldy analyses has led to the development of several summary comorbidity measures over the years. Examples of validated, database-derived comorbidity indices are the Charlson Comorbidity Index (CCI), the Elixhauser Comorbidity Index, The Cumulative Illness Rating Scale (CIRS), the Index of Coexistent Disease (ICED), and the Kaplan Index. These measures have significant differences in the method of development, type of data used, and number and type of diseases included. The CCI and the Elixhauser Index are the most extensively used in health research. The Elixhauser Index identifies 30 major coexisting conditions based on inpatient administrative data using the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) and...
diagnoses-related group (DRG) codes. The CCI, developed using a medical record review data set, includes 19 diseases weighted according to their association with mortality. The CCI score is constructed by assigning a weight to each comorbidity depending on the magnitude of the relative risk associated with each condition. The CCI was derived using a population of medical patients, and has been shown to be reliable and a valid predictor of mortality in a number of populations, including hospital inpatients and the critically ill. These 2 methods also differ from each other in terms of attribution of weights related to prognostic effect of individual conditions. This weighting is present in the 19 clinical conditions comprising the CCI. The Elixhauser methodology does not assign any weight to the 30 comorbidities it defines, and instead focuses exclusively on the number of pathologies present.

The broad goal of this project was to compile a comprehensive list of clinically relevant comorbidity conditions applied to the context of prostate cancer diagnosis, and to assess whether the list of conditions could be expanded or reduced based on an existing comorbidity index (CCI and Elixhauser Index). The objectives of the current study were to 1) identify the type and prevalence of comorbid conditions in administrative data sets; and 2) examine the need to reduce the number of comorbidity conditions or expand it beyond an established comorbidity index based on statewide inpatient/outpatient and cancer registry data sets.

Methods

Data Sources

The Florida Cancer Data System (FCDS), Florida’s population-based statewide cancer registry, was used for this project. FCDS cases were linked with the inpatient and outpatient diagnosis information collected by Florida Agency for Health Care Administration (AHCA). Figure 1 shows the linkage process. AHCA’s hospital inpatient data program collects 3 types of discharge data from 269 inpatient health care facilities: acute care hospitals, long-term psychiatric facilities, short-term psychiatric facilities, and comprehensive rehabilitation facilities. Reportable events include all acute, intensive care, and psychiatric live discharges including newborn live discharges and deaths. The inpatient data comprises 52 data elements. AHCA’s ambulatory data set consists of 59 data elements, including patient demographic information, hospital identification information, payer information, charges, procedures, and diagnosis information.

Time Window to Capture Comorbidity

The first step in creating comorbidity groups was to determine the preexisting and/or coexisting comorbid conditions at the time of prostate cancer diagnosis. To be inclusive, a time window was set to include relevant coexisting conditions that were not related to (or an outcome of) the prostate cancer diagnosis. Time intervals were calculated between the time of diagnosis of prostate cancer and the time of initial treatment of prostate cancer, between prostate cancer diagnosis and inpatient admission, and between prostate cancer diagnosis and outpatient visit. The computations were carried out by stage of prostate cancer at diagnosis. It was noted that for the majority of records (50%-75%), initial treatment, inpatient admission, or outpatient visit happened within 1 year before or after diagnosis of prostate cancer. Analyses also showed that 75% of inpatient admissions for any diseases occurred within 1 year of prostate cancer diagnosis, and more than 75% of outpatient visits for any reasons occurred within 1 year (+/-365 days) of prostate cancer diagnosis. Therefore a time window of 1 year before and 1 year after prostate cancer diagnosis date was used to capture inpatient admissions and outpatient visits for any diseases other than prostate cancer or its complications. All diagnoses of diseases independent of prostate cancer and its possible complications during this 2-year time window were included for comorbidity computation.

Comorbidity Measures

ICD-9-CM diagnosis code 185 was used to identify the prostate cancer patient group. Prostate cancer, the outcome disease, was excluded from the comorbidity groups in this study. The Elixhauser Index was used because it has been extensively validated and allows more disease states to be considered as comorbid conditions when compared to the CCI. This decision was based on the fact that prostate cancer
patients present a wide range of coexisting disease states. This choice is further supported by several studies which have suggested that the Elixhauser method outperforms the CCI method as a predictor of mortality. Another study also suggested that if the model contains individual diagnosis information, the Elixhauser method performs better for in-hospital and 6-month mortality predictions.

The Elixhauser Index used both DRGs and ICD-9-CM diagnosis codes from inpatient databases to identify 30 unweighted comorbidity indicators that are entered as separate indicator variables in a regression model. This project used ICD-9-CM diagnosis codes for both inpatient and outpatient within the 2-year time window centered on the prostate cancer diagnosis date.

Healthcare Cost and Utilization Project (HCUP) Comorbidity Software (versions 1.0–3.4, developed between the year 2001 and 2009), based on the Elixhauser Index, was used. Figure 1 shows the steps to combine data from multiple sources and to develop a final data file. Patient identification was included in both the incidence file received from FCDS and the AHCA inpatient/outpatient data files, and it was used to match merge diagnosis information to the incidence file. After examining the frequencies of all 30 Elixhauser Index categories based on 1 record per patient data, it was concluded that the current Elixhauser listing was adequately inclusive, with exception of the category of cancer. Cancer is complex and this category includes solid tumors vs blood-related tumors, metastatic (secondary) vs primary malignancies, unknown primaries, etc, which makes it quite cumbersome to verify. The following rule was adopted to distinguish if a metastatic cancer should or not be considered as a comorbidity: If prostate stage is localized, then any metastatic cancer in AHCA data is a comorbidity; if prostate stage is late, then metastatic cancers of the lymph nodes (ICD-9 code: 196), bone (spine and ribs, 198.5), brain (198.3), and lung (197.0) in AHCA data should not be considered as a morbidity.

Once patient comorbidities were grouped by the

### Table 1. List of Comorbidity Conditions (N = 60,497)

<table>
<thead>
<tr>
<th>Numbers</th>
<th>Comorbidity</th>
<th>Prevalence</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Congestive heart failure</td>
<td>1,465</td>
<td>2.42</td>
</tr>
<tr>
<td>2</td>
<td>Valvular disease</td>
<td>1,752</td>
<td>2.90</td>
</tr>
<tr>
<td>3</td>
<td>Pulmonary circulation disorders</td>
<td>215</td>
<td>0.36</td>
</tr>
<tr>
<td>4</td>
<td>Peripheral vascular disorders</td>
<td>1,304</td>
<td>2.16</td>
</tr>
<tr>
<td>5</td>
<td>Hypertension, uncomplicated</td>
<td>25,589</td>
<td>42.30</td>
</tr>
<tr>
<td>6</td>
<td>Paralysis</td>
<td>279</td>
<td>0.46</td>
</tr>
<tr>
<td>7</td>
<td>Other neurological disorders</td>
<td>924</td>
<td>1.53</td>
</tr>
<tr>
<td>8</td>
<td>Chronic pulmonary disease</td>
<td>5,528</td>
<td>9.14</td>
</tr>
<tr>
<td>9</td>
<td>Diabetes, uncomplicated</td>
<td>6,331</td>
<td>10.46</td>
</tr>
<tr>
<td>10</td>
<td>Diabetes, complicated</td>
<td>412</td>
<td>0.68</td>
</tr>
<tr>
<td>11</td>
<td>Hypothyroidism</td>
<td>1,572</td>
<td>2.60</td>
</tr>
<tr>
<td>12</td>
<td>Renal failure</td>
<td>1,350</td>
<td>2.23</td>
</tr>
<tr>
<td>13</td>
<td>Liver disease</td>
<td>314</td>
<td>0.52</td>
</tr>
<tr>
<td>14</td>
<td>Peptic ulcer disease excluding bleeding</td>
<td>188</td>
<td>0.31</td>
</tr>
<tr>
<td>15</td>
<td>AIDS</td>
<td>40</td>
<td>0.07</td>
</tr>
<tr>
<td>16</td>
<td>Lymphoma</td>
<td>357</td>
<td>0.59</td>
</tr>
<tr>
<td>17</td>
<td>Metastatic cancer</td>
<td>2,706</td>
<td>4.47</td>
</tr>
<tr>
<td>18</td>
<td>Solid tumor without metastasis</td>
<td>3,410</td>
<td>5.64</td>
</tr>
<tr>
<td>19</td>
<td>Rheumatoid arthritis/collagen vascular diseases</td>
<td>300</td>
<td>0.50</td>
</tr>
<tr>
<td>20</td>
<td>Coagulopathy</td>
<td>851</td>
<td>1.41</td>
</tr>
<tr>
<td>21</td>
<td>Obesity</td>
<td>1,230</td>
<td>2.03</td>
</tr>
<tr>
<td>22</td>
<td>Weight loss</td>
<td>527</td>
<td>0.87</td>
</tr>
<tr>
<td>23</td>
<td>Fluid and electrolyte disorders</td>
<td>3,692</td>
<td>6.10</td>
</tr>
<tr>
<td>24</td>
<td>Chronic blood loss anemia</td>
<td>516</td>
<td>0.85</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Numbers</th>
<th>Comorbidity</th>
<th>Prevalence</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>Deficiency anemias</td>
<td>3,304</td>
<td>5.46</td>
</tr>
<tr>
<td>26</td>
<td>Alcohol abuse</td>
<td>545</td>
<td>0.90</td>
</tr>
<tr>
<td>27</td>
<td>Drug abuse</td>
<td>63</td>
<td>0.10</td>
</tr>
<tr>
<td>28</td>
<td>Psychosis</td>
<td>390</td>
<td>0.64</td>
</tr>
<tr>
<td>29</td>
<td>Depression</td>
<td>1,240</td>
<td>2.05</td>
</tr>
<tr>
<td>30</td>
<td>Endocrine disorders, nutritional and metabolic, immunity</td>
<td>11,667</td>
<td>19.29</td>
</tr>
<tr>
<td>31</td>
<td>Ischemic heart disease</td>
<td>8,385</td>
<td>13.86</td>
</tr>
<tr>
<td>32</td>
<td>Digestive system disease</td>
<td>9,211</td>
<td>15.23</td>
</tr>
<tr>
<td>33</td>
<td>Genitourinary system disease</td>
<td>14,761</td>
<td>24.40</td>
</tr>
<tr>
<td>34</td>
<td>Injury and poisoning</td>
<td>4,937</td>
<td>8.16</td>
</tr>
<tr>
<td>35</td>
<td>Respiratory disorders</td>
<td>2,887</td>
<td>4.77</td>
</tr>
<tr>
<td>36</td>
<td>Infection</td>
<td>2,502</td>
<td>4.14</td>
</tr>
<tr>
<td>37</td>
<td>Other circulatory disease</td>
<td>2,027</td>
<td>3.35</td>
</tr>
<tr>
<td>38</td>
<td>Benign neoplasm and in-situ cancer</td>
<td>2,211</td>
<td>3.65</td>
</tr>
<tr>
<td>39</td>
<td>Other nervous system and sense organs disorders</td>
<td>1,916</td>
<td>3.17</td>
</tr>
<tr>
<td>40</td>
<td>Skin and subcutaneous tissue disease</td>
<td>958</td>
<td>1.58</td>
</tr>
<tr>
<td>41</td>
<td>Musculoskeletal and connective tissue disease</td>
<td>7,109</td>
<td>11.75</td>
</tr>
<tr>
<td>42</td>
<td>Other mental disorders</td>
<td>873</td>
<td>1.44</td>
</tr>
<tr>
<td>43</td>
<td>Other anemias</td>
<td>825</td>
<td>1.36</td>
</tr>
<tr>
<td>44</td>
<td>Congenital anomalies</td>
<td>276</td>
<td>0.46</td>
</tr>
<tr>
<td>45</td>
<td>Brain and other neurological disorders</td>
<td>525</td>
<td>0.87</td>
</tr>
</tbody>
</table>

*Additional comorbidity not in Elixhauser that were identified from the dataset.*
Table 2. Comorbidity Summary by Race, Stage, and Age (N = 60,497)

<table>
<thead>
<tr>
<th>Number of Comorbidities</th>
<th>Total Mean (SD)</th>
<th>Elix Mean (SD)*</th>
<th>Total Median</th>
<th>Elix Median*</th>
<th>% with any</th>
<th>% with any Elix*</th>
<th>% with 1</th>
<th>% with 2</th>
<th>% with 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>2.53(2.61)</td>
<td>1.36(1.50)</td>
<td>2</td>
<td>1</td>
<td>77.04</td>
<td>66.42</td>
<td>20.80</td>
<td>17.12</td>
<td>12.64</td>
</tr>
<tr>
<td>White</td>
<td>2.25(2.34)</td>
<td>1.07(1.29)</td>
<td>2</td>
<td>1</td>
<td>75.13</td>
<td>58.39</td>
<td>22.28</td>
<td>17.51</td>
<td>12.70</td>
</tr>
<tr>
<td>P-value</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0004†</td>
<td>&lt;.0001†</td>
<td>&lt;.00045†</td>
<td>.4115</td>
<td>.8823</td>
</tr>
<tr>
<td>Stage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Localized</td>
<td>2.02(2.14)</td>
<td>0.96(1.18)</td>
<td>1</td>
<td>1</td>
<td>72.82</td>
<td>56.05</td>
<td>23.31</td>
<td>17.88</td>
<td>12.42</td>
</tr>
<tr>
<td>Regional</td>
<td>2.51(2.28)</td>
<td>1.26(1.29)</td>
<td>2</td>
<td>1</td>
<td>83.01</td>
<td>68.47</td>
<td>22.25</td>
<td>20.08</td>
<td>15.83</td>
</tr>
<tr>
<td>Distant</td>
<td>5.13(3.40)</td>
<td>2.58(2.00)</td>
<td>5</td>
<td>2</td>
<td>94.44</td>
<td>85.78</td>
<td>8.51</td>
<td>10.09</td>
<td>11.27</td>
</tr>
<tr>
<td>P-value</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>[40, 65)</td>
<td>1.89(2.04)</td>
<td>0.91(1.14)</td>
<td>1</td>
<td>1</td>
<td>72.25</td>
<td>54.96</td>
<td>25.03</td>
<td>18.51</td>
<td>11.92</td>
</tr>
<tr>
<td>[65, 70)</td>
<td>2.21(2.23)</td>
<td>1.07(1.23)</td>
<td>2</td>
<td>1</td>
<td>76.19</td>
<td>60.92</td>
<td>21.98</td>
<td>19.11</td>
<td>13.67</td>
</tr>
<tr>
<td>≥70</td>
<td>2.66(2.65)</td>
<td>1.29(1.49)</td>
<td>2</td>
<td>1</td>
<td>77.56</td>
<td>62.22</td>
<td>19.69</td>
<td>15.60</td>
<td>12.80</td>
</tr>
<tr>
<td>P-value</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
<td>&lt;.0001†</td>
</tr>
</tbody>
</table>

*Calculated based on Elixhauser Index comorbidity categories only.
†Significant at 5% level.

Elixhauser Index, conditions not captured by the Elixhauser Index were identified and categorized using the following procedure. First, grossly related conditions were grouped and given a common numeric code and a comprehensive clinically meaningful descriptor. Second, if a condition corresponded to either an Elixauser Index or previously defined category, it was assigned to that category. Third, if a condition given a common numeric code and a comprehensive procedure. First, grossly related conditions were grouped resulting in a definitive list of 29 conditions from the Elixhauser Index consisting of the original 30 plus 16 additionally identified categories was then computed to create a data set comprising 1 record per patient.

Cardiac arrhythmia posed a challenge because this condition was excluded from the HCUP Comorbidity Software after the year 2001. However, conditions from cardiac arrhythmias were not spread out nor combined into any other categories within the Elixhauser Index. Conditions related to cardiac arrhythmias were largely symptoms of bigger problems captured in heart failure. Since cardiac arrhythmias are largely risk factors or symptoms leading to congestive heart failure (CHF), those conditions will likely be covered by capturing CHF for patients in earlier and recent years. Furthermore, cardiac arrhythmias may also be associated with other categories such as valvular disease; thus, dropping cardiac arrhythmias eliminates inherent duplication. Based on this assessment, cardiac arrhythmia was removed from the list of 46 comorbidity categories, resulting in a definitive list of 29 conditions from the Elixhauser Index plus 16 additional conditions, for a total of 45 comorbidity categories in the single record per patient data (Table 1).

Data Analysis

The final 1 record per patient data described at bottom of Figure 1 was used for analysis. Descriptive statistics (eg, frequencies, proportions, means, and standard deviations) were performed for all comorbidity conditions and other major study variables. Bivariate analyses including chi-square and analysis of variance (ANOVA) tests were conducted to examine associations of comorbidity with age, race, and stage at diagnosis. Type I error was set to 0.05 and all tests were 2-sided. SAS/STAT software, Version 9.3 of the SAS System for Windows, was used for data linkage and statistical analyses.

Results

The prevalence of the 29 conditions included in the Elixhauser Index was examined using data that combined information from multiple sources. The distribution of the 16 additional categories displayed both low and high frequencies. Relatively low frequencies were observed for congenital anomalies (0.46%), brain and other neurological disorders (0.87%), and other anemias (1.36%). The highest frequencies were found for genitourinary system disease (24.40%), endocrine, nutritional/metabolic and immunity disorders (19.29%), and digestive system disease (15.23%).

The distribution of comorbidities by age, race, and stage at diagnosis was further examined. Results are summarized in Table 2. Several associations between comorbidity and prostate cancer diagnosis were evident. Race and number of comorbid conditions were related in that blacks have a significantly higher mean number of comorbidity conditions compared to whites (2.53 vs 2.25). In addition, a higher proportion of blacks (77.04%) had at least 1 comorbid condition compared to 75.13% for whites. There was also a distinct trend towards increased number of comorbidities with later stage at diagnosis. Seventy-three percent of men with localized disease had no comorbidities, compared to 83.01% among men with regional disease, and 94.44% among those...
with distant disease. As expected, a positive association exists between number of comorbidities and age at diagnosis. Table 2 also shows that, compared to using Elixhauser categories only, the additional 16 categories enabled us to capture at least 1 more comorbidity per patient for various race, stage, and age subgroups. In addition, we were able to depict a disease profile for a much higher percentage of patients (percent with any vs percent with any Elixhauser category) for different patient subgroups using the additional comorbidity categories.

**Discussion**

The role of comorbidity on early diagnosis of cancer and mortality has been extensively examined.\(^{6,7,11,22-24}\) The literature is replete with examples demonstrating the complexity and challenges of comorbidity analysis using a variety of data sources.\(^{17,19-21}\) However, little has been reported for comorbidity, early diagnosis, or mortality of prostate cancer using state cancer registry data. The current study sought to identify the type and frequency of comorbid conditions in a prostate cancer registry and to assess the performance of the existing Elixhauser Index in such a database. The methodology employed in this study supports the utility of the Elixhauser Index in this context and yields an informative picture of the distribution of comorbid conditions as summarized in Tables 1 and 2. More importantly, this parsimonious approach reduces a rather unwieldy data set consisting of multiple ICD-9-CM codes per patient into broad, clinically meaningful categories. This provides a pragmatic data set which facilitates meaningful, descriptive, correlational, and inferential (planned) analyses on the impact of comorbidity. Bivariate analyses found that comorbidity was significantly associated with race, stage, and age at diagnosis. This finding corroborates the current literature.\(^{25,26}\) There was a distinct trend toward an increased number of comorbidities with later stage at diagnosis. As expected, a positive association between age and comorbidity was found.

Although these bivariate analyses are exploratory, the noted relationships will have to be evaluated further in multivariate analysis. The current study demonstrated that the Elixhauser Index is an adequate measure for capturing the most commonly occurring comorbidity conditions among prostate cancer patients, and helps identify a disproportionate burden of common comorbidities among black men. The additional comorbidities uniquely identified in this research, however, tend to be more common among whites compared to blacks. This sets the stage to evaluate the relative contributions of these conditions to both early stage diagnosis and mortality in prostate cancer. This study provides a novel methodology that could be applied to other specific data sets.

Despite the challenges, the study was a necessary step to account for case mix and sickness profile when studying patient outcomes. It is better to include patient characteristics and their coexisting disease states than to assume 1 primary disease is the only thing that matters. In conclusion, our results suggest that it is important to examine the relevance and performance of established comorbidity measures in each disease-specific application. This study tested whether an expanded disease-specific comorbidity index based on the Elixhauser Index is needed for patients with prostate cancer. The Elixhauser Index was found capable to capture the majority of comorbid conditions in this population. However, this study offers important new insights on the challenges and methodology for working with cancer registry data and statewide inpatient and outpatient databases. Specifically, a 1-year time window before and after prostate cancer diagnosis yielded the most meaningful parameter for extraction and computation of comorbidity. Supplementing existing comorbidity information with the additional comorbidities identified in this study may contribute to the improvement of the value of cancer research and the care of cancer patients.

**Acknowledgements**

This study was funded by Grant RSGT-10-082-01-CPHPS from the American Cancer Society. The authors thank the Florida Department of Health and Florida Cancer Data System for providing the prostate cancer data.

**References**


Registry Data Quality Improvement by Identifying Discrepancies between Assigned Codes and Text Descriptions of Birth Defects

Sandra D. Richardson, RN, MS; Deborah J. Fox, MPH; Brooke Wittman, BS

Abstract: Introduction: Birth defects surveillance programs support efforts to prevent and address population health. For 30 years, the New York State (NYS) Department of Health (DOH) Congenital Malformations Registry (CMR) has been receiving reports of children with birth defects diagnosed from birth to age 2 years as required by NYS DOH regulation. Our objective in this effort was to improve the accuracy of British Pediatric Association (BPA) codes assigned to case reports in the NYS CMR. Methods: From 1998 forward, the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code and a text description for reported birth defects have been entered into the CMR database. Upon receipt, CMR staff use reported descriptions and ICD-9-CM codes to recode all birth defects into BPA codes to improve surveillance specificity. To improve CMR data completeness and accuracy for birth years 1998–2010, computer programming was used to identify possible mismatches between birth defect descriptions and BPA codes. First, descriptions were reviewed for text strings related to specific BPA codes, and common spellings, misspellings and abbreviations were identified. Next, 1998–2010 case reports were flagged if they had either the identified text strings or the related BPA codes but not both. All flagged records were reviewed manually by registry staff and necessary data corrections were made. This quality-control process was evaluated, overall and for 78 targeted birth defect groups, using frequency and percent. The number of records flagged for possible discrepancy between BPA codes and text strings, percent reviewed and percent corrected are presented. These findings helped us understand which BPA codes or birth defects required the most attention. Results: A total of 164,726 records were scanned for discrepancies between BPA code and text strings related to 78 birth defects. Of the records scanned, approximately 10% were found to have discrepancies and were flagged for manual review and approximately 8% required correction. Among case records for the targeted birth defects, 24.8% were reviewed and 19% were corrected. Of the records reviewed, 76.8% were corrected. Conclusions: This approach to data quality improvement was effective in identifying and resolving inaccuracies in the NYS CMR. High quality data is valuable for monitoring birth defects trends, allowing interstate comparisons of specific defects, and supporting birth defects research. As a result, prevention efforts and policy decisions aimed at improving public health will be better informed.

Key words: codes, birth defects registries, data quality, quality improvement

Introduction

In the United States, many states have birth defects surveillance programs in order to support efforts to prevent and address specific health problems in their populations. Currently, there are at least 41 state birth defects monitoring programs which collect population-based data used to track trends in prevalence, identify risk factors, and evaluate prevention efforts.1

Established in 1983, the New York State (NYS) Congenital Malformations Registry (CMR) is one of the largest statewide, population-based birth defects registries in the United States, receiving reports for more than 12,000 children annually. Hospitals and physicians are mandated to report children, born or residing in New York State, with a congenital malformation, chromosomal anomaly, or persistent metabolic defect that is diagnosed before age 2 years. By 2006, the reporting system was entirely Web-based, resulting in tremendous improvements in reporting timeliness and completeness.1,7 In this paper, we describe methods implemented by the NYS CMR to identify and correct errors in birth defect coding, which will lead to more accurate prevalence rates.

Methods

NYS CMR Surveillance System

The majority of reports received by the NYS CMR from hospitals arrive soon after the birth or discharge of an infant found to have a birth defect. Hospital medical records departments are provided with a list of reportable conditions. For their convenience, the list includes both the name of the birth defect as well as the respective code from the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM). While hospitals use the ICD-9-CM codes for billing purposes, they can also be useful for casefinding purposes. From 1998 forward, hospitals reporting to the CMR have been required to provide both the ICD-9-CM code as well as a short text description of the
birth defect, and both the codes and narrative descriptions are entered into the CMR database. This practice allows CMR staff to use the reported description to recode the birth defect according to the British Pediatric Association (BPA) diagnostic coding system for pediatrics. The BPA system is the basis for the 6-digit codes for reportable congenital conditions used by the Centers for Disease Control and Prevention to improve surveillance specificity. All reports on any child with multiple case reports from different sources were collapsed into 1 record or case report for this analysis.

Data Cleaning Process

To assess and improve CMR data completeness and accuracy for birth years 1998–2010, we used SAS software version 9.3 (© 2002–2010 SAS Institute Inc) to identify possible mismatches between reported birth defect descriptions and assigned BPA codes. First, narrative descriptions for the specified BPA codes were manually reviewed for text strings related to the BPA codes to identify common spellings, misspellings, and abbreviations used to describe the birth defect (Figure 1). Second, all case reports in the CMR between 1998 and 2010 that had either the identified text strings or the BPA codes, but not both were selected. To accomplish this, birth defect descriptions were scanned for the identified text strings and flagged if there was not a corresponding BPA code. Likewise, records with a specified BPA code and without a corresponding text string were also flagged. All flagged records with possible discrepancy between the specified BPA codes and related descriptions were placed in a file and reviewed manually by registry staff who made any necessary data corrections. Review and correction was not limited to the specified birth defect but included all BPA codes and descriptions in each record. When review of a record was complete, the reviewer provided a comment indicating if any and what type of changes were made. These comments were used to group records into corrected and “no correction needed” categories. This quality-control process was conducted for 78 birth defect groups.

Evaluation

Descriptive statistics (frequency and percent) were used to evaluate this data cleaning process, overall and for 78 targeted birth defect groups. The total number of records flagged for possible discrepancy between BPA codes and text strings highlights the review effort. The percent of records reviewed indicates the magnitude of possible discrepancies identified. The percent corrected details the improvement in data quality. These findings helped us understand which BPA codes or birth defects may require improvement or retraining in coding methods.

Results

Overall, 164,726 NYS CMR records were scanned for discrepancies between BPA code and narrative text strings related to 78 birth defect groups; approximately 10% were found to have possible discrepancies and approximately 8% required correction. For each of the 16,914 records identified as having a possible discrepancy and flagged for manual review, all BPA codes and birth defect descriptions were reviewed. Some of the records reviewed needed 1 or more correction and some needed no correction. Types of correction included adding BPA codes, deleting BPA codes, requesting additional information from the reporting facility, or updating narrative fields using the original case report.

Among case reports for the 78 targeted birth defect groups, 24.8% of records were reviewed and 19.0% were corrected. Of the 16,914 records reviewed, 76.8% were corrected. For birth defect groups, the number of records reviewed, percent of records reviewed and overall percent corrected ranged from 1 to 1,907, 1.4% to 100%, and 1.2% to 100%, respectively. The percent of reviewed records that required correction also varied by birth defect group, from 26.9% to 100%.

Discussion

This data quality improvement process resulted in correction of approximately 8% of NYS CMR records, which was 19% of the 78 targeted birth defect groups for birth years 1998–2010, thereby increasing the value of these data for monitoring birth defects prevalence and trends and for conducting research. Among the 78 birth defect groups, 24.8% of reported cases were identified as having a possible discrepancy between BPA codes and an associated text string; however, not all identified records required correction. Of the 16,914 records reviewed, 76.8% were corrected,
which indicates that the text string searches were effective in identifying records with discrepancies. The initial workload in this data quality improvement process involved developing computer programs. Consistent with previous findings that internal edits and comparisons improved data quality and automation reduced workload\(^8\); we plan to automate our existing programs for future use.

Through this effort we have identified which of the targeted birth defects in the NYS CMR had the most coding problems. Going forward, this information can be used to focus coding methodology or staff training to reduce future coding errors. We have already begun to expand this useful data quality improvement process to include additional birth defects and different time frames.

It is important to note that the records reviewed were identified as having a possible discrepancy between a specified BPA code and related text string; however, the correction may have been to a BPA code that was not the specified defect. This is the result of reviewing and correcting all BPA codes in each record reviewed, and is a limitation of this analysis. In addition, birth defect review order may have influenced the counts and percents for some birth defects. For example, if spina bifida was reviewed first, many club foot cases would have been reviewed and corrected prior to starting review for club foot. For these reasons, we chose not to present results by birth defect. Another limitation was that, for some of the older records, it was difficult to obtain additional information from the reporting facility, which prohibited us from confirming whether a correction was indicated. Of the records reviewed, 580 could not be confirmed and, in this situation, no correction was made.

For 3 birth defects, the number of records reviewed was greater than 100%, meaning more records were reviewed than were actually reported of the specified birth defect. This may indicate that, for these birth defects, the text string search parameters in our computer program were too broad. Refining these text string searches to be more specific to the birth defect could reduce reviewer workload.

This process of identifying discrepancies between BPA codes and descriptive text strings has improved NYS CMR data quality. High quality data is valuable to improving the monitoring of birth defects trends, providing for interstate comparisons of specific defects, and supporting research into the causes of birth defects. This data quality improvement will result in better informed prevention efforts and policy decisions aimed at improving public health.

References

Using Cancer Registries to Assess the Accuracy of Primary Liver or Intrahepatic Bile Duct Cancer as the Underlying Cause of Death, 1999–2010

Anthony P. Polednak, PhD*

Abstract: Inaccuracies in primary liver cancer (ie, excluding intrahepatic bile duct [IHBD]) or IHBD cancer as the underlying cause of death on the death certificate vs the cancer site in a cancer registry should be considered in surveillance of mortality rates in the population. Concordance between cancer site on the death record (1999–2010) and diagnosis (1973–2010) in the database for 9 cancer registries of the Surveillance, Epidemiology, and End Results (SEER) Program was examined for decedents with only 1 cancer recorded. Overreporting of deaths coded to liver cancer (ie, lack of confirmation in SEER) was largely balanced by underreporting (ie, a cancer site other than liver cancer in SEER). For IHBD cancer, overreporting was much more frequent than underreporting. Using modified rates, based on the most accurate numerators available, had little impact on trends for liver cancer in the SEER population, which were similar to trends for the entire US population based on routine statistics. An increase in the death rate for IHBD cancer, however, was no longer evident after modification. The findings support the use of routine data on underlying cause of death for surveillance of trends in death rates for liver cancer but not for IHBD cancer. Additional population-based cancer registries could potentially be used for surveillance of recent and future trends in mortality rates from these cancers.

Key words: cancer registries, cancer surveillance, death certificates, hepatocellular carcinoma, intrahepatic bile duct cancer, liver cancer

Introduction

Trends in age-standardized US mortality rates for common cancers, including primary liver (ie, excluding intrahepatic duct [IHBD]) and IHBD cancers combined, are routinely included in the Annual Report to the Nation on the Status of Cancer. Trends in liver or IHBD cancer as the underlying cause of death, Percy et al2 in a 1990 report used a database at the National Cancer Institute (NCI) for 9 population-based cancer registries of the Surveillance, Epidemiology and End Results (SEER) Program focusing on cancers diagnosed in 1973–1986 and deaths in 1985–1986. Data were coded in the International Classification of Diseases Version 9 (ICD-9) to primary liver cancer (site 155.0, for hepatocellular carcinoma [HCC] and other histologic types), IHBD cancer (site 155.1), or liver not specified as primary or secondary (site 155.2). Exclusions comprised mainly decedents with more than 1 primary cancer diagnosis in SEER, because accuracy of underlying cause of death could not be judged.2 Overreporting (ie, deaths coded with underlying cause of either liver or IHBD cancer but a different site in SEER) was more frequent than underreporting (ie, deaths with liver or IHBD cancer diagnosed in SEER but a different cancer site coded as cause of death).2

Changes in ICD-10 coding, emphasizing morphology of liver cancers and also including a specific code (C78.7) for secondary liver cancer (not available in ICD-9), could result in improvements in accuracy of death-certificate data for liver cancer, as suggested by Percy et al.2 Using death records linked to cancer registries for 3 states (California, Colorado, and Idaho), 74% of deaths (2002–2004) coded in ICD-10 to liver–IHBD cancers were confirmed by cancer registry diagnoses in 1993–2004, indicating 26% overreporting.3,4 Underreporting of liver–IHBD cancer on deaths records was assessed for patients diagnosed with a single primary cancer in 1993–1995 who died in 1993–2004, but this involved small numbers of deaths based on ICD-10 coding.3 The impact of inaccuracies on estimates of the burden of deaths or mortality rates from liver-IHBD cancer in these states was not assessed.3,4

Accurate surveillance of mortality from liver–IHBD cancer is important in assessing the burden of these deaths in the population, for such purposes as planning allocation of resources for cancer control and treatment. Also, declines in cancer mortality rates in the population, in the absence of declines in incidence rates, can suggest real improvement in cancer control (eg, due to the adoption of new cancer treatments or extensive screening programs), whereas trends in relative survival rates of cancer patients can be difficult to interpret due to various biases.5,6 Surveillance should include examining trends in age-specific death rates, because advances in certain treatments for these cancer (eg,
Methods

Analysis of Inaccuracies in Liver or IHBD Cancer as Cause of Death in the SEER Population

This study used SEER*Stat software (Version 8.0.4) with a SEER incidence-based mortality database that included cancers diagnosed starting in 1973–1976 (depending on the registry) through 2010 among residents of 9 SEER areas (the states of Connecticut, Hawaii, Iowa, New Mexico, and Utah, and the metropolitan areas of Atlanta, Georgia; Detroit, Michigan; San Francisco–Oakland, California; and Seattle–Puget Sound, Washington). The SEER-9 population-based registries cover about 10% of the US population, and follow-up of deaths and causes of death was through 2010 for diagnoses in 1973-2010. For this report, deaths in 1999–2010 (all coded to ICD-10) were examined.

The SEER-9 database, with diagnoses as early as 1973–1976, provides a unique resource for analysis of inaccuracies in cancer site on the death record (vs registry diagnosis as the gold standard) for cancers such as liver and IHBD, which have historically low survival rates. For these cancer sites, nearly all deaths in recent calendar years in the entire SEER population should be included in the SEER-9 database, as shown in the earlier study by Percy et al. The present report also calculated death rates in the SEER-9 population that were modified for inaccuracies in underlying cause of death, in order to improve assessment of temporal trends in mortality rates from liver and IHBD cancers.

In ICD-10, and in the International Classification of Diseases for Oncology ICD-O version 3 (ICD-O-3), “liver and intrahepatic bile duct cancer” (site C22) encompasses “liver” (ie, liver excluding IHBD) and IHBD. Only SEER Cause of Death Recode groups were available for deaths in the database; for all analyses of the underlying cause of death. “Liver” was defined by ICD-10 codes C22.0 for liver cell carcinoma (HCC), C22.2–22.4 (hepatoblastoma, angiosarcoma, and other sarcoma), C22.7 (other specified primary liver carcinoma) and C22.9 (liver, unspecified). This SEER recode group is also used in reports on cancer site coded as underlying cause was defined as liver cancer as their only cancer in SEER. These deaths are presumed to represent misreporting of cancer site on death certificates.

Undetected deaths from liver cancer were combined with deaths confirmed as liver cancer in SEER to obtain (using SEER*Stat) modified death rates for analysis of trends in liver cancer mortality rates for the population covered by the SEER-9 registries.

Similar methods were used for IHBD cancer. After exclusions, all deaths with Cause of Death Recode group for IHBD (ie, site C22.1) with a diagnosis of ICD-O-3/WHO 2008 Site Recode C22.1 in the SEER database were regarded as confirmed. Confirmed deaths from IHBD cancer were combined with undetected deaths (ie, those coded to other cancer site) among all diagnoses with ICD-O-3/WHO 2008 Site Recode C22.1 in the SEER database, to obtain modified death rates from IHBD cancer in the SEER-9 population.

Analysis of Trends in Liver and IHBD Cancer Mortality Rates in SEER Population and the United States

For analyses of unmodified death rates based solely on the coded underlying cause of death in the SEER database, the completeness of deaths in the SEER population from liver or IHBD cancer was evaluated, as in the previous report, by using data from a National Center for Health Statistics (NCHS) mortality database. Numbers of deaths (1999–2010) from liver or IHBD cancer in the SEER database were compared with numbers (using the same ICD-10 codes) for 1999–2010 obtained from an NCHS database by combining data for the 5 SEER states and all counties covered by the 4 SEER metropolitan areas. Only total numbers of deaths could be compared, because both databases were de-identified (to protect confidentiality); linkage of records for individual persons was neither feasible nor attempted.

Trends (1999–2010) for unmodified death rates for liver and IHBD cancer for the SEER population based on underlying cause obtained from the SEER-9 database (using SEER*Stat) were compared with those based on modified
rates. These trends were compared with trends in death rates in 1999–2010 for the entire US population based on routine mortality data obtained (using SEER*Stat) from a database with the same SEER Cause of Death recodes.

Age-standardized rates (age 15+ years) per 100,000 were directly adjusted to the age distribution of the 2000 US standard population, using 5-year age groups 15–19 through 80–84, and 85+ years, using SEER*Stat.

Annual percent change (APC) in death rates was estimated as the slope of the line(s) obtained by fitting regression models (using weighted least squares) to the natural logarithm of each annual rate, along with 95% confidence limits (CLs) on each APC, using SEER Joinpoint Regression Program (version 4.0.1, January 2013), which examines changes in the direction and magnitude of trends over time. With 12 years of data (1999–2010), the default option for maximum number of joinpoints is 2 (i.e., 3 line segments). Statistically significant (P < .05) APCs, with zero as the null hypothesis, were identified by using P-values (2-tailed tests) obtained from the joinpoint program.

### Results

**Inaccuracy in Liver Cancer as the Cause of Death**

Among all 13,551 deaths in 1999–2010 at age 15+ years with SEER Cause of Death recode for liver (defined above) as the underlying cause, 11,176 (82.5%) remained after exclusions. Of these 11,176, 82.1% (9,181) were confirmed with a liver cancer diagnosis in SEER, or an apparent over-reporting of 1,995 deaths (Table 1). Other cancer diagnoses in SEER included 2.5% with IHBD or other biliary tract, 9.0% with other specified sites, and 6.3% in “miscellaneous” recode group, which includes unspecified or ill-defined cancer sites. This “miscellaneous” group for incidence data does not include secondary cancers because, in SEER registries, cancers of uncertain primary site are not coded as

<table>
<thead>
<tr>
<th>Cancer Site in SEER (Recodes)</th>
<th>Number</th>
<th>%</th>
<th>Cancer Site in SEER (Recodes)</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liverc</td>
<td>9,181</td>
<td>82.1</td>
<td>Liverb</td>
<td>9,181</td>
<td>86.6</td>
</tr>
<tr>
<td>IHBD</td>
<td>138</td>
<td>1.2</td>
<td>IHBD</td>
<td>421</td>
<td>4.0</td>
</tr>
<tr>
<td>Gallbladder; other biliary tract</td>
<td>145</td>
<td>1.3</td>
<td>Gallbladder; other biliary tract</td>
<td>53</td>
<td>0.5</td>
</tr>
<tr>
<td>Subtotal: Liver, biliary tract</td>
<td>9,464</td>
<td>84.7</td>
<td>Subtotal: Liver, biliary tract</td>
<td>9,655</td>
<td>91.0</td>
</tr>
<tr>
<td>Other specified sitesd</td>
<td>1,004</td>
<td>9.0</td>
<td>Other specified sites</td>
<td>275</td>
<td>2.6</td>
</tr>
<tr>
<td>Miscellaneous (unspecified)e</td>
<td>708</td>
<td>6.3</td>
<td>Miscellaneous (unspecified)f</td>
<td>677</td>
<td>6.4</td>
</tr>
<tr>
<td>Total</td>
<td>11,176</td>
<td>100</td>
<td>Total cancer deaths</td>
<td>10,607</td>
<td>100</td>
</tr>
<tr>
<td>(Other causes or unknown)</td>
<td>(2,765)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cancer Site in SEER (Recodes)</th>
<th>Number</th>
<th>%</th>
<th>Cancer Site in SEER (Recodes)</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>IHBD</td>
<td>1,068</td>
<td>30.9</td>
<td>IHBD</td>
<td>1,068</td>
<td>69.7</td>
</tr>
<tr>
<td>Liverc</td>
<td>421</td>
<td>12.2</td>
<td>Liverb</td>
<td>138</td>
<td>9.0</td>
</tr>
<tr>
<td>Gallbladder; other biliary tract</td>
<td>1,625</td>
<td>47.0</td>
<td>Gallbladder; other biliary tract</td>
<td>182</td>
<td>11.9</td>
</tr>
<tr>
<td>Subtotal: Liver, biliary tract</td>
<td>3,114</td>
<td>90.0</td>
<td>Subtotal: Liver, biliary tract</td>
<td>1,388</td>
<td>90.5</td>
</tr>
<tr>
<td>Other specified sites</td>
<td>217</td>
<td>6.3</td>
<td>Other specified sites</td>
<td>77</td>
<td>5.0</td>
</tr>
<tr>
<td>Miscellaneous (unspecified)e</td>
<td>128</td>
<td>3.7</td>
<td>Miscellaneous (unspecified)f</td>
<td>68</td>
<td>4.4</td>
</tr>
<tr>
<td>Total</td>
<td>3,459</td>
<td>100</td>
<td>Total cancer deaths</td>
<td>1,533</td>
<td>100</td>
</tr>
<tr>
<td>(Other causes or unknown)</td>
<td>(146)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a For description of exclusions, see text. Liver and IHBD cancers were defined by SEER site recode groups (see text).5,7,9
b Liver cancer as underlying cause, as defined by the SEER cause of death recode group which includes ICD-10 code C22.9 (liver, unspecified) (see text).5,7
c Liver cancer diagnosis in SEER database, defined by ICD-O-3 site code C22.0, and excluding certain ICD-O-3 Morphology codes (see text).5,7,d Includes mainly colon-rectum, pancreas, lung-bronchus, prostate, breast, other digestive system and urinary tract site groups as the cause of death, which were combined for this table.

The SEER Cause of Death Recode labeled “miscellaneous” includes mainly unspecified, ill-defined, and secondary (i.e., ICD-10 sites C760-768, C770-779, C809).5,7
f The SEER ICD-O-3/WHO 2008 recode for incidence data includes mainly unspecified and ill-defined sites (see text).7

SEER, Surveillance, Epidemiology and End Results Program; 9 SEER registries were used for this study (see text).7
secondary but to the organ system (not otherwise specified), ill-defined site, or unknown primary site.

Of the 16,633 decedents (1999–2010) with ICD-O-3/WHO 2008 Site Recode group “liver” (C22.0) as the diagnosis in 1973–2010, 14,141 had only 1 cancer in SEER, and of these 13,372 (representing 80.4% of the original 16,633) were not ascertained by autopsy/DCO. Of these 13,372, 1,426 were coded to some other cancer as underlying cause (ie, undetected liver cancer deaths) (Table 1). The other cancer sites were mainly IHBD or other biliary tract, and the “miscellaneous” SEER Cause of Death Recode group which includes secondary cancers and ill-defined or unspecified sites. Non-cancer deaths (n = 2,765, Table 1) included infectious diseases, heart disease, chronic liver disease/cirrhosis, other causes and unknown (not shown).

Apparent overreporting (1,995 deaths) was largely offset by apparent underreporting (1,426 deaths) of liver cancer as the underlying cause. Of the modified number of deaths (ie, 9,181 confirmed plus 1,426 undetected, or 10,607), 4.6% were diagnosed before 1999, 69.4% were coded as microscopically confirmed in SEER, and 83.4% were coded as microscopically confirmed in SEER, and 21.3% as confirmed by radiography (without microscopy) in the SEER database.

Inaccuracy in IHBD Cancer as the Cause of Death

Of the 4,291 total deaths at age 15+ years in 1999–2010 with the Cause of Death Recode for IHBD (site C22.1), the confirmation rate was estimated by using the 3,459 (80.6% of 4,291) deaths with IHBD as the only cancer site in SEER (and not ascertained by autopsy/DCO). Of these 3,459, only 1,068 or 30.9% were confirmed by the diagnosis of IHBD cancer in SEER. Other diagnoses in SEER included the SEER site recode groups for liver, gallbladder and “other biliary tract.” Overreporting of IHBD cancer as the underlying cause of death was estimated at 3,459–1,068 or 2,391 deaths.

In the analysis of underreporting of IHBD cancer as the underlying cause of death, of the 2,192 incident cases of IHBD cancer (site C22.1) diagnosed in 1973–2010 who died in 1999–2010, 1,753 had only 1 cancer diagnosed in SEER; 1,679 (76.6% of all 2,192) were not ascertained by autopsy/DCO. Underreporting (ie, 1,533 with any cancer as underlying cause minus 1,068 with IHBD cancer, or 465) was due largely to the Cause of Death Recode groups for liver, gallbladder, and other biliary tract (Table 1).

Thus, apparent underreporting was much less frequent than apparent overreporting for IHBD cancer deaths. Of the 1,533 deaths used for modified death rates, 7.9% were diagnosed before 1999, and 78.1% were coded as microscopically confirmed in the SEER database.

A limitation of the gold standard is that some hilar or perihilar bile-duct cancers (identified by ICD-O-3 codes M8162–M8163), usually regarded as extrahepatic cancers, are coded to IHBD in SEER registries, due to ambiguities in the ICD-O coding manuals and also the absence of a specific site code for these tumors. The number of deaths coded to M8162–M8163 in the SEER database, however, was only 126. After excluding these deaths, 995 or 70.7% of the remaining 1,407 with IHBD cancer in SEER had IHBD cancer as the cause of death, which is similar to the 69.7% figure in Table 1.

Trends in Liver in IHBD Cancer Death Rates in the SEER Population vs the Entire United States

The analysis of unmodified death rates for liver cancer as underlying cause using the SEER database involved 13,551 deaths at age 15+ years. In comparison, a total of 13,475 deaths coded to liver cancer as underlying cause (ICD-10 codes C22.0, C22.2-22.4, C22.7, and C22.9) were found in the NCHS mortality database for the 9 SEER areas. The numbers were also similar for each individual SEER state (eg, for Connecticut, 1,525 in the SEER database vs 1,509 in NCHS). The analysis of unmodified death rates for IHBD cancer using the SEER database involved 4,291 deaths at age 15+ years. In comparison, 4,261 deaths coded to C22.1 were obtained from the NCHS database for the 9 SEER areas combined.

These findings support the completeness of the SEER-9 database for analyses of trends in liver and IHBD mortality rates in the SEER population in 1999-2010.

Unmodified age-standardized death rates (age 15+ years) for liver cancer were slightly higher for the SEER population than for the entire US population, and deaths in the SEER database accounted for about 9% (13,551/147,757) of all US deaths (Table 2). Modified SEER rates were lower but trends in age-standardized rate for liver cancer were similar to the trends for unmodified SEER rates (Table 2, Figure 1); 95% CL on the APCs overlapped (Table 2).

Deaths coded to IHBD cancer as the underlying cause in the SEER database comprised about 10% (4291/42,174) of all US deaths at age 15+ years from IHBD cancer (Table 2). Unmodified SEER age-standardized rates for IHBD cancer were slightly higher than rates for the entire United States, but both rates increased over time (Table 2, Figure 1). The modified SEER rate showed an early decline (with a statistically significant APC) followed by an increase (not statistically significant, P = .051), with no overall change in 1999 vs 2010 (Table 2, Figure 1).

The increase in unmodified death rates for IHBD cancer reflected a decline in the proportion of deaths coded to IHBD that were confirmed as IHBD in SEER from 43.9% (90/205) in 1999 to 32.1% (115/358), due mainly to an increase in other biliary tract cancers (from 51 in 1999 to 114 in 2010) (data not tabulated).

Trends in Age-Specific Liver Cancer Death Rates in SEER vs Entire United States

In view of the low concordance rates for IHBD cancer and small numbers of deaths in most age groups (data not shown), trends in SEER age-specific death rates after modification for inaccuracies in cause of death were analyzed only for liver cancer. Modified numbers of liver cancer deaths at age 15–34 years in SEER (143 in 1999–2010) were too small for analysis of trends in annual rates. Modified SEER rates, and also US rates, declined for age 35–44 years, whereas the rates for age 45–54 years increased until the mid-2000’s and then declined, and the largest increase was for age 55–64 years; the rates for age 65–74 years changed little over time.
For age 75–84 years slight increases were evident for unmodified and modified SEER rates as well as for US rates (data not shown).

For age 65–74 years, SEER modified rates were considerably lower than US rates (Figure 2), mainly because modified rates excluded decedents with multiple primary cancers recorded in SEER. Among all 16,333 decedents (prior to any exclusions) who had a SEER diagnosis of liver cancer and died in 1999–2010 at age 15+ years, the proportion with more than 1 primary cancer recorded in the SEER database was only 4% for deaths at age 35–44 years, 6% for age 45–54, and 10% at 55–64, but reached 17% at age 65–74 and 24% at age 75–84 years (data not shown).

Discussion

Inaccuracies in the Estimated Number of Liver–IHBD Cancer Deaths in the Population

Apparent errors in liver or IHBD cancer as underlying cause of death, using cancer diagnosis in SEER as the gold standard, involved mainly misreporting of some other site in the liver-biliary tract or secondary liver cancer as primary liver cancer on the death record. This overreporting was offset by underreporting to a much greater extent for liver cancer than for IHBD cancer (Table 1).

Annual numbers of deaths for selected types of cancer as underlying cause in the entire US population, routinely produced by the American Cancer Society and tabulated in SEER reports, include “liver and intrahepatic bile duct” and “gallbladder and other biliary.” Using the data in Table 1, 17,842 deaths were coded to either liver or IHBD as underlying cause, whereas the modified number was 12,140; this suggests that overreporting on death records could have been as high as 47.1% ([17,842 minus 12,140] divided by 12,140). The figure was 31% for overreporting of liver or IHBD cancer as underlying cause of death using ICD-9 codes in 1985–1986 in the SEER-9 population based on much smaller numbers of deaths. Thus, the problem of overreporting of liver or IHBD cancer as the underlying cause has persisted.

Combining the numbers of deaths coded to liver–IHBD or gallbladder–other biliary into a single group would be more accurate, as suggested by the findings for liver and IHBD cancers (Table 1). These cancers are heterogeneous, however, in known risk factors, prognosis and treatment; also, temporal trends differ in incidence rates for specific sites within the biliary tract in SEER and in modified mortality rates for liver vs IHBD cancer (Figure 1).

Trends in Liver and IHBD Cancer Mortality Rates

For liver and IHBD cancers, unmodified age-standardized mortality rates based on routine mortality data on underlying cause were only slightly higher for the SEER population than for the entire US population and trends were similar (Table 2, Figure 1). Trends in mortality rates in the SEER population have been found to be representative of trends for the entire United States for some but not all specific cancer sites.

Table 2. Trends in Age-Standardized Death Rate (15+ years) per 100,000 for Primary Liver Excluding Intrahepatic Bile Duct (IHBD) Cancer, and for IHBD Cancer, as the Underlying Cause of Death for the Entire US Resident Population, and for the SEER Population Before and After Modification for Inaccuracies in Cause of Death

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rate (CL)</td>
<td>Rate (CL)</td>
<td>Rate (CL)</td>
<td>Total No.</td>
<td>APC (CL)</td>
</tr>
<tr>
<td>Liver</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Years</td>
</tr>
<tr>
<td>US</td>
<td>4.5 (4.5, 4.6)</td>
<td>5.2 (5.1, 5.3)</td>
<td>5.7 (5.6, 5.8)</td>
<td>147,657</td>
<td>2.1 (1.9, 2.3)*</td>
</tr>
<tr>
<td>SEER</td>
<td>4.8 (4.5, 5.1)</td>
<td>5.2 (4.9, 5.5)</td>
<td>5.5 (5.2, 5.8)</td>
<td>13,551</td>
<td>1.4 (1.0, 1.7)*</td>
</tr>
<tr>
<td>SEER-M</td>
<td>3.7 (3.0, 4.0)</td>
<td>3.9 (3.6, 4.2)</td>
<td>4.4 (4.1, 4.6)</td>
<td>10,607</td>
<td>1.8 (1.1, 2.4)*</td>
</tr>
<tr>
<td>IHBD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>US</td>
<td>1.2 (1.1, 1.2)</td>
<td>1.5 (1.4, 1.5)</td>
<td>1.8 (1.8, 1.9)</td>
<td>42,174</td>
<td>4.5 (3.5, 5.6)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.9 (–0.0, 4.0)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6.3 (2.6, 10.2)*</td>
</tr>
<tr>
<td>SEER</td>
<td>1.3 (1.2, 1.5)</td>
<td>1.8 (1.6, 1.9)</td>
<td>1.9 (1.7, 2.1)</td>
<td>4,291</td>
<td>3.1 (2.3, 3.9)*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>–11.9 (–20.0, –3.0)*</td>
</tr>
<tr>
<td>SEER-M</td>
<td>0.7 (0.6, 0.9)</td>
<td>0.5 (0.4, 0.6)</td>
<td>0.7 (0.6, 0.8)</td>
<td>1,533</td>
<td>7.5 (–0.0, 15.7)*</td>
</tr>
</tbody>
</table>

*Joinpoint regression analysis showed a complex trend with 2 joinpoints (3 segments).

APC: Annual percent change (%) in rate, obtained from joinpoint regression models (see text).

SEER: Rates in the Surveillance, Epidemiology and End Results (SEER) Program based on underlying cause of death, as in routine mortality statistics.

SEER-M: SEER rates modified after exclusions (ie, decedents with multiple primary cancers and/or diagnosed only by autopsy or death certificate) and taking into account apparent inaccuracies in underlying cause of death (vs cancer diagnosis in the SEER database) (see text).

P <.05 for null hypothesis that APC equals zero.
site (mainly, extrahepatic bile duct). This may be explained by the recent temporal increase (1992–2009) in SEER incidence rates for extrahepatic bile duct cancer.13

For liver cancer, the similarities in mortality trends using modified vs unmodified death rates in the SEER population and in comparison to trends using routine statistics for the entire US population (Table 2, Figures 1 and 2), support the utility of routine data on underlying cause of death for surveillance of trends.

Explaining the trends in liver cancer mortality rates is beyond the scope of the present study. Analyses using data from SEER and National Program of Cancer Registries (NPCR) combined, however, have shown that incidence rates increased for histologically confirmed HCC alone (2001–2006)16 and for all primary liver cancers (2000–2010) in most age groups but not in certain younger age groups (<55 years).17 These incidence trends may largely reflect parallel trends in the prevalence of hepatitis C virus (HCV) infection in the population (which peaked among persons born in 1945–1965).17-19

Study Limitations

Findings must be interpreted within the limitations of the gold standard, the database, and the methodology involved. Some decedents who had been diagnosed with multiple primary cancers may not have been identified in the SEER database (eg, due to non-registration in SEER, or migration).2 The exclusion of decedents identified as having been diagnosed with multiple cancers in a cancer registry (as in other studies of concordance),2,4 however, could have affected the generalizability of the findings on mortality trends in the SEER population. One approach (albeit limited) to this problem involves examining stage at diagnosis of liver cancer among decedents with multiple cancer diagnoses. Using a SEER database with deaths in 1994–2003, 40 decedents had liver cancer diagnosed (1994–2003) at distant stage as their first cancer and at least 1 additional cancer; of these, 47.5% had liver cancer coded as the underlying cause of death,17 which may have been accurate, but review of medical records by an expert committee would be desirable for future studies.17 Nevertheless, the similarities in trends for modified death rates for liver cancer in the SEER population vs the entire United States in age groups <65 years (Figure 2) are important, because decedents with multiple primary cancers were less frequent for these age groups than for older ages.

Another limitation is that the gold standard included registered cancers in SEER that were not histologically confirmed, which were excluded from most of the analyses in 1 previous study2 but not excluded in others.3,4 The use of non-invasive radiologic imaging tests of the liver has been increasing over time,21 and can provide an acceptable diagnosis without biopsy for some patients.22 Radiologic techniques, however, have limitations in differential diagnosis; for example, contrast-enhanced ultrasound alone cannot distinguish IHBD cancer from HCC in some patients, and this technique has been removed from the guidelines for HCC diagnosis recommended by the American Association for the Study of Liver Diseases.22,23

The analyses of concordance (Table 1) involved liver cancer deaths (excluding IHBD) as defined by the SEER Cause of Death Recode group, which is widely used;7,8 deaths coded to specific causes such as C22.0 (HCC) or C22.9 (liver, unspecified) within this group, however, could not be identified in the database. Among all deaths (after excluding multiple primaries and autopsy/DCO cases) in 1973–1985 coded in ICD-8 or ICD-9 to liver unspecified as primary or secondary, Percy et al2 reported that SEER diagnoses included liver (36.8%), IHBD (1.0%), other biliary tract (5.8%), other specified sites (23.6%), and unknown primary site (32.8%).2 The analyses of concordance in Table 1 should be revised using cancer registry databases that can identify deaths coded to ICD-10 C22.9 as the underlying cause. To update other findings reported by Percy et al,2 numbers of deaths from HCC defined by ICD-10 code C22.0 alone vs either C22.0 or C22.9 as the underlying cause should
be examined, before and after modifications based on the cancer site and method of confirmation (microscopic vs radiologic) recorded in a population-based cancer registry.

Some deaths coded to a non-cancer condition as the underlying cause among all patients with a diagnosis of liver or IHBD cancer in SEER (Table 1) may have been related to liver or IHBD cancer. Databases with multiple causes of death for each decedent, study strengths include the quality of SEER data, including standards for low DCO rates (1.5% or less) after follow-back efforts by individual SEER registries, high completeness of reporting from hospital sources, and a focus on key items such as primary cancer site in quality-control efforts.

The Need for Similar Studies Using Additional Population-Based Cancer Registries

A SEER Incidence-Based Mortality database is available for all 18 SEER registries starting with diagnoses in 2000.25 Cancer incidence data starting in 2000 are available for states in the NPCR which meet specified standards for quality and completeness26; linkages with the National Death Index may enhance ascertainment of deaths.27 The addition of underlying cause of death is planned for certain NAACCR analytic files with data from SEER and NPCR.28

Findings from the present study can be used to evaluate the potential for similar studies using other databases. Among the 10,607 decedents (Table 1) used for modified liver cancer death rates, the proportion with a year of diagnosis before 2000 recorded in the SEER database2 declined from 41% for deaths in 2000 to 13% in 2001, 11% in 2002, 5% in 2003, and only 2% in 2005; for IHBD cancer, this proportion declined from 46% for deaths in 2000 to 1% in 2005 (data not shown). Thus, other databases should be useful for studies of modified death rates for these cancer sites for calendar years starting in the mid-2000s.

In comparing trends in mortality rates for the United States and other countries (eg, in Europe), the extent of inaccuracies in underlying cause of death for liver cancer (eg, miscoding of secondary cancer as primary)29 and IHBD cancer30 in each country should be considered, by linking death records with available population-based cancer registry databases. Also to be considered are potential differences in coding practices for perihilar cholangiocarcinoma among cancer registries, as shown in selected Asian and Western countries.31

Conclusions

Within the limitations of the gold standard and the methods used, the findings suggest that liver and (especially) IHBD cancers are overreported as underlying cause of death, and that routine mortality data may be useful for surveillance of temporal trends in death rates for liver cancer but not for IHBD cancer. Similar surveillance efforts should be continued, preferably involving additional population-based cancer registries, because mortality trends could be affected by projected increases in incidence rates for liver cancer in older age groups, but expanded testing for (and early treatment of) HCV infection could prevent some of these cancers.19,32 Reductions in mortality rates could occur through better screening and early detection of cancer in high-risk groups, expanded use of established treatments and the development of more treatment options (especially for IHBD cancer).25,35-37

References

Enhancement and Validation of an Arab Surname Database

Kendra Schwartz, MD, MSPH; Ganj Beebani; Mai Sedki; Mamon Tahhan, MD; Julie J. Ruterbusch, MPH

Abstract: Objectives: Arab Americans constitute a large, heterogeneous, and quickly growing subpopulation in the United States. Health statistics for this group are difficult to find because US governmental offices do not recognize Arab as separate from white. The development and validation of an Arab- and Chaldean-American name database will enhance research efforts in this population subgroup. Methods: A previously validated name database was supplemented with newly identified names gathered primarily from vital statistic records and then evaluated using a multistep process. This process included 1) review by 4 Arabic- and Chaldean-speaking reviewers, 2) ethnicity assessment by social media searches, and 3) self-report of ancestry obtained from a telephone survey. Results: Our Arab- and Chaldean-American name algorithm has a positive predictive value of 91% and a negative predictive value of 100%. Conclusions: This enhanced name database and algorithm can be used to identify Arab Americans in health statistics data, such as cancer and hospital registries, where they are often coded as white, to determine the extent of health disparities in this population.

Key words: Arab American, ethnicity, predictive value, registries, surname lists

Introduction

Arab Americans constitute a large and heterogeneous subpopulation in the United States, and are one of the fastest growing immigrant groups in metropolitan areas. The current number of Americans with Arab ancestry according to the 2011 American Community Survey is approximately 1.7 million. However, the number is estimated at more than 3.7 million by some advocacy groups, with the states of California, Michigan, and New York having the largest populations.

Health statistics are not available for Arab Americans because the US Office of Management and Budget, which provides guidance to the US government regarding race and ethnicity classification, does not recognize Arab American as separate from white. Furthermore, the 2010 US Census form did not contain an ancestry question, making it even more difficult to obtain recent population data about Arab Americans. In Michigan, the number of Arab Americans is estimated to be over 500,000, representing one of the largest concentrations of Arabs in the United States, with some Detroit suburbs being 30% Arab American.

In order to facilitate estimating the health of this important and growing ethnic group, we enhanced an existing Arab and Chaldean name algorithm with new names from Michigan vital statistics and other sources, and validated its identification properties using several methodologies. This algorithm can be used to identify people of Arab descent from health databases, such as health care systems and cancer registries.

Methods

In 2000, Schwartz et al first developed and validated an Arab name algorithm. Additional names were added to the list in 2009 and validated using several methods. The protocol to enhance and validate the name lists was reviewed and approved by the Wayne State University Institutional Review Board.

An electronic file containing birth and death records from the State of Michigan’s Department of Community Health was obtained for the years 2000–2008. Surnames were captured if either the index name (child or decedent) or their parents indicated Arab ancestry or a birthplace in 1 of the 22 Arab League countries. This list of surnames was matched against the validated 2000 name database to remove previously identified Arab-American surnames. The remaining list contained 10,385 unique surnames for review (Figure 1).

Four Arab researchers (2 of Syrian ancestry, 1 of Lebanese ancestry, and 1 of Iraqi Chaldean ancestry) independently reviewed the name list. Each reviewer coded the last names into 1 of 3 categories: Arabic, non-Arabic, or equivocal. The independent reviews were then evaluated for consensus. If all 4 reviewers agreed on the ancestry assignment, no further action was taken. For names with 1 or more discordant review, the last name was further evaluated using a social networking website. Ten profiles with the same surname were randomly reviewed for personal interests (music, TV, movies, etc). If all profiles reviewed either explicitly indicated Arabic ancestry or had Arabic entertainment interests, that name was considered...
As Arabic. If the reviews resulted in mixed results, the name was coded as equivocal. If no indication of Arab ancestry was found, the name was coded as non-Arab. The 4 reviewers, along with the study’s principle investigator, met in person to review all discordant names and Internet reviews to reach consensus.

To determine the sensitivity and positive predictive value of the list, a telephone survey was conducted. Residences with a surname from the list were identified using a publicly available online telephone directory. Telephone calls were made to determine if a person with that surname self-identified as being of Arab or Chaldean descent. The list of surnames to be contacted included the 30 most common surnames as determined by their frequencies from the vital statistical records (2000–2008), and a 5% sample of the remaining unique surnames. We derived 10% of the frequency count of each selected surname to determine the number of households per surname to contact, thereby ensuring more calls to households with the more common surnames. If a fraction resulted, the number was rounded up; for surnames with a frequency of 1, only 1 residence with that name was contacted. Additionally, a random 1% sample (n = 118) of surnames from vital statistic records that did not match the Arab name database was selected as negative controls.

After compiling the list of names to contact for validation, the online phone book engine was used to obtain Michigan phone numbers for each of the sampled surnames. In order to ensure the residence was randomly selected, we first obtained the number of search results reported by the search engine and used a random number generator to identify the residence to be contacted. For example, if the search engine reported 17 results for the surname, the random number generator would incorporate numbers 1–17 and generate a number, eg, 8, and the eighth listing for the surname was contacted. Prior to contacting each residence, we ensured that it was not a duplicate based on the accompanying address.

A script was read to the answering individual identifying the caller as a researcher from Wayne State University. The callers offered to speak in Arabic if the respondent preferred. All respondents were at least 18 years old, possessed the desired surname, and provided a response regarding the ancestry with which each identified. Sensitivity, specificity, positive predictive value, and negative predictive value were calculated based on the results of the phone call surveys.

**Results**

For the 10,385 new unique surnames obtained from the enhancement, 6,755 were coded as non-Arabic, 586 were coded as equivocal, and 3,044 were coded as Arabic after the final review. Adding these names to the established name databases created a dataset with 12,333 Arabic surnames and 643 equivocal surnames.

A total of 663 calls were completed, 610 calls to households with surnames identified from the Arab name databases and 53 to households with names not in the Arab name database. Of the 610 calls to an Arab surname household, 15 responses were removed because the respondents reported that the name was their married name (n = 8) or that they were African American (n = 7). These responses were removed as the name algorithm is only matched against individuals classified as white, and maiden name is preferentially used for females. For the 595 remaining responses, 540 reported an Arab ancestry and 55 reported a non-Arab ancestry. The most common non-Arab ancestry responses were European (German, Irish, French, etc) (n = 14), Pakistani (n = 13), and Asian (n = 8). For the 53 calls to surnames not in the Arab name database, all 53 reported a non-Arab ancestry. To account for the difference in the number of Arab and non-Arab households selected for phone call validation, the non-Arab selection was weighted to match the Arab selection (number of Arab responses/number of non-Arab responses = 595/53 = 11.2).

Based on the phone survey validation, the calculated sensitivity of the Arab surname list was 100% and the positive predictive value was 91%. The specificity was 91% and the negative predictive value was 100%.

**Discussion**

We developed and recently enhanced an Arab-American name algorithm that contains more than 12,000 unique surnames and has a positive predictive value of 91%. This algorithm can be used for identification of persons of Arab and Chaldean ancestry in registries and health databases that do not routinely capture that information. As the Arab American community continues to grow, there is a need to estimate the disease burden in this population group. Very few studies have been conducted looking at specific diseases in this population; however, there are indications of health disparities in this ethnic group when
compared to non-Hispanic whites.5-8 This name algorithm provides a tool to identify Arab ancestry in health databases that can then be used to quantify disparities as a first step to addressing them.

Name algorithms for identification of specific race/ethnicity have been developed and used for similar purposes and indeed have been endorsed by the Institute of Medicine as a method of indirect estimation for health care quality improvement.9 The first cancer registration surname use was by R. Buechley in 1976 to identify Hispanic ethnicity.10 US cancer registries now routinely use the National Hispanic Identification Algorithm (NHIA)11 and the National Asian Pacific Islander Identification Algorithm (NAPIIA)12, while a South Asian Name and Group Recognition Algorithm (SANGRA) was developed for use in British health studies.13

Working with the US Social Security Administration, Nasseri et al developed a Middle Eastern name algorithm that has been used to describe the cancer burden among California residents with Middle Eastern ancestry.14 Middle East in this algorithm was defined as birth in an Arab state as well as the non-Arab states of Israel, Turkey, Pakistan, and Afghanistan. A probabilistic Arab name algorithm was similarly developed using US Social Security Administration data as the source of names, but limited the names to those with birth in 1 of the 22 Arab League States except Comoros and expanding Palestine to include West Bank and Gaza Strip as these are available in US Social Security Administration data.15 A validation of this algorithm using self-reported ancestry from Michigan birth certificates as the gold standard resulted in a positive predictive value of only 57%. Our rigorous and multistep approach to validation is no doubt the reason for our much higher positive predictive value of 91%. We have found that using only native country as a proxy for ancestry results in numerous misclassifications.

Even with good test characteristics, caution must be observed when using our name algorithm. First, it is designed to be used for identifying persons of likely Arab or Chaldean ancestry and therefore linked only with white if race is available, in order to avoid misclassification of black Muslims. In fact, misclassification of non-Arab Muslims (such as Pakistanis and Southeast Asians) is a concern. In Michigan, these population groups are much smaller than Arab and Chaldean ancestries; however, in other parts of the country where there are larger populations of non-Arab Muslims, the degree of misclassification could be higher.

Our algorithm also preferentially uses maiden name if available to identify Arab/Chaldean women, although Arab women often keep their maiden surnames after marriage.16,17 Women who are not Arab and marry a man of Arab ancestry do often take their husband’s name (our most common source of European names), which is why it is important to use maiden name if it is available.

Another challenge to the use of our name algorithm is the heterogeneity of the Arab population. While Arabs do have a common history and sense of community, in addition to the common surnames among Arabs as a whole, each Arab country or region has its own unique surnames that are not found in other regions (such as last names which refer to land, like Al-Bayaty or Baghdad). Because our surname list was collected using primarily Michigan vital statistics, where Lebanese and Iraqi are the 2 largest groups, it may not have similarly good test characteristics in other areas of the country where there may be fewer immigrants from Lebanon or Iraq and more Egyptians, such as New York or New Jersey.9

The high sensitivity, specificity, and positive and negative predictive value provide confidence in using this validated name algorithm. The strength of our validation process is in the multiple steps: 1) name review by Arabic and Chaldean speakers; 2) social media searches (an innovative use for this type of research); and 3) self-report of ancestry. The telephone interviewers were Arabic speakers, which increases the confidence in our results. It is important to continue to conduct health studies to identify disparities among Arabs and Chaldeans. The best studies would use self-report of Arab or Chaldean ancestry; however, that information is often not collected and as long as the US Office of Management and Budget continues to identify Arab/Chaldean as white, there will be a need for validated algorithms such as ours. Our goal is to continue to enhance this resource on a regular basis and welcome opportunities to work with other investigators interested in understanding the disease burden among Arab Americans. Perhaps in the future, the database and algorithm might be maintained and made available in a manner similar to the NHIA and NAPIIA databases.

References


Impact of Race/Ethnicity and Socioeconomic Status on Adjuvant Chemotherapy Use among Elderly Patients with Stage III Colon Cancer

Mei-Chin Hsieh, MSPH, CTR; Yu-Wen Chiu, DrPH; Cruz Velasco, PhD; Xiao-Cheng Wu, MD, MPH, CTR; Mary B. O’Flarity, MN; Vivien W. Chen, PhD

Abstract: Background: It is well recognized that stage III colon cancer patients who received chemotherapy postoperatively can have a reduced risk of recurrence and an improved survival rate. This study examined the impact of race/ethnicity and socioeconomic status (SES) on receipt of chemotherapy within 4 months after resection among stage III colon cancer patients enrolling in Medicare Parts A and B and trends of utilizing adjuvant chemotherapy. Methods: Stage III colon cancer patients diagnosed between 2000 and 2007 were obtained from the Surveillance, Epidemiology, and End Results–Medicare data. Multilevel logistic regression was used to estimate the association between predictor variables and adjuvant chemotherapy, and the Cochran-Armitage test was used to assess for linear trends. Results: Of 13,608 stage III colon cancer patients aged 66 and older, 56% received adjuvant chemotherapy within 4 months of surgical resection. Blacks or patients residing in the least affluent areas were less likely to receive the adjuvant chemotherapy within 4 months after resection, both before and after adjusting for race/ethnicity and other independent variables. A significantly decreasing trend was observed, from 58% in 2000 to 53% in 2007, for all patients combined. Trends of receiving chemotherapy within 4 months after resection were varied more in racial/ethnic groups than in SES groups. Conclusions: After adjusting for demographic and clinical factors, there are persistent racial/ethnic and SES disparities in the use of adjuvant chemotherapy among Medicare-insured elderly patients with stage III colon cancer. The shortage of chemotherapy drugs and the change of Medicare drug administration reimbursement could be attributive factors in the decline of using adjuvant chemotherapy within 4 months of surgical resection.

Key words: adjuvant chemotherapy, colon cancer, Medicare, race/ethnicity, socioeconomic status

Introduction

The surgical resection of the primary tumor and regional lymph nodes is the standard treatment for locoregional colon cancers. However, patients with stage III colon cancer have higher risk of both local and distant recurrence after resection than those with stage I and II colon cancer. Randomized clinical trials demonstrated that stage III colon cancer patients benefited from adjuvant chemotherapy after surgical resection with a reduced risk of tumor recurrence and improved survival. In 1990, the National Institute of Health Consensus Development Conference recommended adjuvant chemotherapy for all stage III colon cancer patients after surgical resection. In addition, administering adjuvant chemotherapy to patients under 80 years old with stage III colon cancer within 4 months of diagnosis was endorsed by the National Quality Forum (NQF) in 2007 as one of the quality measures.

Despite similar benefits of postoperative chemotherapy demonstrated in both older and younger stage III colon patients, the percentage of elderly patients receiving adjuvant chemotherapy is much lower than that of younger patients, particularly for those 80 years of age and older. In addition, patients primarily insured by Medicare were twice likely not to receive adjuvant chemotherapy than those who were privately insured. The racial/ethnic disparities on receiving the guidelines-recommended care have been found for colon and other cancer sites; furthermore, socioeconomic status (SES) has been recognized as a factor affecting treatment accessibility for cancer patients.

Our objectives were to 1) examine the impact of race/ethnicity and SES on receipt of chemotherapy among patients enrolling in Medicare Parts A and B only (fee-for-service) with stage III colon cancer, 2) identify factors associated with not receiving the guidelines-recommended care, and 3) evaluate trends of utilizing adjuvant chemotherapy by race/ethnicity and SES in this study cohort. The outcome was the status for receiving adjuvant chemotherapy within 4 months after surgical resection.

Patients and Methods

Data Sources

Data were obtained from the Surveillance, Epidemiology and End Results (SEER)-Medicare 2000–2007...
linked database. This database contained cancer cases from 16 SEER population-based cancer registries (Connecticut, Detroit, Hawaii, Iowa, New Mexico, Seattle, Utah, Atlanta, Rural Georgia, Kentucky, Louisiana, New Jersey, and California including San Francisco, San Jose, Los Angeles and Greater California) covering about one quarter of the US population with detailed claims information from the Medicare program. The SEER data provide information on each cancer incident including patient demographics, tumor histology and staging, cancer directed treatment, and follow-up information. Medicare, a federally funded program, provides health insurance to persons aged 65 years and older, and to persons with end-stage renal disease or with disabilities. Medicare Part A covers hospitalization, short-term convalescence and rehabilitation in a skilled-nursing facility, hospice, and some home health care agencies. Medicare Part B, a voluntary program, covers physician and outpatient services as well as durable medical equipment. Ninety-seven percent of the elderly enroll in Part A; of these, 96% also enroll in Part B.27-28 Each Medicare file contains claims from multiple providers such as hospital, physician, and home health care agencies. Every Medicare claims file includes a Health Care Procedure Classification Code (HCPCS) and an International Classification of Diseases, Ninth Revision (ICD-9) diagnosis code to describe the nature of the billed service. The HCPCS is composed primarily of Current Procedural Terminology (CPT)-4 codes developed by the American Medical Association with additional codes specific to the Centers for Medicare and Medicaid Services (CMS). Additionally, each claim contains the dates of service, reimbursement amount, encrypted provider numbers, and beneficiary demographic data.28

Patients

The study cohort was limited to Medicare beneficiaries continuously enrolling in Medicare Parts A and B but excluded those enrolling in Medicare-managed care plans after cancer diagnosis. We selected Medicare-enrolled patients aged 66 years and older who were diagnosed with microscopically confirmed stage III colon cancer (ICDO-3 topology codes C18.0-C18.9) during the years 2000 to 2007 and who underwent the surgical resection within 6 months of diagnosis. Non-epithelial cancer (sarcomas and lymphomas) of the colon were further excluded. The cancer stage was based on the American Joint Committee on Cancer (AJCC) staging third edition for 2000–2003 cases and sixth edition for 2004–2007 cases. The surgical procedures used to define the colon resection included ICD-9 procedure codes 45.7x, 45.8x, 48.4x, 48.5x, and 48.6x from hospital inpatient and outpatient claims and Current Procedural Terminology (CPT) codes 44140–44147, 44150–44160, 44202–44239, 45110–45170, and 45395–45397 from physician and outpatient claims.

Initially, we identified 15,479 potentially eligible stage III colon cancer patients. Patients who were diagnosed with non-colorectal secondary cancer within 10 months of primary diagnosis (n = 394 cases) were excluded because it could affect the first course treatment plan. Also excluded were patients with the number of positive regional nodes examined coded to negative, no node examined, or unknown due to conflict with stage III definition (n = 198 cases). We also excluded patients with unknown census tract or census tract coded to either a post office box or unknown coding method (n = 420 cases). Finally, we removed patients who died within 30 days after surgery (n = 839 cases) since, in general, adjuvant chemotherapy would unlikely be administered to the patient within 30 days of surgery. A total of 13,608 eligible patients were included in the final analysis.

Definition of Adjuvant Chemotherapy Utilization

Chemotherapeutic information can be obtained from the Medicare outpatient, physician, inpatient, and durable medical equipment (DME) files. We did not restrict to only the standard intravenous chemotherapeutic agents or oral chemotherapy drugs that are administered to colon cancer such as 5-fluorouracil (5-FU), irinotecan, oxaliplatin, leucovorin, and capecitabine, but included all chemotherapy-related administrations received within 4 months after surgery. For this study, the definition of chemotherapy included intravenous agents and oral drug (HCPCS codes J0640, J8500-J9999; National Drug Codes [NDC] 000041100xx, 000041101xx, 548684143xx, and 548685260xx), chemotherapy administration (ICD-9-CM procedure code 9925; CPT codes 964xx and 965xx; HCPCS codes Q0083-Q0085; revenue center codes 0331, 0332, and 0335), and medical supervision of chemotherapy (ICD-9-CM diagnosis codes V851, V8511, V862, and V672). We also included chemotherapy related codes used exclusively in 2005, which included HCPCS codes C8953-C8955, G0355-G0363 and NDC codes 545695717xx.

Description of Independent Variables

Race/ethnicity was extracted from SEER data and supplemented by Medicare when the race and/or ethnicity were unknown in SEER data. Race/ethnicity was classified to white, black, Hispanic (regardless of race), or American Indian/Alaska Native/Asian or Pacific Islander (AI/AN/API). Since patient SES was not available, SES of the census tract where the patient resided at time of diagnosis was used as a surrogate of patient SES. Ninety-five percent of the study cohort had the census tract coded to perfectly matched address, 1.2% coded census tract based on ZIP plus 4 or ZIP plus 2, and only 3.7% of patients coded to ZIP code centroid. A SES composite index was created using principal components analysis based on 3 social and economic measures at census tract level obtained from the 2000 United States Census. These 3 measures were: 1) the proportion of population 25 years and older with less than a high school education, 2) the percent of tract residents living below the federal poverty level, and 3) the median household income for census tract in 1999, as described previously.29 We then grouped the SES score into quartiles. Additionally, the urban/rural continuum codes were defined based on the population size of metropolitan (metro) in the counties of patient’s residency at diagnosis and the degree of urbanization which was developed by United States Department of Agriculture (USDA)30 and categorized into metro and non-metro areas. Additional demographic variables were
sex, age at diagnosis (66–69, 70–74, 75–79, 80+), and marital status (single including divorced and separated, married, widowed, and unknown).

Clinical variables included anatomic subsite, histological grade, number of positive nodes, intestinal obstruction condition, creation of an intestinal stoma (colostomy or ileostomy) during the surgical resection, and comorbid conditions. Anatomic subsites of colon were categorized into right colon (C18.0–C18.3), transverse colon (C18.4), left colon (C18.5–C18.7), and overlapping or colon not otherwise specified (C18.8–C18.9), and histological grade was grouped into well/moderately differentiated, poorly/undifferentiated/anaplastic, and unknown. The patient’s comorbid conditions were obtained from the hospital inpatient, outpatient, and physician claims up to 12 month before diagnosis of colon cancer. We employed the Deyo-Romano version of Charlson Comorbidity Index to assess patient comorbidities. Other predictor variables were year of diagnosis and hospital characteristics. The year of diagnosis was grouped into 2 periods: 2000–2003 and 2004–2007. Hospital characteristics were based on where the surgical resection was performed, and were categorized according to the American College of Surgeons’s (ACoS) accreditation of Commission-on-Cancer (CoC) Program (ACoS hospital versus non-ACoS hospital).

Data Analysis
The likelihood of receiving adjuvant chemotherapy within 4 months of surgical resection among elderly colon patients with stage III disease was estimated using multilevel logistic regression which took into account the intra-class correlation. Because SES score quartile data were defined at census tract level of the 16 SEER registries, traditional logistic regression will underestimate the standard errors when independence assumption is violated. We created a unique identification (ID) for each census tract using the combination of SEER registry ID, county code, and census tract code. SES and unique census tract ID were included as random effects. The SAS GLIMMIX procedure was used to fit multilevel logistic regression models. No interaction terms were evaluated in this analysis. The linear trend of receiving adjuvant chemotherapy over time was assessed by the Cochran-Armitage test. We used SAS version 9.3 (SAS Institute, Cary, NC) to conduct all statistical analyses and tests were conducted at the 0.05 significance level.

Results
Between 2000 and 2007, 13,608 eligible Medicare beneficiaries with resected stage III colon cancer were included in the study cohort; 80.9% were white; 8.2%, black; 5.3%, Hispanic; and 5.6%, AI/AN/API. Overall, 56% of patients received adjuvant chemotherapy within 4 months of colon resection. Blacks had the lowest percentage (50%) and AI/AN/API had the highest percentage (63%) among all racial/ethnic groups (Table 1). Approximately 28% of whites resided in the most affluent (first quartile) SES area when diagnosed compared to only 8% of blacks. In contrast, the majority of blacks (61%) and Hispanics (43%) lived in the least affluent (fourth quartile) SES area. AI/AN/API patients were evenly distributed in the 4 SES groups (Table 1). We also observed that 41% of white patients were diagnosed at aged 80 and older compared to only 29% blacks and 32% Hispanics. Furthermore, blacks had a higher percentage (45%) of having comorbid conditions and intestinal stoma (15%) than other racial/ethnic groups.

In the univariate analysis, all predictor variables were significantly associated with receiving adjuvant chemotherapy except urban/rural county at diagnosis and hospital type (Table 2). In particular, 82% of stage III colon cancer patients aged 66–69 years received adjuvant chemotherapy within 4 months of resection but only 30% of patients age 80 and older did. Compared with whites, blacks were slightly less likely to receive adjuvant chemotherapy (odds ratio [OR], 0.78; 95% confidence interval [CI]: 0.68–0.88); whereas AI/AN/API were more likely to receive adjuvant chemotherapy (OR, 1.32; 95% CI: 1.13–1.54). Also, the odds of receiving adjuvant chemotherapy were significantly lower for patients residing in less affluent areas (second, third or fourth quartile SES) than those residing in most affluent (first quartile SES) area (Table 2).

After adjusting for SES, the likelihood of receiving adjuvant chemotherapy among racial/ethnic groups was comparable with those in univariate analysis. However, when all other predictor variables were adjusted (Model II), there were no significant differences of receiving adjuvant chemotherapy between Hispanic and white or AI/AN/API and white (Table 2). In contrast, the odds of receiving chemotherapy after surgery in blacks was 20% lower than whites when controlling for SES only (Model I: OR, 0.83; 95% CI: 0.73–0.94) and remained statistically significant after adjusting for all other predictor variables (Model II: OR, 0.69; 95% CI: 0.59–0.80) (Table 2). Patients residing in the third or fourth quartile SES areas were less likely to receive adjuvant chemotherapy than those who resided in the first quartile in univariate analysis and in Model I; however, only patients residing in the fourth quartile SES areas remained marginally significant after adjusting for all other variables (OR, 0.86; 95% CI: 0.76–0.97) (Table 2, Model II).

For other predictors, we found that patients who were married at diagnosis had 68% (OR, 1.68; CI: 1.49–1.89) higher odds of receiving adjuvant chemotherapy than single patients after adjustment; additionally, colon cancer patients with 4 or more positive lymph nodes were more likely to receive recommended chemotherapy. In contrast, patients of older age, with intestinal obstruction, intestinal stoma, or comorbid conditions, or who were diagnosed in the later time period (between 2004 and 2007), were less likely to receive adjuvant chemotherapy than their counterparts (Table 2). Although the use of adjuvant chemotherapy in females was 45% (OR, 0.69; 95% CI: 0.65–0.74) lower than males in univariate analysis; this association was no longer significant after adjustment for other predictors (Table 2).

Overall, we observed a decreasing trend from 58% in 2000 to 53% in 2007 for all cases combined (P <.001). Figure 1a shows the percentages of stage III colon cancer patients receiving adjuvant chemotherapy by diagnosis year and race/ethnicity. In this study, the percentages of receiving adjuvant chemotherapy varied by racial/ethnic...
Table 1. Adjuvant Chemotherapy Status, Demographic, and Clinical Characteristics by Race/Ethnicity, 16 SEER Registries, 2000–2007

<table>
<thead>
<tr>
<th>Variables</th>
<th>White</th>
<th>Black</th>
<th>Hispanic</th>
<th>AI/AN/API</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 11,011)</td>
<td>(n = 1,120)</td>
<td>(n = 715)</td>
<td>(n = 762)</td>
</tr>
<tr>
<td>Adjuvant Chemotherapy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>43.7</td>
<td>50.1</td>
<td>40.0</td>
<td>37.0</td>
</tr>
<tr>
<td>Yes</td>
<td>56.3</td>
<td>49.9</td>
<td>60.0</td>
<td>63.0</td>
</tr>
<tr>
<td>SES†</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st (most affluent)</td>
<td>27.7</td>
<td>8.2</td>
<td>12.9</td>
<td>24.9</td>
</tr>
<tr>
<td>2nd</td>
<td>28.7</td>
<td>10.5</td>
<td>17.5</td>
<td>23.0</td>
</tr>
<tr>
<td>3rd</td>
<td>26.2</td>
<td>20.7</td>
<td>26.9</td>
<td>26.1</td>
</tr>
<tr>
<td>4th (least affluent)</td>
<td>17.3</td>
<td>60.6</td>
<td>42.8</td>
<td>26.0</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>41.5</td>
<td>35.5</td>
<td>43.2</td>
<td>44.8</td>
</tr>
<tr>
<td>Female</td>
<td>58.5</td>
<td>64.5</td>
<td>56.8</td>
<td>55.3</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>66–69</td>
<td>14.4</td>
<td>19.6</td>
<td>20.1</td>
<td>18.1</td>
</tr>
<tr>
<td>70–74</td>
<td>21.1</td>
<td>27.6</td>
<td>23.1</td>
<td>24.2</td>
</tr>
<tr>
<td>75–79</td>
<td>23.8</td>
<td>23.9</td>
<td>24.5</td>
<td>23.8</td>
</tr>
<tr>
<td>80+</td>
<td>40.7</td>
<td>28.8</td>
<td>32.3</td>
<td>34.0</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>12.5</td>
<td>27.2</td>
<td>19.9</td>
<td>12.3</td>
</tr>
<tr>
<td>Married</td>
<td>50.3</td>
<td>31.4</td>
<td>46.2</td>
<td>59.5</td>
</tr>
<tr>
<td>Widowed</td>
<td>33.3</td>
<td>36.2</td>
<td>29.2</td>
<td>26.6</td>
</tr>
<tr>
<td>Unknown</td>
<td>3.9</td>
<td>5.2</td>
<td>4.8</td>
<td>1.6</td>
</tr>
<tr>
<td>Urban/rural</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metro areas</td>
<td>82.8</td>
<td>89.9</td>
<td>92.6</td>
<td>93.2</td>
</tr>
<tr>
<td>Non-metro areas</td>
<td>17.2</td>
<td>10.1</td>
<td>7.4</td>
<td>6.8</td>
</tr>
<tr>
<td>Anatomic subsite</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right</td>
<td>57.4</td>
<td>50.2</td>
<td>59.7</td>
<td>45.7</td>
</tr>
<tr>
<td>Left</td>
<td>31.3</td>
<td>38.0</td>
<td>31.2</td>
<td>44.0</td>
</tr>
<tr>
<td>Transverse/overlapping/unknown§</td>
<td>11.3</td>
<td>11.8</td>
<td>9.1</td>
<td>10.4</td>
</tr>
<tr>
<td>Histological grade</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well/moderately differentiated</td>
<td>65.1</td>
<td>74.0</td>
<td>69.8</td>
<td>73.9</td>
</tr>
<tr>
<td>Poorly/undifferentiated/unknown#</td>
<td>34.9</td>
<td>26.0</td>
<td>30.2</td>
<td>26.1</td>
</tr>
<tr>
<td>Intestinal obstruction</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>88.6</td>
<td>89.1</td>
<td>87.3</td>
<td>87.4</td>
</tr>
<tr>
<td>Yes</td>
<td>11.4</td>
<td>10.9</td>
<td>12.7</td>
<td>12.6</td>
</tr>
<tr>
<td>Intestinal stoma</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>89.7</td>
<td>84.6</td>
<td>90.2</td>
<td>91.7</td>
</tr>
<tr>
<td>Yes</td>
<td>10.3</td>
<td>15.4</td>
<td>9.8</td>
<td>8.3</td>
</tr>
<tr>
<td>Number of positive nodes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–3</td>
<td>66.8</td>
<td>71.7</td>
<td>63.9</td>
<td>64.0</td>
</tr>
<tr>
<td>≥4</td>
<td>31.4</td>
<td>27.1</td>
<td>34.1</td>
<td>34.5</td>
</tr>
<tr>
<td>Unknown</td>
<td>1.8</td>
<td>1.2</td>
<td>2.0</td>
<td>1.4</td>
</tr>
<tr>
<td>Comorbidity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>63.6</td>
<td>55.1</td>
<td>60.8</td>
<td>61.4</td>
</tr>
<tr>
<td>1</td>
<td>22.6</td>
<td>24.8</td>
<td>22.4</td>
<td>26.0</td>
</tr>
<tr>
<td>≥2</td>
<td>13.8</td>
<td>20.1</td>
<td>16.8</td>
<td>12.6</td>
</tr>
<tr>
<td>Diagnosis year</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000–2003</td>
<td>53.9</td>
<td>51.8</td>
<td>46.7</td>
<td>50.0</td>
</tr>
<tr>
<td>2004–2007</td>
<td>46.2</td>
<td>48.2</td>
<td>53.3</td>
<td>50.0</td>
</tr>
<tr>
<td>ACoS§ hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>78.4</td>
<td>69.4</td>
<td>85.6</td>
<td>69.8</td>
</tr>
<tr>
<td>Yes</td>
<td>21.6</td>
<td>30.6</td>
<td>14.4</td>
<td>30.2</td>
</tr>
</tbody>
</table>

¥ACoS, American College of Surgeons. †AI/AN/API, American Indian/Alaska Native/Asian or Pacific Islander. ‡SES, socioeconomic status. §The percentage of transverse colon and overlapping lesion of colon/unknown subsite of colon were combined due to small number of cases for some racial/ethnic groups. #The percentage of poorly/undifferentiated grade and unknown grade were combined due to small number of cases for some racial/ethnic groups.

Blacks had the lowest percentages of receiving chemotherapy during the 8-year study period, while AI/AN/API had the highest percentage. A sustained decline occurred from 2004 to 2006 for whites and from 2004 to 2007 for blacks. For Hispanic and AI/AN/API, a sharp decline appeared in 2005 and 2006, and then increased again in 2007. However, a statistically significant decline trend was observed in whites only. The trends of receiving adjuvant chemotherapy among SES groups displayed the least variation (Figure 1b). In general, stage III colon cancer patients residing in most affluent SES (first quartile) had a slightly higher percentage of receiving adjuvant chemotherapy than those of residing in other SES areas overtime, except 2004. In addition, we found statistically significant decline trends for patients residing in first or second quartile SES areas (Figure 1b).
<table>
<thead>
<tr>
<th>Variables</th>
<th>Count</th>
<th>% Receiving chemotherapy</th>
<th>Unadjusted</th>
<th>Adjusted Model I</th>
<th>Adjusted Model II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race/ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>11,011</td>
<td>56.3</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>1,120</td>
<td>49.9</td>
<td>0.78 (0.68, 0.88)</td>
<td>0.83 (0.73, 0.94)</td>
<td>0.69 (0.59, 0.80)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>715</td>
<td>60.0</td>
<td>1.16 (1.00, 1.36)</td>
<td>1.22 (1.04, 1.42)</td>
<td>1.07 (0.89, 1.28)</td>
</tr>
<tr>
<td>AI/AN/API †</td>
<td>762</td>
<td>63.0</td>
<td>1.32 (1.13, 1.54)</td>
<td>1.34 (1.15, 1.56)</td>
<td>1.14 (0.96, 1.36)</td>
</tr>
<tr>
<td>SES ‡</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st (most affluent)</td>
<td>3,428</td>
<td>59.2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd</td>
<td>3,578</td>
<td>56.7</td>
<td>0.90 (0.82, 0.99)</td>
<td>0.90 (0.82, 1.00)</td>
<td>0.93 (0.83, 1.03)</td>
</tr>
<tr>
<td>3rd</td>
<td>3,512</td>
<td>55.7</td>
<td>0.87 (0.79, 0.95)</td>
<td>0.87 (0.79, 0.96)</td>
<td>0.90 (0.80, 1.01)</td>
</tr>
<tr>
<td>4th (least affluent)</td>
<td>3,090</td>
<td>53.5</td>
<td>0.79 (0.72, 0.87)</td>
<td>0.81 (0.73, 0.90)</td>
<td>0.86 (0.76, 0.97)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5,613</td>
<td>61.6</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>7,995</td>
<td>52.6</td>
<td>0.69 (0.65, 0.74)</td>
<td></td>
<td>1.01 (0.93, 1.10)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>66–69</td>
<td>2,085</td>
<td>81.9</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70–74</td>
<td>2,978</td>
<td>75.1</td>
<td>0.67 (0.58, 0.76)</td>
<td></td>
<td>0.68 (0.59, 0.78)</td>
</tr>
<tr>
<td>75–79</td>
<td>3,246</td>
<td>65.1</td>
<td>0.41 (0.36, 0.47)</td>
<td></td>
<td>0.42 (0.37, 0.49)</td>
</tr>
<tr>
<td>80+</td>
<td>5,299</td>
<td>30.4</td>
<td>0.10 (0.09, 0.11)</td>
<td></td>
<td>0.10 (0.09, 0.12)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1,918</td>
<td>53.7</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>6,678</td>
<td>66.8</td>
<td>1.74 (1.57, 1.93)</td>
<td></td>
<td>1.68 (1.49, 1.89)</td>
</tr>
<tr>
<td>Widowed</td>
<td>4,483</td>
<td>42.2</td>
<td>0.63 (0.57, 0.70)</td>
<td></td>
<td>0.99 (0.87, 1.12)</td>
</tr>
<tr>
<td>Unknown</td>
<td>529</td>
<td>53.7</td>
<td>1.00 (0.82, 1.21)</td>
<td></td>
<td>1.14 (0.92, 1.41)</td>
</tr>
<tr>
<td>Urban/Rural</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metro areas</td>
<td>11,496</td>
<td>56.4</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-metro areas</td>
<td>2,112</td>
<td>56.3</td>
<td>1.00 (0.91, 1.10)</td>
<td></td>
<td>0.95 (0.85, 1.07)</td>
</tr>
<tr>
<td>Anatomic subsite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right</td>
<td>7,657</td>
<td>55.2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left</td>
<td>4,432</td>
<td>59.4</td>
<td>1.19 (1.10, 1.28)</td>
<td></td>
<td>1.08 (0.99, 1.18)</td>
</tr>
<tr>
<td>Transverse</td>
<td>1,250</td>
<td>53.4</td>
<td>0.93 (0.83, 1.05)</td>
<td></td>
<td>0.98 (0.86, 1.13)</td>
</tr>
<tr>
<td>Overlapping/Unknown</td>
<td>269</td>
<td>52.4</td>
<td>0.89 (0.70, 1.14)</td>
<td></td>
<td>0.99 (0.74, 1.30)</td>
</tr>
<tr>
<td>Histological grade</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well/moderately differentiated</td>
<td>9,058</td>
<td>57.0</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poorly/undifferentiated</td>
<td>4,196</td>
<td>55.5</td>
<td>0.94 (0.87, 1.01)</td>
<td></td>
<td>0.98 (0.90, 1.07)</td>
</tr>
<tr>
<td>Unknown</td>
<td>354</td>
<td>48.9</td>
<td>0.72 (0.58, 0.89)</td>
<td></td>
<td>0.65 (0.51, 0.83)</td>
</tr>
<tr>
<td>Intestinal obstruction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>12,043</td>
<td>57.8</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1,565</td>
<td>44.9</td>
<td>0.60 (0.53, 0.66)</td>
<td></td>
<td>0.63 (0.56, 0.72)</td>
</tr>
</tbody>
</table>
Table 2, cont. Distributions and Odds Ratios (ORs) with 95% Confidence Interval (CI) of Receiving Adjuvant Chemotherapy for Stage III Colon Cancer Patients, 16 SEER Registries, 2000–2007

<table>
<thead>
<tr>
<th>Variables</th>
<th>Count</th>
<th>% Receiving chemotherapy</th>
<th>Unadjusted OR (95% CI)</th>
<th>Adjusted Model I OR (95% CI)</th>
<th>Adjusted Model II OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intestinal stoma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>12,171</td>
<td>57.6</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1,437</td>
<td>45.7</td>
<td>0.62 (0.56, 0.69)</td>
<td>0.62 (0.54, 0.70)</td>
<td></td>
</tr>
<tr>
<td>Number of positive nodes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–3</td>
<td>9,104</td>
<td>55.2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≥4</td>
<td>4,270</td>
<td>59.1</td>
<td>1.17 (1.09, 1.26)</td>
<td>1.22 (1.12, 1.33)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>234</td>
<td>49.6</td>
<td>0.80 (0.62, 1.04)</td>
<td>0.80 (0.59, 1.07)</td>
<td></td>
</tr>
<tr>
<td>Comorbidity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>8,521</td>
<td>60.4</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>3,124</td>
<td>53.9</td>
<td>0.77 (0.70, 0.83)</td>
<td>0.78 (0.71, 0.86)</td>
<td></td>
</tr>
<tr>
<td>≥2</td>
<td>1,963</td>
<td>42.7</td>
<td>0.49 (0.44, 0.54)</td>
<td>0.49 (0.44, 0.55)</td>
<td></td>
</tr>
<tr>
<td>Diagnosis year</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000–2003</td>
<td>7,224</td>
<td>58.2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2004–2007</td>
<td>6,384</td>
<td>54.3</td>
<td>0.85 (0.80, 0.91)</td>
<td>0.83 (0.77, 0.90)</td>
<td></td>
</tr>
<tr>
<td>ACoS® hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>10,553</td>
<td>56.5</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3,055</td>
<td>55.7</td>
<td>0.96 (0.89, 1.05)</td>
<td>0.95 (0.87, 1.05)</td>
<td></td>
</tr>
</tbody>
</table>

†ACoS, American College of Surgeons. †AI/AN/API, American Indian/Alaska Native/Asian or Pacific Islander. ‡SES, socioeconomic status.

Discussion

It is well established that stage III colon cancer patients benefit from adjuvant chemotherapy after surgical resection. In this study, we observed racial/ethnic disparities for elderly Medicare fee-for-service beneficiaries with stage III colon cancer. Blacks tend to have a lower probability of receiving guideline adjuvant chemotherapy than whites. This finding is consistent with previous studies. In our analysis, the difference in the likelihood of receiving adjuvant chemotherapy between whites and blacks is especially noticeable after adjusting for SES, demographics, clinical variables, diagnosis year, and hospital characteristics. A recent study compared the use of oxaliplatin, a novel chemotherapeutic agent approved in 2004, after colon resection; however, no statistical significance was observed between white and black patients. This could be due to there being only 3 years (2004–2006) of SEER–Medicare data included in their analysis or the concern of use of new chemotherapy drug on patients.

Similar to previous studies, which found stage III colon patients who were residing in the least affluent SES areas tended to have a lower probability of receiving postoperative chemotherapy than those residing in most affluent SES areas, our study showed decreasing odds of receiving adjuvant chemotherapy with decreasing SES (from most affluent to least affluent SES) in unadjusted and adjusted models. However, VanEenwyk et al reported that patients residing in the least affluent SES areas were twice as likely not to receive adjuvant chemotherapy than those residing in the most affluent SES areas. We observed only marginal significance after adjusting for all other predictors. This discrepancy could be attributable to differences in the study populations or methods of defining SES. Our study population was limited to the Medicare-enrolled Parts A and B beneficiaries which may have been more homogenous in SES than other studies using state cancer registry data. A recent survey conducted via phone interview found
Medicare beneficiaries, age 65 or older, tended to live in more deprived socioeconomic conditions than those who had employer insurance.27 Our study also used census tract–level SES rather than ZIP-code level10 which, by its definition, is a more homogenous group with regard to socioeconomic characteristics than ZIP-code level SES.

Consistent with findings of previous studies, we found that age, marital status, number of positive lymph nodes, comorbidity, and year of diagnosis were significant predictors of receiving adjuvant chemotherapy.7,8,10,14 In particular, patients aged 80 and older or patients with 2 or more comorbidities were much less likely to receive recommended chemotherapy than younger patients or patients without comorbidities. Previous surveys showed that patients’ comorbid conditions were the primary reason for physicians not recommending the adjuvant chemotherapy to stage III colon cancer patients, followed by age.28-30 The lower likelihood of patients aged 80 and older to receive adjuvant chemotherapy could be due to increasing comorbidity or reduced benefit because of the life expectancy of patients.28-29 Furthermore, our study showed that stage III colon cancer patients with intestinal obstruction condition or creation of an intestinal stoma (colostomy or ileostomy) were substantially less likely to receive chemotherapy than those without such conditions.

Previous studies showed an increasing trend over time of receipt of adjuvant chemotherapy for colon cancer stage III patients.7,9 We did not observe the same pattern; instead, we found a slightly declining trend of use of adjuvant chemotherapy for all cases combined in the 8-year study period. The decline occurred in 2005 for all races/ethnicities except blacks and continued until 2006 when the percentages of not receiving adjuvant chemotherapy within 4 months after resection reached their lowest for most racial/ethnic groups. The decline of guideline-recommended chemotherapy utilization could be attributable to the shortage of chemotherapy drugs.31-32 The drug shortage has been recognized as a serious issue for over a decade, especially for the chemotherapy agents.33 Several reasons could cause the drug shortages; for example, contamination or shortages of raw materials, limited profit margins for generic drugs, and manufacturing plants being shut down because of quality-control issues.32 Another possible explanation for the decline in adjuvant chemotherapy is the change of the Medicare reimbursement system regarding physician-administered drugs under Part B.34 In 2004, the Congressional Budget Office issued the Medicare Modernization Act (MMA) stating that, effective in 2005, drug reimbursements would cap at the average sale price (ASP) plus 6% to cover practice costs.31-32,34-35 The 6% of ASP may be less than the cost of administration for some generic chemotherapy drugs; therefore, this policy not only reduced drug payments but reduced the demand for generic drugs as well.34

This study has several strengths. Medicare claims provide reliable data on patients receiving chemotherapy.36 The lack of complete chemotherapy is a broad issue for population-based cancer registries. Warren et al conducted a chemotherapy-agents comparison study between SEER–Medicare and National Cancer Institute–funded Patterns of Care (POC) Studies (serving as a gold standard) and found 88% agreement on receiving chemotherapy (with kappa statistic 0.73) and 90% of sensitivity for colon cancer patients.36 Our analysis also included oral chemotherapy drugs obtained from the Medicare durable medical equipment (DME) file which can enhance the completeness of chemotherapy data. The comorbidity information was not collected by any registries for cases diagnosed before 2003. While it is required by CoC for cases diagnosed in 2003 and after (Facility Oncology Registry Data Standards [FORDS]),37 this information may not be complete in database for population-based cancer registries. SEER–Medicare claims contain ICD-9-CM diagnosis codes, ICD-9-CM procedure codes, and HCPCS which serve as useful sources for obtaining the patient’s comorbid conditions.

However, due to the nature of Medicare claim data, several limitations have been identified in using SEER–Medicare data;17,38 some of which apply to our study. The population of this study did not cover all Medicare beneficiaries because services provided to a Medicare beneficiary by supplement health care system did not bill to Medicare. Also, for a beneficiary with managed care enrollment, the claims or encounter data are not required to be submitted to Medicare.27 As a result, our study population is limited to Medicare beneficiaries enrolled in Parts A and B only which may not be generalizable to the entire elderly population aged 66 and older in the United States. Although Medicare claims have a high level of agreement (88%) with SEER POC data on obtaining chemotherapy administration information, there still exist minor discrepancies in receiving chemotherapy for colon cancer patients; however, the impact is considered to be minimal.

In conclusion, there are persistent racial/ethnic disparities in utilization of recommended adjuvant chemotherapy among elderly patients with stage III colon cancer after adjusting for other predictors. Blacks had the lowest percentage of receiving chemotherapy within 4 months after surgical resection in the 8-year study period. The receipt of adjuvant chemotherapy among patients with Medicare fee-for-service enrollees was marginally associated with SES, after adjusting for other demographic and clinical factors. The change in Medicare drug administration reimbursement and drug shortages reduce the use of adjuvant chemotherapy for all races/ethnicities. It also diminished the racial/ethnic disparities in utilization of adjuvant chemotherapy in 2005 and 2006; whereas, the disparities reappeared in 2007. Further research is necessary to identify root causes of racial/ethnic disparity among elderly patients having equal access to treatment choice.

References


**Using the Cancer Registry to Meet the Commission on Cancer Clinical Trials Accrual Standard**

Alan Houser, MPH; Dan Curran, MS, CTR; Valerie Spadt, CTR

**Key words:** accrual standards, clinical trials, database, software

**Introduction**

Clinical trials are an important tool for innovation in cancer treatments. Therefore, accrual into trials has been highlighted for Commission on Cancer (CoC)-accredited hospital programs. The current Standard 5.21 and Standard 1.92 which take effect in 2015 require a minimum percentage of patient enrollment for compliance, as well as an opportunity for commendation at a higher percentage. The standards do not define a role for the hospital cancer registry staff but, at C/NET Solutions, we believe that the data collection and management efforts of the registry can be leveraged to effectively screen patients for clinical trials accrual.

The registry, however, faces several challenges with clinical trial screening:

- The hospital may be participating in many clinical trials, each with complicated and sometimes conflicting eligibility criteria. How does the registrar keep in mind all of the criteria while tracking patient enrollment status?
- Clinical trials requirements have to be interpreted and mapped to data fields that are used in the registry. A simple example is trial NCT01420081 with 1 criterion which excludes patients with “active brain metastases.” The registry has a data field called “CS METS AT DX-BRAIN” that records brain metastasis at diagnosis. This field could be useful in evaluating this particular criterion. However, each clinical trial may have dozens of criteria and they are often much more complicated than the example.
- Cases must sometimes be abstracted in a short time period in order to meet a trial’s criteria. For example, trial NCT01547741 requires that “the interval between the last surgery for breast cancer (treatment or staging) and randomization must be no more than 84 days.” A registry whose cases are required to be submitted to a state agency 6 months after diagnosis may not collect treatment or staging data in time to select an eligible patient. The same may be the case for laboratory results.

Recognizing the challenges faced by cancer registrars, how can cancer registry software systems be used to identify and track clinical trial patients? C/NET Solutions has developed a system to perform these tasks, but the principles addressed in this article should be applicable to any cancer database management system. The key to this process is to develop a series of queries that will exclude ineligible patients when they are applied to the cancer registry database. The task of interpreting the clinical trial criteria and writing the query using cancer registry fields is a one-time task. The query may be run against the cancer database on a regular basis to identify eligible patients. Many of the criteria may be repeated in other clinical trials and so a library of queries may be used repeatedly with only minor modification. Query writing can be challenging, but, once set up, the registrar is provided with a systematic method for screening patients for clinical trial eligibility. The details of each trial do not have to be recalled by the registrar in order to perform the screening.

The clinical trial query is written so that missing or unknown data do not exclude the patient from the pool of potential trial enrollees. For example, with the NCT01420081 trial cited above, the query not only includes cases that are free of brain metastases but also includes patients with an unknown status. Additional data may be abstracted later that will confirm the presence or absence of metastatic disease. Knowing that the patient is potentially eligible for a trial will focus attention on them and will prompt the registrar to review the medical record for additional information and to follow the patient for updates.

Once the potential clinical trial patients are identified, the information is shared with the clinical trials coordinator. The query can be used to generate a report or export data that can be given to the coordinator.

**Methods**

Three cancer registries participated in retrospective pilot studies. A total of 8 cancer clinical trials for which the registries had identified patients eligible for trials for the past 1 to 2 years were selected for the studies. C/NET Solutions staff provided the registries with the code required to run reports in our CNeXt cancer database software. The code was designed to select patients eligible for any of the 8 trials.

The list of patients previously selected by the registries was compared against those selected by the software. For some trials, the registries gave us feedback about some issues in the software specifications and another round of testing was performed after the queries were retuned.
Results

CNExT software was able to identify the same patients as those selected previously by the cancer registries in each of the 8 trials. In 2 of the tests, additional patients were identified that were missed by the registry’s manual screening process (Table 1).

Discussion

The retrospective study demonstrated that querying hospital cancer registry databases is a promising method of identifying cancer clinical trial patients despite the issues mentioned in the introduction to this article. The single biggest challenge for using hospital cancer registry data in clinical trial selection is populating the patient’s abstract early enough to make the determination of eligibility. Recent changes in CoC standards and developments in cancer registry technology should make cancer registries even more valuable for identifying eligible patients for clinical trials.

Beginning in 2014, the implementation of CoC Standard 5.2 Rapid Quality Reporting System (RQRS) will affect CoC accreditation surveys. Facilities gain a commendation for their participation in this standard. Before RQRS, the CoC received only complete cases during a yearly call for data from approved programs. With RQRS, cases are sent in as soon as a minimum data set (tumor size and histology, lymph node status, and staging, among others) is collected. The record is updated at least quarterly. Real-time clinical quality measures are reported back to the programs, thus encouraging programs to report treatment data as soon as possible. These same timely data will enable registries to more effectively screen for clinical trial participation.

It is becoming more common for cancer registries to interface with multiple hospital data sources. CNExT software, for example, interfaces with pathology, billing, and radiation oncology (in testing) data. Not only can data be abstracted more quickly because cancer databases are populated from these data sources, but queries can be run against the incoming data before the cancer registrar processes the data queues. C/NET Solutions is developing a function that will flag potential clinical trial patients in these queued data sources so that the registrar can prioritize these patients for clinical trials screening.

By using customized screens when processing case-finding, registrars can focus on coding specific data fields that may impact the automated screening process by providing more details (such as status of brain metastases) that could make the case more or less eligible for a trial.

References


<table>
<thead>
<tr>
<th>ClinicalTrials.gov Identifier</th>
<th>Site/Histology</th>
<th>Subset of Cases Screened</th>
<th>Subset Size (number of cases)</th>
<th>Eligible -Manually Identified by Facility</th>
<th>Eligible / Identified by CNExT Screening*</th>
</tr>
</thead>
<tbody>
<tr>
<td>NCT00769379 Breast Breast analytic cases Dx 2011</td>
<td>105</td>
<td>23</td>
<td>23/23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCT01547741 Breast Breast analytic cases Dx 2012</td>
<td>110</td>
<td>9</td>
<td>9/9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCT01547741 Breast Cases Dx 2013</td>
<td>498</td>
<td>1</td>
<td>1/1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCT01604889 Metastatic Melanoma Cases Dx 2013</td>
<td>498</td>
<td>14</td>
<td>14/14</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCT00075764 Breast Breast cancer cases Dx 2007–2009</td>
<td>372</td>
<td>3</td>
<td>10/58</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCT00408408 Breast Breast cancer cases Dx 2007–2009</td>
<td>372</td>
<td>3</td>
<td>6/8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCT01611558 Ovarian Cases Dx 2013</td>
<td>498</td>
<td>7</td>
<td>7/7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCT01616303 Ovarian Cases Dx 2013</td>
<td>498</td>
<td>1</td>
<td>1/1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NCT01420081 Endometrial Cases Dx 2013</td>
<td>498</td>
<td>16</td>
<td>16/16</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*First number is the number of cases eligible. The second number includes some screened cases that were not eligible because the data were not available in the registry to exclude them.
Raising the Bar: Working Under Frigid Conditions

Michele Webb, CTR

In 1974, construction began on the Trans-Alaska Pipeline System. It was a massive, 3-year project that came about after the 1973 oil crisis in the United States. The entire system included 12 pump stations, over 800 miles of pipeline and the Valdez Marine Terminal.

The builders of the pipeline faced a wide range of challenges caused by the bitter cold and the rugged, isolated landscape. It was one of the first projects forced to deal with permafrost, requiring the development of special construction techniques to accommodate the frozen ground.

Many Texans went to Alaska to work on the pipeline. As you might expect, the differences in climate were profound, and the Texans found they were able to work only a few hours at a time before they could no longer stand the frigid weather conditions. The native Eskimos, on the other hand, were seemingly able to work effortlessly and indefinitely in the cold. Based on these observations, a study was formed to find out why the Eskimos seemed to be physically superior to the Texans. Results indicated that there was no physical difference in the thickness of their skin, blood, or any other physical characteristic that would explain the Eskimo’s ability to work under frigid conditions.

Having accounted for the physical factors of the work, another study was formed to look at the psychological factors, and this is where things start to get interesting. Researchers found that the Eskimos’ perspective on their work was that, although they knew it was cold, they had a job to do and were focused on the task at hand. After interviews and observations with the Texans were compiled, researchers noted that the Texans were focused on the challenges within the task.

We often see this same principle play out in the cancer registry when we keep practicing the same old processes and behaviors that contribute to declining productivity, reductions in supportive services, and negative shifts in morale and mindset about the future of cancer registry. Rather than focusing on the fact that there is a job to do to support patient care, we often focus on the challenges of doing so. We miss the lesson that being a cancer registrar is hard work, but that work is not our enemy. When the work of meeting the needs of patient care or providing support to physicians, administrators, and hospitals changes—or when the need for the cancer registry to reinvent itself stares us in the face—we often give up on the task because we think it should be easier.

The only thing that comes easy is deciding that we will be a valued member of our cancer care team. Beyond that, we need to work out that desire with persistence and gumption. The late Nelson Mandela said, “It always seems impossible until it is done.” The conditions may be frigid and brutal, but that should not be our focus. Collection, delivery and promotion of complete, high-quality cancer data and registry support services will not be accomplished without a battle.

We can learn this lesson from the Eskimo. The world is cold, but there is a job to be done. If we focus on the task of honoring our profession and holding the hands of physicians and patients who are the ultimate benefactors of our work, we will not be susceptible to the negativity, limited attitudes, and changing conditions that surround us.

Michele is a cancer registry speaker, educator, coach, and independent contractor living in Rancho Cucamonga, California. She is the founder of www.CancerRegistrar.com, www.RegistryMindset.com, and http://MicheleWebb.com, offering cancer registry leadership, mentoring, and continuing education opportunities. Your comments are welcomed by email to michele@michelewebb.com.
The Journey from Office to Home

Melissa Riddle, CTR

Once upon a time, in a cancer registry world not so far away, there lived a tired and frustrated CTR whose days were full of meetings, deadlines, trainings, and attending school programs, as well as seeing to her family’s needs. She found herself moaning and groaning about how things were so hurry-scurry in her day-to-day life. “Is there no way to balance my life between the family I love and my career?”

This is no fairy tale, but the real life I lived just a few short years ago. I began a journey to find the balance I so desperately needed, and found it in working from home. However, working from home is not the easiest of roads to take. To help you find the balance you may be seeking, I want to share with you the things I have learned on my own journey.

Before your journey begins, you must have an efficient working environment. It is best if you can set up a separate room as an office with a locking door. You need an up-to-date computer, a safe and reliable Internet connection, antivirus software, a scanner/fax machine, a shredder, and a safe or lock box to secure confidential information. First and foremost is to ensure that the Health Insurance Portability and Accountability Act (HIPAA) standards of privacy are in place, similar to the security you would have in an office. No one in your home should have access to this information. My work computer is dedicated only to work. Also, be sure to keep in mind that you are now your own information technology (IT) personnel. If your computer crashes or gets a dreaded virus, it is up to you to get it fixed (unless your company has supplied you with a computer). It is always a good idea to have your computer covered with a plan from a reputable company for those unforeseen circumstances. Most facilities have IT personnel on staff to help you with connection issues; however, other computer issues will be your responsibility. Now that your world is in order, you can begin your new journey.

I found that leaving the world of cubicles and offices was not as easy as I had imagined. The fairy tale in my head of creating my own schedule and having time for everything was just that—a fairy tale. In order to have a balanced life, you need to be a schedule maker and keeper. Start by creating a to-do list for the day or week and include both professional and personal duties. Next, look at each item on your list and dedicate a set amount of time you think that it will take to complete the task. I always allow an extra 30 minutes for each task because I never know what issues may arise. Organize your schedule based on each task that must be completed for the day or week.

The key to this is to remain focused on the schedule you created. Do not allow yourself to be distracted by personal emails, Facebook (ie, candy crush), household chores, or personal phone calls. Let your family and friends know that when you are in your office at home, this is business and it should be treated as such. Unfortunately, the distractions of life will occur and emergencies will arise, but that is the advantage of working from home—your schedule can be flexible. If you need structure and are not a good schedule keeper, working from home may not be easy for you. Consider taking some time-management courses or asking your employer to give you a set schedule of tasks that must be completed each day.

Another important key to successfully working from home is to have mentors and a network of CTRs to discuss difficult cases. This network may include registrars you previously worked with, state association colleagues, a central registrar state educator, or just that long-time mentor who has always been there for you. Other resources such as the SEER Inquiry System (http://seer.cancer.gov/seerinquiry/index.php?page=search) or CAnswer Forum (http://cancerbulletin.facs.org/forums) can also be very useful. Most outsourcing companies have an educator or other person on staff to help you. Your facility may give you a contact person if you have a difficult case. I would advise you to ask the person giving you guidance to provide you with the manual and page referenced. This is to ensure that the guidance they are giving isn’t just their opinion or how they interact with others besides email and phone calls. Because I am a people person, this was my most challenging issue. This was a deep valley on my journey and I had to find more ways to interact with others. I became more involved with my children’s schools through the parent-teacher organization, as well as by participating in field trips, sports, and other fun events. This made working from home more enjoyable because I was beginning to find balance. So, if you are a people person like I am, here are a few ideas to help you interact outside of work: book clubs, fitness groups (Zumba, Get Fit), volunteering, hobby clubs, or a group/club that shares a similar passion with you. Whatever it may be, find the thing that makes you feel good and complete.

As you can see, the fairy tale of working from home has its own set of difficulties. Don’t be led into thinking work will be easy because you are at home. At times it is much harder and you have to be self-motivated. Keep those contacts and resources handy in your new world. Yes, the journey is long and the road is not smooth, but in the end, it is worth every sacrifice because you are doing what you love. We are cancer registrars, after all, and adapting to change is what we do best!

Melissa is currently a contract registrar for MedPartners HIM and can be contacted by email at riddlemelissa@ymail.com.
Special Feature

How I Do It: “Down and Dirty” Texting—A Template for Documenting Text in the Abstract

Pamela S. Warren PhD, CTR

Introduction

How to document in text fields! This is a hot topic for cancer registrars and, while some state registries are very specific about what they want to see in these text fields, others are not. Creating a texting template to follow can improve text documentation.

Many discussions about completing text fields mention all the items that need to be included, but rarely say just how to do it. Sometimes a template helps keep it simple. I have found over the years that if I am consistent with the way I put data in the text fields, it actually saves time. Surprisingly, I still run into cancer registrars who do not put in dates, ages, or other necessary data items, and who continue to spell things out completely when it is not necessary. While we may have a lot more space for documenting text now, it still takes time to spell everything out, and may take even more time if there is not a consistent way to document pertinent information.

Completing the text fields means putting together the story of a patient’s journey with cancer from abnormal finding through treatment. My preference is to complete all the text first and then complete the coding in the abstract. This gives me an understanding of the entire picture, which often saves time and frustration, especially with those more complex cases.

My philosophy for documenting in the text fields is that I should be able to abstract from what has been written. Every code should have corresponding text in the text fields. Additionally, I want to be able to know where I got the information from, should I have to go back and look at the data for a study, or to answer questions. Also, I don’t want to have to try to figure out what I meant because I’ve abbreviated badly or not used punctuation. I worked for a hospital once in a temporary position, and when my work was critiqued, nothing could be understood because there was no punctuation and everything ran together.

Method

Below are some suggestions for documenting in the text fields. This is not a perfect process, and I encourage continuous improvements to individual texting techniques that can be shared with others. After all, the cancer registry field is ever-changing, and cancer registrars are proficient at keeping up with those changes. The following are the text fields included in this discussion:

- Physical Exam Text
- Xray/Scan Text
- Scopes Text
- Lab Text
- Path Text
- Surgery Text
- Beam Radiation Text
- Chemo Text
- Hormone Text

Data that should be included in the text fields are date, place, physician’s name, what was done (procedures), and the results. These examples reflect what the text might look like and are not intended to be from a single case. They will be from several different sites.

Documentation below under Physical Exam Text includes age, race, gender, how you found the information, where this patient’s cancer path started, family history, positive tobacco use, comorbidities, size of tumor on mammogram (which might help with clinical staging), site, and the time period for prior mammogram. This is the beginning of the story.

Physical Exam Text

60 yowf, per dr Jones 3/15/13 H&P, found w byrad 5 on routine mammo w rt UOQ 1.5cm breast mass, non-palpable at ABC Mammo on 3/1/13, (last one 3 yrs ago). Fam hx ca neg, TOB +current 20 yrs. COPD, HTN. EOTH neg.

Xray/Scan Text

3/1/13 ABC Mammo, routine mammo: Rt UOQ 1.5cm breast mass. (per Dr. Jones 3/1/13 H&P). 3/14/13 Allied Hosp, CT chst: neg. Bilat dx mammo: Lt brst neg, Rt UOQ brst= 2 cm mass susp for malig.

You will notice a chest CT that was negative. This is done when there is only one scan for distant metastasis and it is negative. If there are several scans and they are all negative, simply document “all scans neg for regional & dist mets.” Sometimes every lymph node region possible will be mentioned. If they are all negative you can simply say “all nodes neg.” If some are positive, only list the positive nodes.
Scopes Text
3/1/13 ABC Hosp: Dr. Jones: Colonoscopy w bx of 3 polyp & apple core lesion.

Sometimes it is good to remember that unnecessary information is not helpful to you or others who will be reading your text. In the case of scopes with biopsies, the findings will be documented in the pathology text so it does not need to be documented here.

Labs Text
3/1/13 ABC hosp: PSA pre surg 14.0. 3/16/13 Post surg PSA 1.0.

or
3/1/13 ABC hosp: ER/PR +, Her2 equiv by IHC, neg by FISH.

Path Text
3/1/13 ABC Hosp: (13-4167) Rt UOQ brst bx= DCIS.

or
3/15/13 ABC Hosp: (13-5000) Rt lumpectomy= IDC, Nott grd 3, 10 mm, margins neg, 0/2 SLN, unifocal, LV inv neg, pT1c, pN0, ER/PR +, Her2 neg by IHC.

Surgery Text
3/1/13 ABC Hosp: Dr. Jones: TAH/BSO, no LN surg.

or
3/1/13 ABC Hosp: Dr. Jones: Rt. MRM, Rt ALN Diss.

Beam Radiation Text
3/1/13-4/27/13 ABC Hosp: Dr. Smith: 45cGy @19mV, Boost 600cGy @6mV, Rt Breast, 25f/35d

Chemo Text

or
3/1/13 ABC Hosp: Dr. E. Jones: wkly carboplatin & taxol planned, pt stopped due to intolerance. No further tx.

or

If you have several of the same types of services (scans, for example) and they occur at the same facility on the same day, you don’t need to reenter the date and place for each of them. But, if you have several different studies at the same facility on different days, you will need to enter the different dates. If they occur at different facilities, you will need to enter date and place for each of them.

Even if all activity is completed at the same facility, each heading (Chemo, Radiation, Surgery, etc) needs to begin with the date, place, and doctor. This keeps communication clear for those who will be using this data and who have no information or understanding about your facility.

Hormone Text
3/1/13 ABC hosp: Dr. Smith: per consult 2/29/13 pt will receive Tamoxifen when chemo is complete.

Sometimes cancer registrars are required to submit a case before all recommended treatment is completed. This is often the case for breast cancer cases and hormone treatment as seen above. Document what you know, and add any new information when it becomes available.

My final suggestion is to get into the habit of always putting your data in the same order. This makes it easy to see when you leave something out. Also, your rhythm of abstracting may be smoother and simpler, taking less time. Additionally, those who consistently review your data (such as state registries) will be able to review your text more easily and efficiently.

Conclusion
The goal of this article was to provide some “down and dirty” text completion suggestions. The cancer registry profession is riddled with constant change, and cancer registrars are experts at adapting. Nonetheless, some aspects of our job still prove to be challenging. Completing the text fields in a useful, concise, and consistent way may save time and frustration while increasing accuracy and understanding. I hope you will find the suggestions presented here useful in making your job easier.

Happy abstracting and remember to share what you know and stay open to learning.
IMPACT OF RACE/ETHNICITY AND SOCIOECONOMIC STATUS ON ADJUVANT CHEMOTHERAPY USE AMONG ELDERLY PATIENTS WITH STAGE III COLON CANCER

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:
• Discuss how race, ethnicity, and socioeconomic status (SES) affect the use of adjuvant chemotherapy in elderly patients with stage III colon cancer
• Describe factors that contribute to the decline of adjuvant chemotherapy utilization
• Explain the benefits of adjuvant chemotherapy for patients with stage III colon cancer

1. The standard treatment for locoregional colon cancers is:
   a) surgical resection of the primary tumor and immunotherapy
   b) neoadjuvant radiation therapy and immunotherapy
   c) surgical resection of the primary tumor and regional lymph node dissection
   d) neoadjuvant chemotherapy and regional lymph node dissection

2. In 2007, the National Quality Forum (NQF) endorsed the administration of adjuvant chemotherapy as a quality measure for stage III colon cancer patients:
   a) under 70 years old
   b) under 80 years old
   c) within 365 days of diagnosis
   d) within 6 months of diagnosis

3. Despite similar benefits of postoperative chemotherapy demonstrated in both old and young stage III colon cancer patients, the following group of patients was least likely to receive adjuvant chemotherapy:
   a) privately insured; under the age of 80
   b) insured by Medicare; under the age of 80
   c) privately insured; over the age of 80
   d) insured by Medicare; over the age of 80

4. The study cohort included stage III colon cancer patients who:
   a) underwent surgical resection within 6 months of diagnosis
   b) had a non-epithelial cancer
   c) enrolled in a Medicare-managed care plan after diagnosis
   d) were less than 66 years of age

5. The majority of potentially eligible stage III colon cancer patients who were excluded from the study were patients who:
   a) developed a non-colorectal second primary
   b) died within 30 days after surgery
   c) had no nodes examined
   d) had an unknown census tract

6. According to Table 1, Adjuvant Chemotherapy Status, Demographic, and Clinical Characteristics by Race/Ethnicity, 16 SEER Registries, 2000–2007, patients most likely to receive adjuvant chemotherapy within 4 months of colon resection were:
   a) white
   b) black
   c) Hispanic
   d) American Indian/Alaska Native/Asian or Pacific Islander

7. According to Table 2, Distributions and Odds Ratios (ORs) with 95% Confidence Interval (CI) of Receiving Adjuvant Chemotherapy for Stage III Colon Cancer Patients, 16 SEER Registries, 2000–2007, there were no significant differences in the receipt of adjuvant chemotherapy between which of the following groups?
   a) Single and married
   b) Intestinal stoma and no intestinal stoma
   c) ACoS hospital and non-ACoS hospital
   d) Under age 69 and over age 80

8. Previous surveys show that the primary reason physicians do not recommend adjuvant chemotherapy to stage III colon cancer patients is the:
   a) patient’s marital status
   b) comorbid conditions
   c) number of positive lymph nodes
   d) year of diagnosis

9. According to the study authors, the decline of guideline-recommended chemotherapy utilization could be attributed to:
   a) the shortage of chemotherapy drugs
   b) increased Medicare payments for physician-administered drugs
   c) increased demand for generic drugs
   d) a lack of benefit in stage III colon cancer patients

10. The study authors conclude that the receipt of adjuvant chemotherapy for stage III colon cancer patients is:
    a) marginally associated with socioeconomic status
    b) not impacted by Medicare drug reimbursement
    c) highest in elderly black patients
    d) associated with a surplus of chemotherapeutic drugs

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.
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.

1 A B C D
2 A B C D
3 A B C D
4 A B C D
5 A B C D
6 A B C D
7 A B C D
8 A B C D
9 A B C D
10 A B C D

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

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:

March 31, 2015

Quiz Identification Number:

4004.01

JRM Quiz Article:

IMPACT OF RACE/ETHNICITY AND SOCIOECONOMIC STATUS ON ADJUVANT CHEMOTHERAPY USE AMONG ELDERLY PATIENTS WITH STAGE III COLON CANCER

☐ 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.

Please check one:

☐ Enclosed is check #________ (payable to NCRA)

☐ Charge to the following card:

☐ MasterCard (16 digits) ☐ Visa (13 or 16 digits) ☐ American Express

Card Number ____________________________ Exp. Date ______

Signature __________________________________________

Print Cardholder’s Name _____________________________

Telephone # ________________________________

For Internal Use Only

Date Received: ____________________________

Amount Received: _______________________

Notification Mailed: ____________________

Mail to: NCRA Executive Office
JRM CE Quiz
1330 Braddock Place
#520
Alexandria, VA 22314
Correction to “ICD-O-3 Terminology Approved for Use with Cases Diagnosed January 1, 2014 and After” in the Fall 2013 Journal of Registry Management

The fall issue of the Journal of Registry Management (JRM) contained an article, “ICD-O-3 Terminology Approved for Use with Cases Diagnosed January 1, 2014 and After,” discussing new ICD-O-3 terms associated with existing codes that have been approved by the North American Association of Central Cancer Registries (NAACCR) for use with 2014 diagnoses and forward. The article also included a list of terms with new codes that would be effective in 2015. Shortly after that issue of JRM went to press, the Change Management Board of NAACCR rescinded its approval of the new codes and terms that would have become effective for 2015 cases, citing financial issues related to incorporating the new codes into the Collaborative Stage Data Collection System. Because of this, Table 2 on page 142 of the Fall 2013 issue of JRM is no longer valid. Table 1 is correct as printed.

The Change Management Board of NAACCR directed the ICD-O-3 Update Work Group to develop a list of current codes so that cases using the new terms can be reported in a timely manner to cancer registries. The table below has been reviewed by pathologists and lists the best current code to use for the following new terms until the new codes are incorporated into ICD-O-3 in the United States. A document called Guidelines for ICD-O-3 Update Implementation has been prepared and is pending NAACCR approval prior to its release in early 2014.

ICD-O-3 Terminology Changes Effective January 1, 2015

<table>
<thead>
<tr>
<th>New Code</th>
<th>Description</th>
<th>Current Code (Use This Code)</th>
</tr>
</thead>
<tbody>
<tr>
<td>8163/3</td>
<td>Pancreatobiliary-type carcinoma (C24.1)</td>
<td>8140/3</td>
</tr>
<tr>
<td></td>
<td>Adenocarcinoma, pancreatobiliary type (C24.1)</td>
<td>8140/3</td>
</tr>
<tr>
<td>8213/3</td>
<td>Serrated adenocarcinoma</td>
<td>8210/3</td>
</tr>
<tr>
<td>8265/3</td>
<td>Micropapillary carcinoma, NOS (C18., C19.9, C20.9)</td>
<td>8260/3</td>
</tr>
<tr>
<td>8552/3</td>
<td>Mixed acinar-ductal carcinoma</td>
<td>8523/3</td>
</tr>
<tr>
<td>9395/3</td>
<td>Papillary tumor of the pineal region</td>
<td>9362/3</td>
</tr>
<tr>
<td>9425/3</td>
<td>Pilomyxoid astrocytoma</td>
<td>9421/3</td>
</tr>
</tbody>
</table>
Reviewer acknowledgement: JRM gratefully acknowledges the individuals who have served as manuscript reviewers or have otherwise assisted in the review process during the past year. Their wise counsel and contributions to the Journal have been most valued.

Multiple Author Index—Vol. 40 (2013)

A

Abantanga, Frank

Adjei, Ernest

Adunlin, Georges

Ali, Askal Ayalew

Asgari, Maryam M.

Awuah, Baffour

B

Bailey, Marie

Barbero, Pablo

Bedard, Tanya

Beebani, Ganj

Belinske, Stephanie H.

Bidondo, Maria Paz

Boscoe, Francis P.

Bower, Carol
Buckley, Paul M.

Charles, Adrian

Chen, Vivien W.

Chiu, Yu-Wen

Collins, Elaine

Copeland, Glenn

Cote, Michele L.

Curran, Dan

D

Datta, S. Deblina

Dolecek, Therese A.

Druschel, Charlotte M.

Duong, Linh M.

E

Eide, Melody J.

F

Feldman, Jason D.

Fletcher, Suzanne W.

Forrester, Mathias B.

Fox, Deborah J.


Fritz, April

Fulton, John P.

G

Gili, Juan Antonio
Goovaerts, Pierre

Groisman, Boris

Gwede, Clement K.

H

Harrison, Denise
Roberson DC, Harrison D. Fall 2013 Continuing Education Quiz. Fall;40(3):144.

Henry, Lisa

Hernandez, Monique N.

Houser, Alan

Hsieh, Mei-Chin

Huang, Youjie X.

Hurlbut, Annette

J

Jiggae, Evelyn

K

Kahn, Amy R.

Kirby, Russell S.

Koering, Sue

Kruczko, Carol

L

Lee, David J.
Liascovich, Rosa

Lowry, R. Brian

MacKinnon, Jill A.

Mbah, Alfred K.

McCarthy, Bridget J.

McKenzie, Anne

Menck, Herman R.

Merajver, Sofia D.

N

Naam, Suzan

Nembhard, Wendy N.

O

O’Brien, Kieran S.

O’Flarity, Mary B.

Osei-Bonsu, Ernest

P

Patel, Divya A.

Polednak, Anthony P.


Q

Quayson, Solomon

R

Richardson, Lisa C.

Richardson, Sandra D.

Riddle, Melissa
Roberson, Deborah C.
Roberson DC, Harrison D. Fall 2013 Continuing Education Quiz. Fall;40(3):144.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.

Ruterbusch, Julie J.
Tanner, Jean Paul

Tao, Zhen

Thaivalappil, Silpa S.

V
Velasco, Cruz

Voti, Lydia

W
Wang, Ying

Warren, Pamela S.

Warton, E. Margaret

Watson, Kim

Watson, Linda

Webb, Michele


Webster, Pamela S.

Williams, Judy

Wittman, Brooke

Wu, Xiao-Cheng

X
Xiao, Hong

Z
Zhang, Xiuling
Key Word Index—Vol. 40 (2013)

A

Accrual standard

Accuracy

Adenocarcinoma

Adjuvant chemotherapy

Administrative data

Alberta

Algorithm

American College of Surgeons Commission on Cancer

Arab American

Argentina

B

Basal cell carcinoma

Birth defects


Birth defects registries

Brain

Breast cancer

British Columbia

C

Cancer

Cancer committee

Cancer registrar

Cancer registration
Cancer registries


Cancer registry


Cancer surveillance


Central nervous system

Cerebral palsy

Cervical carcinoma in situ

Cervical intraepithelial neoplasia

Clinical trials

Codes

Coding system

Colon cancer

Comorbidity

Comparative effectiveness research

Congenital anomalies

Congenital malformation registry

Consumers

D
Database

Data linkage

Data management

Data quality

**Date of diagnosis**

**Death certificates**


**Developing countries**

**Elixhauser**

**Engagement**

**Epidemiology**


**Ethnicity**


**First course treatment**
Shimer SE. Prostate Cancer Treatment Modalities and Survival Outcomes: A Comparative Analysis of Falmouth Hospital Versus Massachusetts and Nationwide Hospitals. Summer;40(2):78-83.

**Florida Cancer Data System**

**Follow-up**

**Ghana**

**Granular ethnicity**

**Hepatitis C virus**

**Hepatocellular carcinoma**


**Hospital discharge data**

**Hospital electronic medical record**

**Hysterectomy**
ICD-9-CM

ICD-10-CM

Incidence

Infant mortality

Intrahepatic bile duct cancer

L

Link

Liver cancer

M

Malignant

Mammogram

Match

Maternal and child health

Medicare

N

National Cancer Data Base
Shimer SE. Prostate Cancer Treatment Modalities and Survival Outcomes: A Comparative Analysis of Falmouth Hospital Versus Massachusetts and Nationwide Hospitals. Summer;40(2):78-83.

New York State hospitals

Non-malignant

O

Online reporting

Osteosarcoma

P

Patterns

Poison center

Predictive value

Primary site
Prostate cancer
Shimer SE. Prostate Cancer Treatment Modalities and Survival Outcomes: A Comparative Analysis of Falmouth Hospital Versus Massachusetts and Nationwide Hospitals. Summer;40(2):78-83.

Public health surveillance

Quality improvement

Race

Race/ethnicity

Record consolidation

Record linkage

Register

Registries

Registry

Screening

SES

Skin cancer

SNOlMED

Software

Squamous cell carcinoma

Surname Lists

Surveillance

Survey
Title Index—Vol. 40 (2013)

A

An Automated Algorithm for Consolidating Dates of Diagnosis from Multiple Sources.

A Survey on Readiness and Needs Regarding the Transition from ICD-9-CM to ICD-10-CM.

B


C

Cancer Registry Enrichment via Linkage with Hospital-Based Electronic Medical Records: A Pilot Investigation.

Collaborating with Consumers: The Key to Achieving Statutory Notification for Birth Defects and Cerebral Palsy in Western Australia.

Conflicting Race/Ethnicity Reports: Lessons for Improvement in Data Quality.

Construction of Comorbidity Index for Prostate Cancer Patients Linking State Cancer Registry with Inpatient and Outpatient Data.

T

Time to treatment

Transition

Treatment

U

Unlinked records

V

Vaccine

Vaccine Adverse Event Reporting System (VAERS)

Validation

Vital statistics
Creation and Evaluation of a Multi-layered Maternal and Child Health Database for Comparative Effectiveness Research.


Edits: An Electronic Tool for Cancer Registry Data Quality.

Enhancement and Validation of an Arab Surname Database.

Enhancing Methods for Population-Based Birth Defects Surveillance Programs.


Fall 2013 Continuing Education Quiz.
Roberson DC, Harrison D. Fall 2013 Continuing Education Quiz. Fall;40(3):144.

Feasibility of Matching Vaccine Adverse Event Reporting System and Poison Center Records.

Feasibility of Using Central Registry Data to Assess Timeliness of Breast Cancer Care in Delaware.


ICD-O-3 Terminology Approved for Use with Cases Diagnosed January 1, 2014 and After.

Impact of Race/Ethnicity and Socioeconomic Status on Adjuvant Chemotherapy Use among Elderly Patients with Stage III Colon Cancer.

On Using Health Informatics to Advance Your Career.

Prostate Cancer Treatment Modalities and Survival Outcomes: A Comparative Analysis of Falmouth Hospital Versus Massachusetts and Nationwide Hospitals.
Shimer SE. Prostate Cancer Treatment Modalities and Survival Outcomes: A Comparative Analysis of Falmouth Hospital Versus Massachusetts and Nationwide Hospitals. Summer;40(2):78-83.

Raising the Bar: Busyness Does Not Equal Competence.

Raising the Bar: Was Chicken Little a Cancer Registrar?

Raising the Bar: What Cancer Registrars Can Learn from Diana Nyad.

Raising the Bar: Working Under Frigid Conditions.
Registry Data Quality Improvement by Identifying Discrepancies between Assigned Codes and Text Descriptions of Birth Defects.

Respecting Cancer Committee Members as Volunteers: Tools for the Cancer Registrar.

Spring 2013 Continuing Education Quiz.

Strategies to Achieve Sustainability and Quality in Birth Defects Registries: The Experience of the National Registry of Congenital Anomalies of Argentina.

Summer 2013 Continuing Education Quiz.

Surveillance and Interpretation of Trends in US Age-Specific Incidence Rates for Primary Liver Cancer, in Relation to the Epidemic of Hepatitis C Infection.

The Impact of the Benign Brain Tumor Cancer Registries Amendment Act (Public Law 107-260) on Non-malignant Brain and Central Nervous System Tumor Incidence Trends.

The Journey from Office to Home.

Treatment Patterns for Cervical Carcinoma In Situ in Michigan, 1998–2003.

Use of Treatment Information from a State Central Cancer Registry in Prostate Cancer Research.

Using Cancer Registries to Assess the Accuracy of Primary Liver or Intrahepatic Bile Duct Cancer as the Underlying Cause of Death, 1999–2010.

Using the Cancer Registry to Meet the Commission on Cancer Clinical Trials Accrual Standard.

Validation of a Large Basal Cell Carcinoma Registry.

Winter 2013 Continuing Education Quiz.
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.

**Topic:**
1. Birth Defects Registries
2. Cancer Registries
   - Cancer Collaborative 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.


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](http://www.ncra-usa.org/jrm).
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 often provide perspectives, 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 email 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 appear in the text; 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.

Affirmations

Copyright. Authors submitting a manuscript do so on the understanding that if it is accepted for publication, copyright in the article, including the right to reproduce the article in all forms and media, shall be assigned exclusively to NCRA. NCRA will not refuse any reasonable requests by the author(s) for permission to reproduce any of his or her contributions to the Journal. Further, the manuscript’s accompanying cover letter, signed by all authors, must include the following statement: “We, the undersigned, transfer to the National Cancer Registrars Association, the copyright for this manuscript in the event that it is published in Journal of Registry Management.” Failure to provide the statement will delay consideration of the manuscript. It is the author’s responsibility to obtain necessary permission when using material (including graphs, charts, pictures, etc.) that has appeared in other published works.

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.

Reprints

Authors receive 5 complimentary copies of the Journal in which their manuscript appears. Additional copies of reprints may be purchased from the NCRA Executive Office.
NCRA’s 2014 Annual Educational Conference

May 15-18, 2014

Gaylord Opryland Resort & Convention Center
Nashville, TN

Working in Harmony to Deliver Excellence

NCRA: Celebrating its 40th Anniversary in 2014